SYSTEMATIC REVIEW

Patients' and prescribers' experiences of managing neuropathic pain with medication: a scoping review

[version 1; peer review: awaiting peer review]

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Abstract

Background: Neuropathic pain (NP) is a chronic condition that affects patients' quality of life. Prescribing for NP within primary care is variable. There is a need to understand NP medicine management from both patient and prescribers' perspectives. This scoping review aimed to identify, synthesise and identify gaps in the literature on the experiences of: i) prescribers in prescribing medicines to manage the symptoms of NP and ii) people with NP who use prescribed medicines to manage their symptoms.

Methods: Four electronic bibliographic databases (Medline, CINAHL, Embase and PsycInfo) were searched from inception to the end of October 2022 using a structured search strategy. The findings were synthesised and presented using a modified framework for monitoring opioid prescribing called the 5 A's framework. The 5 A's are Analgesia, Activities of daily living, Adverse effects, Aberrant behaviour, and Activities and actions of healthcare professionals.

Results: From the 10,995 records identified, 11 studies were included in the review. All the studies focused on patients' experiences, with no studies about the experiences of prescribers in managing NP. Patients reported that medicines seem to work at the outset but, over time, are less effective in relieving their pain. Patients took less than the prescribed dose of their medicine, depending on their pain level on the day. Taking medication allowed patients to participate in activities they would not otherwise have been able to do, often resulting in less isolation and loneliness.

Conclusions: This scoping review has highlighted patients' experiences of using medicines to manage NP. Results provide insight into how patients cope with inadequate pain control and the impact this has on patients' lives. More research is required to explore the experiences of people living with non-specific types of NP as well as the experiences of prescribers who prescribe medicines to manage NP.

Open Peer Review

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Any reports and responses or comments on the article can be found at the end of the article.

Keywords
Neuropathic pain, chronic pain management, primary care, medication, experiences, scoping review

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Introduction

Pain is classed as 'chronic' when it lasts longer than three months. Neuropathic pain (NP) is a chronic condition that affects around 8% of the population of the United Kingdom (UK) (Torrance *et al.*, 2006; Torrance *et al.*, 2013). The International Association for the Study of Pain (IASP) defines NP as 'pain caused by a lesion or disease of the somatosensory nervous system' (International Association for the Study of Pain (IASP), 2017). Often, NP causes tissue and nerve damage that can result in: i) Hypersensitivity, which is characterised by spontaneous pain (no stimuli exist but the person feels pain); ii) allodynia, which is when painless tactile stimulus or warmth are perceived as pain; and iii) hyperalgesia, which is when painful stimuli make the person feel pain of greater intensity (Yan *et al.*, 2017).

People with NP may experience signs and symptoms including the following: i) burning, ii) shooting, iii) stabbing, iv) coldness, v) tightness, vi) paresthesias or electric shock-like sensations, vii) muscle weakness, viii) loss of deep tendon reflexes, and ix) absent or impaired sensation to light, touch, pinprick, vibration, and temperature (Wright & Rizzolo, 2017). NP is different from chronic primary pain (CPP). CPP is chronic pain in one or more anatomical regions that is characterised by significant emotional distress (such as anxiety, depression or anger and frustration) or functional disability (for example reduced participation in social roles and interference in daily life activities) (National Institute for Health and Care Excellence (NICE), 2021). NICE provides guidance on the management of neuropathic pain in the UK (NICE, 2013).

Previous systematic literature reviews have focused on the experiences of people with various types of chronic pain (Toye *et al.*, 2013; Toye *et al.*, 2017) and the experiences of prescribers in managing chronic pain but not specifically NP (Kennedy *et al.*, 2019; Toye *et al.*, 2017). It is therefore important to understand the experiences of people who have NP, to identify areas for improving the management of the condition.

