

Understanding the patient experience of living with notalgia paresthetica: A qualitative interview study



Elizabeth D. Bacci, PhD,^a Brooke M. Currie, MPH,^b Rozanne Wilson, PhD,^a Jenny Qian, MS,^c Catherine Munera, PhD,^c and Kristine Nograles, MD, MSc^c
Seattle, Washington; Bethesda, Maryland; and Stamford, Connecticut

Background: Notalgia paresthetica (NP) is a chronic sensory neuropathy that causes intense pruritus, typically affecting the upper portion of the back and lasting for months to years. The impacts of pruritus and the full symptom experience are not well documented.

Objective: To describe patients' NP symptom experience and the impacts of living with NP-related itch.

Methods: Semistructured, one-to-one qualitative telephone interviews were conducted in adults living with NP. The worst itch severity during the previous 24 hours was assessed using an 11-point numerical rating scale.

Results: Thirty participants (23 females; aged 41-80 years) completed interviews. Seventeen NP-related symptoms were described, with daily itch being the most common. Participants' itch ranged from severe to very severe (50%) and was experienced for a median of 2.8 years. Most (73%) participants were not receiving treatment for NP at the time of the study. Other reported symptoms included skin pain or sensitivity and secondary symptoms from itching (skin discoloration, lumps or bumps, bleeding or scabbing). NP-related itch was frequently reported to affect mood, interfere with sleep, and disrupt self-care.

Limitations: Only English-speaking participants living in the United States were included.

Conclusion: This study highlights the patient experience of living with NP and findings reveal that there remains an unmet need for effective therapeutic options to address NP-related itch. (JAAD Int 2022;8:94-101.)

Key words: burden; dermatology; impact; itch; notalgia paresthetica; patient experience; patient perspective; pruritus; qualitative interviews; sleep disturbance; symptoms; treatment needs.

INTRODUCTION

Notalgia paresthetica (NP) is a common chronic sensory neuropathy localized to the mid-to-upper portion of the back, typically unilateral, which can last for months to years and is characterized by hyperpigmented skin patches that cause intense localized neuropathic pruritus (itch) and pain.¹⁻³ In addition to chronic itch, patients with NP may

experience burning or cold sensations, surface numbness, tingling, paresthesia, foreign body sensation, or tenderness.^{2,4} NP is thought to be caused by damage to the thoracic nerves,² most frequently from vertebrae degeneration and disc herniation, although it remains unclear whether the damage is peripheral or radicular.^{2,5} A recent case series of 117 patients with NP confirmed that the disease mostly

From Evidera, Seattle^a; Evidera, Bethesda^b; and Cara Therapeutics, Stamford.^c

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Correspondence to: Elizabeth D. Bacci, PhD, Evidera, 615 2nd Ave, Suite 500, Seattle, WA 98104. E-mail: elizabeth.bacci@evidera.com.

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affects middle-aged women and found that the intensity of pruritus did not differ by age, sex, skin type, or comorbidities.⁵ NP is typically diagnosed on the basis of patient history and physical examination; however, it is likely underdiagnosed, and thus its true prevalence is unknown.

A variety of pharmacologic and nonpharmacologic treatments are used to provide symptomatic relief for people living with NP, including topical agents, oral therapies, injections (botulinum toxin), physical therapy, exercise, and targeted procedures. However, none of these treatments are approved for NP, and the only evidence of their clinical efficacy is from case reports. Additionally, guidelines for treating NP have not been published.^{3,5-8}

To help select and develop effective treatments, the US Food and Drug Administration encourages considering the patient perspective.⁹ However, in the case of NP, the experience of patients is not well documented. Therefore, this qualitative interview study of patients with NP was conducted to detail the symptom experience of patients with NP and explore how the disease impacts their lives.