In the UK, people with NP usually first seek professional help from their GP practice (Sullivan Mark *et al.*, 1991). However, patients face several challenges when seeking help to manage their pain. These challenges include short consultation times, poor communication between healthcare professionals and patients including managing the health professional and patient relationship (Salisbury, 2019; Toye *et al.*, 2021). GPs face high demand for their services and as a result, it can be difficult for patients to get appointments (Healthwatch, 2021). Anecdotally, the pandemic due to COVID has also made it more difficult for patients to see their GPs face-to-face.

It is important therefore, to understand the evidence available on the experiences of the clinicians including general practitioners, pharmacist independent prescribers and advanced nurse practitioners, who prescribe to this group of patients to highlight areas of good practice and to identify areas where support is required, and improvements that need to be made. Given the impact that NP has on patients, it is important to understand patients' experiences and health professionals' perspectives. This will help us identify gaps in the literature with a view to identifying areas for further research.

Methods

The scoping review used the methodological framework first proposed by Arksey and O'Malley (Arksey & O'Malley, 2005). The methodological framework consists of five stages, which include:

1. Identifying the research question(s).
2. Identifying relevant studies.
3. Study selection.
4. Charting the data.
5. Collating, summarising, and reporting the results.

The reporting of this review follows the PRISMA extension for scoping reviews (PRISMA-ScR) (Mshelia, 2022; Tricco *et al.*, 2018). No review protocol was created for this scoping review.

Stage 1: Identifying the research question

The research questions for this review were developed to identify studies that focused on the experiences of people who had NP and who used prescribed medicine to manage their symptoms. We were also interested in understanding the experiences of prescribers in primary care settings with managing these patients. The research questions for this scoping review were:

1. What are the experiences of clinicians in GP practices in prescribing medicines to people who have NP?
2. What are the experiences of people who use medicines prescribed in GP practices to manage the symptoms of their NP?

Based on these questions, the aims of this scoping review were to identify, synthesise and identify gaps in the literature on:

1. The experiences of prescribers in prescribing medicines to manage the symptoms of NP.
2. The experiences of people with NP who use prescribed medicines to manage their symptoms.

Stage 2: Identifying relevant studies

Four electronic bibliographic databases (MEDLINE (RRID:SCR_002185), EBSCO CINAHL (RRID:SCR_022707), EMBASE (RRID:SCR_001650) and PsycINFO (RRID:SCR_014799)) were searched from inception to the end of October 2022. With the assistance of a librarian, a search strategy was developed, which used a combination of free text terms and medical subject headings for each database (see Box 1). Search descriptors included qualitative research, neuropathic pain, treatment, experiences, and health care professionals. Figure 1 provides the PRISMA flow chart.

Box 1. Search strategy for Medline.

1 Qualitative Research/ (45438)
2 Interview/ (27777)
3 (theme$ or thematic).mp. (74480)
4 qualitative.af. (181037)
5 questionnaire$.mp. (607210)
6 ethnograph$.mp. (8272)
7 phenomenol$.af. (18163)
8 (grounded adj (theor$ or study or studies or research or analys?s)).af. (9015)
9 (action research or cooperative inquir$ or co operative inquir$ or co-operative inquir$).mp. (3273)
10 (field adj (study or studies or research)).tw. (13059)
11 theoretical sampl$.af. (511)
12 ((purpos$ adj4 sampl$) or (focus adj group$)).af. (47207)
13 ((lived or life) adj experience$).mp. (8020)
14 cluster sampl$.mp. (5545)
15 observational method$.af. (557)
16 content analysis.af. (19083)
17 (constant adj (comparative or comparison)).af. (3460)
18 ((discourse$ or discurs$) adj3 analys?s).tw. (1705)
19 narrative analys?s.af. (913)
20 exp Chronic Pain/ (11763)
21 Chronic pain.tw. (27277)
22 cncp.tw. (168)
23 cnmp.tw. (108)
24 'chronic non cancer pain'.tw. (405)
25 'non malignan* pain'.tw. (303)
26 exp NEURALGIA/ (19009)
27 Facial Neuralgia/ (1240)
28 CAUSALGIA/ (674)
29 exp Peripheral Nervous System Diseases/ (140876)
30 exp Somatosensory Disorders/ (20745)
31 ((neur* or nerv*) adj3 (compress* or damag*)).tw. (38373)
32 (neuropath$ or neuralgi$ or radiculopathy).tw. (122436)
33 Autonomic neuropathies/ (14099)
34 ((pain* or discomfort*) adj3 (central or complex or nerv* or neuralg* or neuropath*)).tw. (26002)
35 hereditary sensory.tw. (532)
36 exp Diabetic Neuropathies/ (21336)
37 exp Phantom Limb/ (1796)
38 Spinal Cord Injuries/ (35573)
39 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 (331868)
40 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 (890214)
41 Prescri*.tw. (166815)
42 Drug therapy/ (29932)
43 medication therapy management/ (1760)
44 medication management.tw. (2179)
45 Pain Management/ (30311)
46 Drug Prescriptions/ (26321)
47 Prescriptions/ (3056)
48 pharmacological treatment.mp. (12211)
49 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 (245690)
50 experience*.tw. (853017)
51 "Quality of Life"/ (175036)
52 Health Knowledge, Attitudes, Practice/ (102425)
53 50 or 51 or 52 (1089655)
54 39 and 40 and 49 and 53 (632)

Stage 3: Study selection

After removing duplicate titles, two reviewers independently screened the titles, abstracts and full text articles for potential studies for inclusion (CM, M-CK). Any disagreements were discussed and resolved with a third reviewer (GM). Relevant studies were included if they met the inclusion criteria outlined in Table 1.

Due to the monetary and time constraints involved in translation, only studies written in English were included in the review.

Studies were excluded if they focused on the treatment of chronic non-cancer pain unless it specified the treatment of NP. Studies focused on the prescription and/or use of only opioids to manage chronic non-cancer pain were also excluded.

Stage 4: Charting the Data

A table was developed to assist with data extraction. The variables we captured data on were the title, population, setting & sampling, data collection method, findings, limitations, and conclusions. Details of the information extracted from each study can be found in Table 2. NVivo (RRID:SCR_014802) version 12 was used to manage the data mapping process, a free alternative to this software is Taguette.

Results

Stage 5: Collating, summarising and reporting the results

This process followed the approach by Thomas & Harden (2008) who recommend a three-stage approach to synthesizing findings from qualitative studies. These stages are:

1. Free line-by-line coding of the findings of primary studies
2. The organisation of the 'free codes' into related areas to construct 'descriptive themes'
3. The development of 'analytical' themes.

The main themes described in each study were identified, coded and analysed. These themes were then arranged into categories and synthesised into analytical themes.