METHODS

Study design and conduct

This is a cross-sectional qualitative study of adults with a diagnosis of NP. Purposive sampling was used to identify and recruit 30 patients with NP aged 18 to 80 years from 4 clinical sites across the United States on the basis of a review of patient databases, charts, and daily appointment schedules. At the time of screening, the participants also had to have a clinically confirmed diagnosis of NP for ≥ 6 months on the basis of the patient's medical chart and/or their physician, have self-reported chronic itch related to NP for ≥ 6 weeks, have moderate-to-severe pruritus as indicated by a score of ≥ 4 on the worst itch numerical rating scale (WI-NRS) (an 11-point scale assessing the severity of their worst itch during the previous 24 hours and ranges from 0 for no itch to 10 for worst imaginable itch),¹⁰ and be able to speak and understand English. Participants were excluded if they had pruritus because of a condition other than NP (except for concomitant brachioradial pruritus), a history of skin disease or presence of a skin condition other than those related to

NP that could interfere with describing their experience living with NP, or an impairment or other condition that could interfere with their ability to provide written consent.

All the participants completed a single one-on-one telephone interview, lasting approximately 90 minutes, that was conducted in English. A semistructured

interview guide was developed for this study that used concept elicitation methods to gain insights into the participant's NP symptom experience and how living with NP-related itch affects their daily lives (eg, physical, psychologic, social, and work impacts). The guide also included targeted questions and probes for the interviewer to further discuss NP symptoms and the impact of itch reported by the participants. Experienced scientific staff (RW, RM, CL, SKS)

CAPSULE SUMMARY

- Notalgia paresthetica is a poorly understood neuropathy characterized by chronic, intense pruritus in the mid-to-upper portion of the back.
- Patients with notalgia paresthetica are bothered by their itch, and their mood, sleep, and self-care activities are negatively impacted. Despite the available treatments, there remains an unmet need for effective therapeutic options to address the symptoms.

(Supplementary Table I, available via Mendeley at <https://doi.org/10.17632/6sps3ps6mh.1>) were trained on the semistructured interview guide before interviewing participants, and the guide was piloted during a mock interview to assess the accuracy and flow of the questions and probes. Only the participant and the trained interviewer were present during the interview, and participants did not know the interviewer before the study but were informed briefly about the interviewer's qualifications during the interview. As part of the interviews, participants again completed the WI-NRS questionnaire. After the interview, participants completed a brief sociodemographic questionnaire and were remunerated for their participation. Following the interviews, clinical site staff documented basic clinical information of the participants.

Ethics. Before the interview, participants provided consent for participation in this study and for audio recording for verbatim transcription of the interviews. All study documents were approved by a central institutional review board (Advarra institutional review board [approval number Pro00044607]). The study was conducted in accordance with the International Council for Harmonisation Good Clinical Practice and the Declaration of Helsinki.

Analysis

Interview recordings were professionally transcribed, and the transcripts were reviewed for

Abbreviation used:

NP: notalgia paresthetica

quality assurance purposes and to remove any personal health information. The transcripts were analyzed using a thematic content analysis approach, with patient statements being the unit of analysis (eg, words and phrases) to capture concepts and themes. An initial coding framework was developed on the basis of the concepts addressed in the semistructured interview guide (deductive coding) and subsequently updated to include codes for concepts that emerged during the interviews (inductive coding). Before the transcripts were independently coded, an agreement check was performed on a single transcript (RW, RM, FZ) (Supplementary Table I) to ensure that all relevant responses were captured in a similar manner and that coders were interpreting and using codes consistently, as intended. Once it was determined that they consistently understood the coding process, 2 coders (RM, FZ) (Supplementary Table I) independently coded half of the transcripts each in ATLAS.ti version 8.4. Following coding, 3 study team members (RW, RM, SKS) (Supplementary Table I) reviewed the coded output to ensure quality control. Specifically, the team members sequentially reviewed the synthesized data to identify inconsistencies or potential errors that required clarification, which were then flagged for investigation, and the final decisions were based on consensus discussion. Qualitative results were summarized and interpreted by the authors to assess participants' endorsement of symptom and impact concepts (including concept saturation, where no new concepts are endorsed by participants) as well as identify key themes emerging from the interviews. Participants were not involved in the interpretation stage of this study and did not provide feedback on the findings.