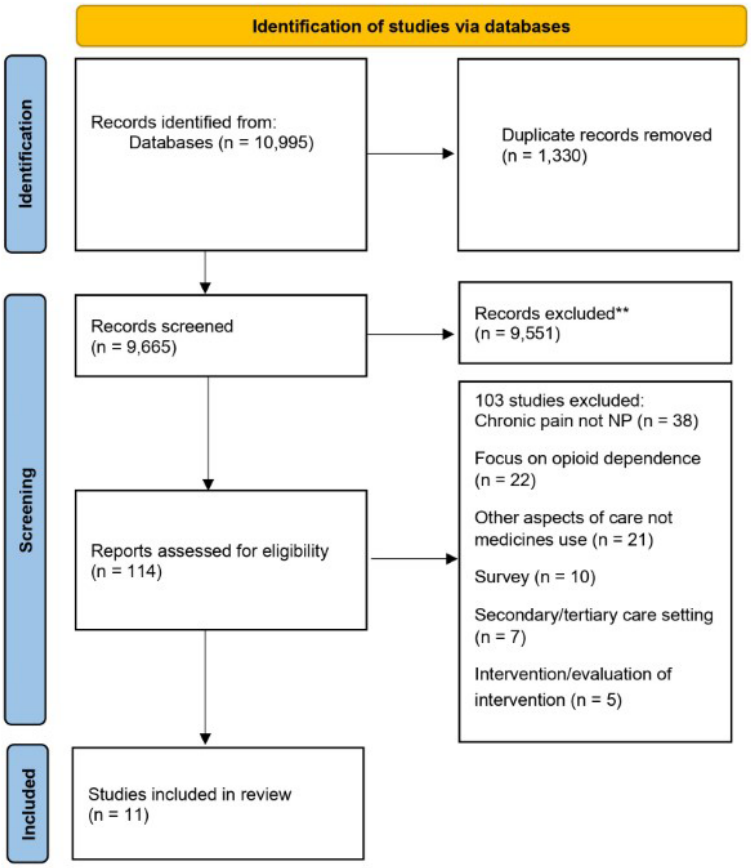

Figure 1. PRISMA flowchart. NP, neuropathic pain.

Table 1. Inclusion and exclusion criteria.

	Inclusion criteria	Exclusion criteria
Population	- Prescribers who prescribe medicines to people with neuropathic pain. - Patients with neuropathic pain.	- Prescribers based in secondary care settings, health care professionals who do not prescribe medicines for people with neuropathic pain. - Patients with no specific neuropathic pain condition *e.g.,* people with chronic pain without a neuropathic component.
Intervention	Medicines prescribed to manage neuropathic pain symptoms.	Approaches other than medicines for managing neuropathic pain *e.g.,* psychological approaches.
Comparators	None	None
Outcomes	Experiences and behaviours of prescribers and patients.	Outcomes such as quality of life, costs, knowledge and attitudes.
Study design	Qualitative study designs.	Other study designs including surveys, analysis of secondary data and literature reviews.
Setting	Primary care settings, out-patient clinics.	Secondary care settings, home.

Table 2. Summary of included studies on patient experiences.

Article	Population (n)	Setting & Sampling	Data collection method	Aims & objectives	Findings	Limitations	Conclusions
Allsop *et al.*, 2015; United Kingdom	Patients with Trigeminal neuralgia (TN); n = 16	United Kingdom, Maximum variation sampling from a list of outpatients of a neurosurgery department.	Focus group	To report the impact of TN on quality of life and contribute to better understanding of current clinical practice with the aim of improving patient care.	4 themes emerged from the data: 1. Diagnosis and support with TN 2. Living in fear of TN pain 3. Isolation and social withdrawal 4. Medication burden and looking for a cure	Participants were recruited from a regional outpatient department so their views may vary from those of TN patients in other parts of the country.	The study highlights the impact on quality of life of both unpredictable episodic pain and complications from treatment.
Buscemi *et al.*, 2018, Italy	Patients with spinal cord injury (SCI) related chronic neuropathic pain (CNP); n = 9	Purposive sample of SCI patients on an outpatient clinic list.	Focus group, virtual interview via email, face-to-face interview	To explore how Italians with SCI related CNP live with their pain, what they knew about CNP, their experience of healthcare in Italy in the context of SCI and CNP and how their health was managed within their particular health and personal contexts.	Themes identified included: 1. The continuous influence of pain in life. 2. Constructing knowledge about living with CNP 3. Developing specialist practice	Participants self- selected to participate in the study. A self-selecting sample may consist more of participants who are more willing or well enough to participate.	The study deepens the understanding of the challenges of living with SCI related CNP.
Closs *et al.*, 2007, United Kingdom	Patients with neuropathic pain (NP); n = 10	Purposive sample of patients who had previously participated in a study on chronic pain.	Focus groups	To add to our understanding of approaches that might be useful for people living with NP.	Themes identified that were related to medicines use included: 1. Ineffective medications 2. Dealing with side effects 3. Acknowledging tolerance and addiction 4. Seeking prescribed medication 5. Use of illicit drugs	The small sample size means it is not possible to generalize the findings to the whole population of people living with the symptoms of NP.	The way that individuals manage their NP is poorly understood and requires further exploration.
Hearn *et al.*, 2015, United Kingdom	Patients with spinal cord injury (SCI) related chronic neuropathic pain (CNP); n = 8	SCI patients attending a national specialist spinal cord injury clinic who were one-year post-discharge.	Semi-structured interviews	To achieve understanding of the experience of chronic neuropathic pain post-SCI in order to explore what those living with it consider important in their experience.	Themes related to medicines use include: 1. Excessive reliance on insufficient medication 2. Losing faith in healthcare professionals 3. Lack of input into own care	Participants self- selected to participate in the study. A self-selecting sample may consist more of participants who are more willing or well enough to participate.	This study allows for a deeper understanding of the experience of living with SCI-related CNP by listening to the stories of those living with it.
Henwood & Ellis, 2004, Canada	Patients with spinal cord injury (SCI) related chronic neuropathic pain (CNP); n = 24	Purposeful sample of SCI outpatients in a state rehabilitation centre	Focus groups	To explore the experiences of SCI patients living with CNP	Constant comparative analysis. Themes related to medicines use include: 1. Medication failure 2. Pain impact	Although 3 focus groups were held, it is not possible to definitively state that data saturation was reached. Retrospective self-reporting can be subject to inaccuracy.	Medication failure was a common outcome. Strategies such as use of warm water, swimming and increased activity provided temporary relief.