RESULTS**Participant characteristics**

Thirty participants completed interviews between August 2020 and October 2020 (Table I; and Supplementary Table II, available via Mendeley at <https://doi.org/10.17632/6sps3ps6mh.1>). The average age of the participants was 64 years (range, 41-80 years), and most participants were women ($n = 23$; 77%), non-Hispanic ($n = 29$; 97%), and White ($n = 28$; 93%) and had at least some college level education ($n = 28$; 93%). The mean WI-NRS score at

Table I. Participant characteristics

Characteristic	Total sample (N = 30)
Age (y), mean (SD) [range]	63.8 (11.1) [41-80]
Female sex, n (%)	23 (77)
Hispanic, n (%)	1 (3)
Race, n (%)	
White	28 (93)
Black or African American	2 (7)
Employment status, n (%)	
Employed, full-time or part-time	11 (37)
Homemaker	1 (3)
Unemployed	2 (7)
Retired	16 (53)
Highest level of education, n (%)	
Secondary or high school	2 (7)
Associate degree, vocational, technical, or trade school, some college	10 (33)
University or college degree	9 (30)
Postgraduate degree	9 (30)
Itch severity at the time of interview	
WI-NRS score *, mean (SD) [range]	5.8 (2.5) [1-10]
WI-NRS score * category, n (%)	
Mild (≥ 1 -<4)	6 (20)
Moderate (4-6)	9 (30)
Severe (7-8)	12 (40)
Very severe (9-10)	3 (10)
Years experiencing NP-related pruritus, median [range]	2.8 [0.7-45.0]
Currently receiving treatment, n (%)	8 (27)
Hydrocortisone (topical cream)	2 (7)
Capsaicin (topical cream)	1 (3)
Fluocinonide (topical cream)	1 (3)
Gabapentin	1 (3)
Triamcinolone (topical cream), diphenhydramine	1 (3)
Other	2 (7)

WI-NRS, Worst itch numerical rating scale.

*Self-reported worst itch severity during the previous 24 hours, scored on an 11-point numerical rating scale, which ranged from 0 for "no itch" to 10 for "worst imaginable itch."

the time of the interview was 5.8 (SD, 2.5), with 50% ($n = 15$) of participants having severe or very severe itch. Participants had experienced NP-related itch for a median time of 2.8 years (range, 0.7-45.0). Most participants ($n = 22$; 73%) were not receiving treatment for NP at the time of interviews; among those that were receiving treatment ($n = 8$), the most common treatment ($n = 6$) was a topical cream (eg, hydrocortisone).

Concept elicitation results

Diagnosis and treatment experience. Most participants ($n = 27$; 90%) reported that itching on

their back had led them to go to the doctor, and 3 (10%) participants indicated that their NP was diagnosed during a regularly scheduled annual skin check-up. Nearly all ($n = 28$; 93%) participants remembered when they were received their first diagnosis of NP, and all of these participants reported receiving their diagnosis from a dermatologist. All ($n = 29$) participants, when asked, shared that they had previously sought treatment. When asked if those treatments were helpful, the consensus seemed to be that none of the treatments that they received could completely cure or stop the itch, with most participants indicating that the treatment was not helpful ($n = 20$; 67%) or limited or somewhat helpful ($n = 6$; 21%) (Supplementary Table III, available via Mendeley at <https://doi.org/10.17632/6sps3ps6mh.1>).

Symptom experience. The participants described 17 NP-related symptoms, with all participants reporting that they experience itch (Table II). Saturation of symptom concepts was achieved within the first 15 interviews (Supplementary Table IV, available via Mendeley at <https://doi.org/10.17632/6sps3ps6mh.1>). The participants used a variety of terms to describe their itch experience, including “irritating,” “tingling,” and “burning,” and most frequently described their itch as extreme or intense ($n = 8$; 27%) or like an insect bite or sting ($n = 8$; 27%) (Table II). Most participants reported experiencing itch daily ($n = 25$; 83%) and during the day and at night ($n = 24$; 80%), although 61% ($n = 18$) reported that the itch was “worse at night.” All participants reported that they experienced itch in the upper-to-middle portion of the back. The participants reported weather- or temperature-related factors that triggered their itch, including hot weather or heat ($n = 10$; 33%), sweating ($n = 10$; 33%), dry weather ($n = 8$; 27%), hot showers ($n = 6$; 20%), and exposure to sunlight ($n = 6$; 20%). For many participants, the itch experience (ie, severity, duration, and exact location) varied from day to day ($n = 22$; 74%) and even within a single day ($n = 21$; 70%). Representative quotes related to the participants’ itch experience are provided in Table III. Patients also reported other symptoms that were caused by their itching, including lumps or bumps ($n = 7$; 23%), bleeding or scabbing ($n = 5$; 17%), skin discoloration ($n = 5$; 17%), burning or hot sensation ($n = 4$; 13%), and painful or raw skin ($n = 4$; 13%) (Table II).