Article	Population (n)	Setting & Sampling	Data collection method	Aims & objectives	Findings	Limitations	Conclusions
Kennedy *et al.*, 2017, Ireland	Patients aged over 50 who had chronic non-malignant pain (CNMP); n = 27	All members of Chronic Pain Ireland were invited to participate in the study.	In-depth semi-structured telephone interviews	To describe the perceptions and experiences of analgesics by ageing and elderly individuals with CNMP and identify factors that affect their use.	Thematic analysis. Themes related to medicines use include: 1. Pain severity and analgesic efficacy 2. Adverse effects 3. Addiction and tolerance	Interviews were conducted by telephone resulting in a loss of non-verbal cues gained from face-to-face interaction and the opportunity to use visible aids during the discussion.	People with CNMP view analgesics as an important method of managing pain and rely upon them when other interventions are difficult to access.
Lofgren & Norrbrink, 2012, Sweden	Patients with spinal cord injury (SCI) related chronic neuropathic pain (CNP); n = 18	Purposive sample of people with SCI-related NP from website of patient organization as well as five national rehabilitation units.	Diaries and thematized individual research interviews	To explore and obtain increased knowledge about: i Strategies and treatments used by individuals with NP following SCI for handling long term pain ii Their experience, needs and expectations of SCI-related NP management	Content analysis and constant comparison. Themes related to medicines use include: 1. Drugs- the healthcare solution 2. The gap in my meeting with healthcare	One of the authors had been involved in the rehabilitation of some participants and had knowledge that might have influenced the analysis.	In order to improve treatment outcomes, patients' knowledge, experience and wishes should be recognized and taken into account.
Lönnstedt *et al.*, 2011, Sweden	Patients with chronic neuropathic pain (CNP); n = 11	Purposive sample of patients registered at a pain clinic	Semi-structured interviews	To describe the lived experiences of patients with NP.	Content analysis. Themes related to medicines use include: 1. Having constant pain and needing treatment 2. Pain having an impact on daily life	All participants were chosen from one clinic thus the results may be biased.	Pain was more manageable when taking some classes of medication compared with others. Fear of developing side effects led to non-adherence. There were concerns about the risk of becoming addicted to medication.
Li *et al.*, 2018, Taiwan	Patients with spinal cord injury (SCI) related chronic neuropathic pain (CNP); n = 13	Purposive sample of SCI patients in a neurorehabilitation department.	Semi-structured interviews	To understand the NP experienced by SCI	Content analysis. One theme related to medicines use was: 1. Seeking pain relief methods	Only patients from one neurorehabilitation centre were recruited. This might have introduced bias into the results.	Patients avoided using medicines due to side effects. They preferred to use non-pharmacological approaches such as massage, acupuncture, exercise and physical therapy.