Impacts of NP. Eighteen unique itch-related impact concepts were identified during the interviews. Saturation of the impact concepts was reached within the study sample (Supplementary

Table II. Symptoms endorsed

Symptom concept	Total sample ($N = 30$) n (%)
Itch or pruritus	30 (100)
Lumps or bumps	7 (23)
Bleeding or scabbing	5 (17)
Skin discoloration (eg, darkening or reddening of skin)	5 (17)
Painful or raw skin	4 (13)
Burning or hot sensation	4 (13)
Sensitive skin	3 (10)
Tenderness	3 (10)
Numbness	3 (10)
Other*	12 (40)

*Dry or rough skin ($n = 2$), irritation or tickle ($n = 2$), rash ($n = 2$), stinging ($n = 2$), crawling or tingling skin ($n = 1$), skin patches ($n = 1$), thinner skin in affected area ($n = 1$), and throbbing ($n = 1$).

Table V, available via Mendeley at <https://doi.org/10.17632/6sps3ps6mh.1>). The main impacts elicited were on sleep, daily activities, work or school, emotions or mood, social life, relationships, concentration, and finances (Table IV). Most of the participants reported that NP-related itch affected their emotion, daily routines, and sleep. Many ($n = 13$; 43%) participants considered the need to relieve their itch to be the most bothersome aspect of their condition. On a 10-point numerical rating scale where 1 was “never” and 10 was “constantly,” most participants ($n = 22$; 73%) indicated that their itch bothered them at a level of ≥ 5 (median = 6, range = 1-10) (Supplementary Table VI available via Mendeley at <https://doi.org/10.17632/6sps3ps6mh.1>). Many participants ($n = 12$; 40%) reported that the itch interfered with their sleep, and some participants ($n = 11$; 37%) reported difficulty staying asleep. Notably, a majority of those who reported that itch interfered with sleep had rated their itch as severe or very severe on the WI-NRS.

Some participants ($n = 10$; 33%) described how itch would affect their daily activities, including self-care or personal hygiene practices (eg, needing back scratchers at home or when traveling and needing to apply lotion to alleviate the itch). Almost half of the participants reported emotional impacts as a result of their NP-related itch ($n = 12$; 41%), the most common of which was feeling irritated or annoyed ($n = 21$; 70%). Some participants noted feeling nervous or anxious ($n = 4$; 13%), emotional ($n = 17$; 59%), or embarrassed ($n = 1$; 3%). A few participants reported impacts on their social life ($n = 2$; 7%), finances ($n = 1$; 3%), concentration ($n = 4$; 13%), and relationships ($n = 1$; 3%). Representative quotes related to impacts of NP are provided in Table V.

Table III. Representative quotes related to pruritus

Subtheme	Representative quotes
Description	001-003: It's like a mosquito bite or something. It just itches, and the more you scratch it, the more it itches. 004-010: You kind of want to scratch it and then maybe you start to dig a little bit. That's how I would describe it... It's just irritating. It's not sharp, it's not excruciating, it's just annoying. 004-009: It feels like a small bee sting but not, it doesn't hurt as much as it just itches, and sometimes it burns a little bit. But it's just an intense pinprick, very focused itch. It feels just like something is contacting my skin and I need to get it off.
Frequency	005-008: Oh, I have it every day, like all day. 001-006: Oh, it's every day... I don't know how much of every day. 004-011: ...lately it's been daily. But I have gone, there have been well periods where I didn't itch for a couple of weeks. But it comes and goes. I feel like a lot of things factor into it, my stress level, the environment, certainly different types of clothing, to feel that there's nothing touching it.
Intensity	005-014: Really intense. It feels like right after a big, black fly has bitten you, or a mosquito has bitten you. It just starts itching and it's like you just can't get—you can't get enough scratching, or you know, any relief from it. 001-008: I don't know just coming on the day. I mean sometimes it's so intense you can itch it to the bone... It drives me crazy.... Oh, the average would probably be just something that's just perhaps just 7 or 8, and then sometimes a 2. So, maybe average would be like a 4 or 5. 001-011: It varies. ... this week it was just flared up a little bit and I could feel it and then it just went away. ... there's been times when it's made me get up and get out of bed and try and put some cream on it because it's pretty intense.
Duration	002-006: The itch usually is from out a few hours, or it eases up a little bit. I would say about 2 hours. 001-001: Depends on if I scratch it or something. If I scratch it, it usually will end. If I don't scratch it, it would probably last forever.