Health Open Research 2023, 5:1 Last updated: 13 NOV 2024

Article	Population (n)	Setting & Sampling	Data collection method	Aims & objectives	Findings	Limitations	Conclusions
Norrbrink *et al.*, 2021, Sweden.	Patients with spinal cord injury (SCI) related chronic neuropathic pain (CNP); n = 18	Convenience sample of people with SCI and NP in an SCI rehabilitation centre.	Semi-structured interviews	To explore the participants' expectations, experiences, and desires with these drugs.	Content analysis. 3 themes were: 1. Balancing between pain and side-effects. 2. Desiring competence and structure in pain management. 3. From hope to personal solutions	Low numbers of individuals who met the inclusion criteria.	Many participants described bothersome cognitive side-effects. This led to many participants choosing to live with pain and the unwanted side-effects from the pain itself instead.
Reddington *et al.*, 2021, United Kingdom	Patients with sciatica; n = 33	Purposive sample of patients from GP practices	Semi-structured interviews	To explore participants' experiences of medication for the management of sciatica.	Thematic analysis. Themes include: 1. Experiences of pain & the need for medication. 2. The perceived effect of medication & participant responses. 3. The side effects of analgesia for sciatica.	Only English-speaking participants were included in the study. This means the findings of the study may not be representative of non-English speaking patients.	The use of medication was associated with significant side-effects leading to cessation of the medication and perceived heightened levels of pain, fear and inability to cope.

We modified a framework that was originally proposed as a means of monitoring the outcome of opioid therapy in people who had chronic non-malignant pain (Passik & Weinreb, 2000). The framework is built upon 4 A's, which are: **A**nalgesia, **A**ctivities of daily living, **A**dverse effects, and **A**berrant behaviour. After initial coding of the included studies, it became necessary to modify the framework as we needed a way to capture the theme relating to patient interactions with health care providers and healthcare systems. We therefore added a fifth 'A' representing '**A**ctivities and actions of healthcare professionals'. The final framework, therefore, comprised of 5 A's: **A**nalgesia, **A**ctivities of daily living, **A**dverse effects, **A**berrant behaviour and **A**ctivities and actions of healthcare professionals.

This framework should not be confused with the 5A's opioid therapy monitoring tool (Pain Management Network, 2014), which is also an adaptation of the original framework by Passik and Weinreb (Passik & Weinreb, 2000) that is used for monitoring treatment with opioids.

Study characteristics

A total of 11 studies were included in the review. All 11 studies focused on the experiences of patients. We found no studies that met our inclusion criteria that focused on the experiences of prescribers. Out of the 11 studies that focused on patient's experiences, four were conducted in the UK, three in Sweden and one in Canada, Ireland, Italy and Taiwan. Most of the included studies focused on participants with NP due to spinal cord injuries (Buscemi *et al.*, 2018; Hearn *et al.*, 2015; Henwood & Ellis, 2004; Li *et al.*, 2018; Lofgren & Norrbrink, 2012; Norrbrink *et al.*, 2021) while others focused on trigeminal neuralgia (Allsop *et al.*, 2015), sciatica (Reddington *et al.*, 2021) and chronic pain, which included NP (Closs *et al.*, 2007; Kennedy *et al.*, 2017; Lönnstedt *et al.*, 2011).