Continued

Table III. Cont'd

Subtheme	Representative quotes
	001-011: ...sometimes I just kind of feel the sensation and it goes away within maybe 10 min or so. And then I've had other episodes, mainly during the night... I would say it lasts for over an hour.
Variability	005-004: I just really notice it's more intense in the evening, but that may be because I'm more trying to relax and not moving as much. 005-024: Well I mean it itches most days, but I mean I can't say it's 365 days a year.
Location	001-007: ...there's only 1 location and it's basically the center of my back. 004-008: It could migrate a little bit up or down, but it's pretty much located in the center part of my back. 004-009: It's below my left shoulder... you get itches all over for different reasons, but this particular itch is always in exactly the same place.

DISCUSSION

This qualitative study detailed the symptom experience of patients living with NP and how NP-related itch affects their daily lives. Chronic, frequent itch, often severe, was experienced by all the participants, and most had been experiencing itch for several years. NP-related itch was considered bothersome, frustrating, irritating, or annoying, and it often interfered with staying asleep and falling back to sleep after waking, especially for patients with more severe itch. Although NP-related sleep disturbance shares some features of atopic dermatitis- and psoriasis-related sleep disturbance,¹¹⁻¹³ it did not appear to affect the ability to fall asleep. NP-related itch also affected patients' mood, emotions, and self-care. Besides itch, patients with NP experienced pain or sensitivity and secondary symptoms from itching (skin discoloration, lumps or bumps, and bleeding or scabbing). These findings parallel the study results in a recent study comparing brachioradial pruritus and NP because the indicators of worst itch were similar between NP patients in both studies, and sleep was similarly minimally impacted as found in the current study.¹⁴

The findings of this study confirm that itch is the most common symptom experienced by patients living with NP,¹⁵ that it may last for many years,¹ and that, in addition to chronic pruritus, symptoms include burning or cold sensations, tingling, numbness,

Table IV. Impacts endorsed

Impact concept	Total sample (N = 30) n (%)
Sleep	
Sleep (general)	12 (40)
Ability to stay asleep *	11 (37)
Ability to fall back to sleep †	7 (24)
Ability to fall asleep *	2 (7)
Daily activities	
Self-care or personal hygiene*	10 (33)
Daily activities (general)	1 (3)
Work or school	
Work productivity	4 (13)
Work or school (general) ‡	2 (10)
Emotions or mood	
Irritable or annoyed or bothered*	21 (70)
Worry or stress or anxiety*	4 (13)
Emotions or mood (general) †	17 (59)
Embarrassment*	1 (3)
Social life	
Social life (general)	2 (7)
Sports*	1 (3)
Relationships	
Family, romantic, or friend relationship	1 (3)
Others	
Distraction or trouble with concentrating*	4 (13)
Financial burden*	1 (3)

*Impact concept was spontaneously mentioned during the discussion; the interview guide did not include a question that directly asked participants about this impact.

†N = 29.

‡N = 20 because 7 participants indicated that they did not work (paid employment) and 3 were not asked this question.

paresthesia, tenderness, or foreign body sensation.^{2,4}

This study also showed that despite the available treatments, NP-associated itch and other symptoms of NP have a great impact on the daily lives of patients.