Analgesia

Most of the studies reported on the extent to which participants felt relief from their pain following the use of medication (Allsop *et al.*, 2015; Buscemi *et al.*, 2018; Closs *et al.*, 2007; Hearn *et al.*, 2015; Henwood & Ellis, 2004; Lönnstedt *et al.*, 2011; Lofgren & Norrbrink, 2012; Reddington *et al.*, 2021). However, for many participants, medicines were less effective the longer they had been taking them (Allsop *et al.*, 2015; Closs *et al.*, 2007; Reddington *et al.*, 2021). There was an understanding that the pain would never completely disappear, and so participants accepted some level of pain was inevitable (Buscemi *et al.*, 2018; Hearn *et al.*, 2015). Participants described a cycle of receiving a new medicine, intensifying treatment or increasing doses with it, followed by discontinuation (Henwood & Ellis, 2004). This cycle repeated itself until either the participant felt hopeless or accepted that there was never going to be a remedy for the pain (Henwood & Ellis, 2004). Participants sometimes opted to live with the pain and refused to continue taking prescribed medication altogether because the medicines did not give them relief from the pain (Closs *et al.*, 2007; Henwood & Ellis, 2004; Lofgren & Norrbrink, 2012).

Activities of daily living

Participants reportedly experienced some improvement in their ability to walk, undertake household chores, work, drive and sleep when taking prescribed medications (Allsop *et al.*, 2015; Buscemi *et al.*, 2018; Closs *et al.*, 2007; Lönnstedt *et al.*, 2011). The medicines allowed participants to participate in activities, which they could not have been otherwise able to participate in, hence reducing feelings of isolation and loneliness that they experienced due to their pain (Allsop *et al.*, 2015; Buscemi *et al.*, 2018). There was a struggle to achieve a balance between reducing the burden of their pain on their daily lives and coping with the side- effects of treatment (Allsop *et al.*, 2015; Closs *et al.*, 2007; Lönnstedt *et al.*, 2011).

Adverse effects

The adverse effect of medication was the most popular theme that emerged from the studies. The side-effects reported ranged from mild abdominal discomfort to feelings of lethargy, hallucinations and confusion (Allsop *et al.*, 2015; Buscemi *et al.*, 2018; Closs *et al.*, 2007; Hearn *et al.*, 2015; Henwood & Ellis, 2004; Kennedy *et al.*, 2017; Li *et al.*, 2018; Lönnstedt *et al.*, 2011; Lofgren & Norrbrink, 2012; Norrbrink *et al.*, 2021; Reddington *et al.*, 2021). Some classes of drugs, such as gabapentinoids and opioids were reported to have worse side effects than others such as antidepressants (Kennedy *et al.*, 2017). Participants in the included studies expressed frustration at having to trade-off between the level of pain relief and side effects they experienced (Budh *et al.*, 2006; Li *et al.*, 2018; Lönnstedt *et al.*, 2011; Norrbrink *et al.*, 2021). Some participants stopped taking their medicines due to the severity of the side effects, even though the medicines provided relief from the pain (Li *et al.*, 2018). The severity of side effects had an influence on participants' activities such as work. Some chose to stop taking their medication so that they could go to work as they felt the medication negatively affected their cognitive abilities (Allsop *et al.*, 2015; Closs *et al.*, 2007; Henwood & Ellis, 2004; Reddington *et al.*, 2021).

Aberrant behaviour

This theme relates to behaviours such as adherence, over and under-dosing. Many participants reported instances where they deliberately changed the frequency or timings of their medication (Allsop *et al.*, 2015; Buscemi *et al.*, 2018; Henwood & Ellis, 2004; Kennedy *et al.*, 2017; Li *et al.*, 2018; Lofgren & Norrbrink, 2012; Lönnstedt *et al.*, 2011). This was often done to reduce the severity of side effects. A few participants also took more or less of their medicine, depending on their level of pain on the day (Allsop *et al.*, 2015; Li *et al.*, 2018). It was not uncommon for participants to use other licit and illicit drugs, such as over the counter analgesics, alcohol, benzodiazepines, cannabis and marijuana, together with, or instead of their NP medication (Closs *et al.*, 2007; Henwood & Ellis, 2004).

There was a fear of becoming addicted to the NP medication among participants (Kennedy *et al.*, 2017). This also drove their

aberrant behaviour and influenced their feelings about using the medicines. Some also expressed a fear about how these medicines are viewed and labelled by others if seen to be taking such 'strong' medicines (Kennedy *et al.*, 2017; Lönnstedt *et al.*, 2011; Norrbrink *et al.*, 2021). This fear also affected how and when they used their medicines.

Activities and actions of healthcare professionals

This theme captures the experiences of patients' interactions with the health system and health care professionals. Many participants were frustrated with the process of receiving a diagnosis (Allsop *et al.*, 2015). Some patients reported that they were referred to different specialties and underwent several diagnostic tests before they received a diagnosis. This process took several months during which time, they still had to live with the pain, often managing their symptoms with over-the-counter medication. This delay often led to a loss of trust in the health care professionals and the health system. Some participants also felt that health care professionals failed to acknowledge that they were living with the condition and therefore had some expertise about their condition (Closs *et al.*, 2007; Hearn *et al.*, 2015). There was a sense that health care professionals could be patronising in their approach to patients (Lofgren & Norrbrink, 2012). The participants were of the opinion that the health care professionals sometimes gave them medicines because they did not have any useful alternatives (to medicines) to offer (Adigwe *et al.*, 2013; Buscemi *et al.*, 2018; Closs *et al.*, 2007; Hearn *et al.*, 2015).

Discussion

This scoping review aimed to identify, synthesise and identify gaps in the literature on the experiences of prescribers with regards to prescribing medicines to manage the symptoms of NP, as well as the experiences of people with NP who use prescribed medicines to manage their symptoms. There was no literature on the experiences of prescribers who prescribe medicines for patients with NP. Hence, this review only reports on the experiences of patients who use prescribed medicines to manage their NP symptoms.

The studies included in this review suggest that patients who have symptoms of NP have had concerns with using medication to manage their symptoms. This finding is not different from those of other studies of patients who have other types of chronic pain (Nichols *et al.*, 2020; Toye *et al.*, 2013). Although this scoping review highlights the experiences of patients with regards to the use of medicines to manage NP, there were more studies focused on specific types of NP including trigeminal neuralgia and NP due to spinal cord injury as opposed to NP in general. Consequently, future research should focus on studies that explore the experiences of people living with symptoms of NP without focusing on a specific type or area of the body affected by the NP symptoms.

Findings from the review, indicate that many of the participants experienced partial or no relief from their pain. There was insufficient information to understand alternative treatment options patients with NP tried or the severity of NP being experienced. The findings also suggest that patients tend to stop seeking treatment if the medication does not offer pain relief or if they experience side effects. Therefore, there is a need for further research to better understand the factors that affect those who are undertreated and to identify those who are untreated in the community.

A NICE guideline for the management of chronic pain has recently been published in the UK (NICE, 2021). There has been some debate around the recommendations contained in this guideline especially its support of prioritising non-pharmacological treatment options over pharmacological treatment options (Connect health, 2021; Kmietowicz, 2021). Although the guideline refers to chronic pain and not NP specifically, it is of interest whether the management of NP in primary care settings is altered over time, as a direct or indirect consequence of this guideline.

As far as we are aware, this is the first review focused on the perspectives of patients on the pharmacological management specifically, of NP. A key strength of this scoping review is that we followed Arksey and O'Malley's methodological framework and PRISMA-ScR reporting guidelines. One limitation of this scoping review is that we included only papers published in English. This means that our review only captures the perspective of English-speaking participants.

Conclusions

This scoping review has explored the experiences of people with NP who use prescribed medicines to manage their pain. We have described their experiences as it relates to analgesia, activities of daily living, adverse effects, aberrant behaviour and activities and actions of healthcare professionals. We did not find any studies focused on the perspectives of prescribers. Therefore, there is a need for a study based in the UK that assesses the current experiences of prescribers in primary care settings with regards to prescribing medicines to manage NP.

Data availability

Underlying data

All data underlying the results are available as part of the article and no additional source data are required.

Reporting guidelines

Zenodo: PRISMA-ScR checklist for 'Patients' and prescribers' experiences of managing neuropathic pain with medication: a scoping review'. https://doi.org/10.5281/zenodo.7425703 (Mshelia, 2022).

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