This study adds to the limited information on the symptom experience of NP and its impact on patients. Notably, although all participants shared that they wanted treatment for their NP-related itch, several indicated that previous treatment(s) was limited or not helpful, and most of the participants were not undergoing treatment at the time of this study. Thus, the study highlights that there remains an unmet need for effective therapeutic options to address NP-related itch. Conventional treatments for pruritus such as antihistamines and topical corticosteroids are typically ineffective for NP.³ Other treatment options include topical anesthetic or anti-inflammatory agents, physical therapy, and systemic and procedural treatments; however, there is no

Table V. Representative quotes related to impacts of notalgia paresthetica

Subtheme	Representative quotes
Everyday impact	004-007: It's bothersome but it's not like I'm in pain.
	004-011: Well it's irritating so it's distracting. So if I'm in a meeting and all of a sudden my back itches, it's hard to stay focused on the task at hand... I have back scratchers in places... If I go on a business trip or a vacation, it can be like, shoot, I don't have a back scratcher... it's something that you have to deal with so it's distracting... it can really play a psychological effect on you to make you a little nuts.
Bother associated with itch	002-001: ...it bothers me, because if something is constantly in your body and constantly—just like a nagging headache... That's the way the itch is. I just have it all the time, and most times I want to scratch it, so that's what I'm working on now...
	004-005: It can't be really satisfied... if it's itching particularly bad at night I can get into really scratching and I end up just causing myself to bleed because there's no real way to satisfy the itch.
Sleep	001-002: I would say it wakes me up every night... I don't sleep well.
	005-004: ...when it itches, it itches severely like you can't scratch it hard enough I would say. It could wake me up, it wakes me up in the middle of the night. I have a hard time getting to sleep because as soon as I lay down it'll start, but it has woken me up in the middle of the night just with an instant I have to itch...
Daily activities	001-004: ... I'm aware of it, you know, quite often, like, when we travel, you know? I usually have to take a back scratcher with me.
	001-003: Well, it doesn't affect my life other than it's annoying, but it doesn't stop me from doing things. But I do have a back scratcher in every room of my house.
Work and school	004-011: ... Like if I was up the night before because it itched and I didn't sleep well, I'm certainly less productive the next day...
	001-002: Well, if it breaks my concentration, yes I am less productive yeah.
Mood and emotion	001-008: Oh, yeah. It drives me insane, so yeah. It just makes me a little anxious and crazy. But when it's, you know, at the peak.

Continued

Table V. Cont'd

Subtheme	Representative quotes
	002-003: Affects my mood... It puts you in a worse mood—puts you in a worse mood.
Social life	002-006: Well, it's a little embarrassing if I'm...rubbing my back...I mean itching gets me, my attention to the itch and I can't recall if there's somebody or I've got to corner myself otherwise, just sort of get that erased...
Relationships	004-011: ...my family, my husband, we all know I have an itchy spot. It's the butt of a lot of jokes and everybody knows that it's all funny until, 'I'm not kidding, scratch my back right now.' ... 001-002: Well, I think my husband doesn't appreciate being... because I try it when I'm falling asleep I start fidgeting, and then I start reaching back and scratching. He's like could you lie still? You know, so I probably disrupt his sleep.

strong evidence supporting the use of any of these therapies.³ Indeed, treatment guidelines for NP have not been published, no treatments have been approved to treat it, and the only evidence of treatment efficacy is from case reports.^{3,5-8} As supported by the US Food and Drug Administration,⁹ the information about the patient experience described here should help guide the development and selection of new treatments for NP.

This qualitative study had the advantage of allowing concepts about NP to be collected with little bias. A limitation is that although the study provided some initial information on the frequency and severity of symptoms and impacts, quantitative studies (ie, patient surveys) would be needed to provide more precise information. Another potential limitation was that the sample was small; however, the sample was sufficiently large to reach concept saturation. Additionally, the assessment of spinal stenosis was not required as an inclusion criterion; however, radiological abnormalities are not consistently identified in NP. Finally, the generalizability of the findings could be limited because all the participants were from the United States.

Overall, this qualitative study highlights the most frequently experienced symptoms and impacts associated with NP, indicating that there is a need for additional, effective treatments to improve the quality of life in patients experiencing this dermatologic condition.

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Conflicts of interest

Dr Bacci is employed by Evidera and received funding from Cara Therapeutics. Authors Currie and Dr Wilson were employed at Evidera at the time the study was conducted and received funding from Cara Therapeutics. Author Qian and Drs Munera and Kristine Nograles are employed by Cara Therapeutics.

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