Title: Lived experiences and support needs of women who developed chemotherapy-induced peripheral neuropathy following treatment for breast and ovarian cancer

Abstract

This study explored lived experiences of women who developed chemotherapy-induced peripheral neuropathy (CIPN) following treatment for breast and ovarian cancer. It also explored cancer survivors' perceptions of information and advice offered by clinicians about CIPN and for managing CIPN. The study was advertised through cancer charity websites and social media accounts. Purposeful, convenience sampling was carried out using set eligibility criteria. Individuals with diagnosis of breast or ovarian cancer who experienced or are still experiencing CIPN were recruited. Fifteen semi-structured interviews were conducted. Data were analysed using interpretative phenomenological analysis (IPA). Similar to previous studies, participants used comparisons to describe their symptoms. Four main themes emerged from the analysis: (1) struggle to process CIPN information, (2) information and trust are key in the treatment decision-making process, (3) experience of symptom-reporting and (4) challenges of managing symptoms. Findings suggest interventions to improve understanding of CIPN risk are needed in practice. A better and broader understanding of the patient experience of CIPN could pave the way for improved communication, assessment and management of symptoms. Results suggest the need for interventions to guide cancer survivors to recognise and report CIPN symptoms early and address the impact of CIPN symptoms in their lives.

Keywords: chemotherapy-induced peripheral neuropathy, chemotherapy, patient experience, cancer, survivorship, phenomenology

Introduction

There is clear evidence that symptoms of chemotherapy-induced peripheral neuropathy can affect an individual long after treatment has finished (Hershman *et al.* 2014). Chemotherapy-induced peripheral neuropathy (CIPN) is an umbrella term used to denote nerve damage caused by neurotoxic chemotherapy drugs (Park *et al.* 2013 Miltenburg & Boogerd 2014). An example is Paclitaxel, a neurotoxic drug, used as first-line chemotherapy treatment for ovarian cancer which may be combined with platinum-based compound that also has neurotoxic effects (NICE, 2015). Symptoms of CIPN are mainly characterised by numbness and tingling of the hands and feet, but also include other symptoms such as pain, muscle weakness and sensitivity to cold (Tofthagen *et al.* 2012). The onset, nature, duration and severity of symptoms depends on the drug and cumulative dose (Argyriou *et al.* 2012). To date, evidence-based treatment for CIPN is lacking while prevention is limited to dose reduction, delay or discontinuation of treatment (Hershman *et al.* 2014).

CIPN is known to negatively affect the quality of life of those who develop it (Mols *et al.* 2014, Tanay *et al.* 2016). Individuals become more prone to falls and injury (Tofthagen *et al.* 2012, Mohile 2013, Gewandter *et al*. 2014). Carrying out activities which involve the hands and feet, such as driving, typing on computers, writing, sewing, painting and handling tools, become difficult or challenging (Tanay *et al.* 2016). Patients and their caregivers report financial losses as a result of having to reduce their working hours or having to give up their job due to dexterity problems. Studies in the United States (US) show patient and carer work loss amounted to $4,220 per patient over a nine-month period (Calhoun *et al.* 2001). There is also a potential economic impact to the health service. A study by Pike *et al.* (2012) in the US showed that healthcare providers spend up to $17,344 more if patients develop CIPN, due to extra outpatient drugs and devices, more outpatient visits and hospitalisations (Calhoun *et al.* 2001).

In the United Kingdom (UK), previous nationwide patient satisfaction surveys show CIPN is a persistent problem for cancer survivors. Free-text responses from a survey conducted by the Department of Health in England suggest there is inadequate preparation about the extent to which CIPN could affect them and insufficient advice

is provided on its management (Corner and Wagland 2012). As survival rates for many types of cancer increase and improve (Cancer Research UK 2015), providing information about potential side effects of treatment and access to advice about symptom management is paramount to promote recovery, health and wellbeing after treatment (NCSI 2013). Despite its negative effect on cancer survivors' quality of life long after treatment is completed and substantial personal and healthcare costs, patient perception of CIPN risk are not prominent in the cancer experience and only surface when symptoms are severe (Tanay *et al.* 2016). It is also unclear from the literature what influences patients' perception of CIPN risk and current clinical management from patients' views. It is vital that research is conducted to gain better understanding of current clinical management of CIPN as perceived by patients. Consequently this study aimed to address the lack of research exploring the lived experience of CIPN of people with cancer survivors in the UK (Tanay *et al.* 2016).

Aim

This study aimed to explore lived experiences of UK cancer survivors living with symptoms of CIPN following treatment of breast and ovarian cancer. It also explored cancer survivors' perceptions of information and advice offered by clinicians about CIPN and for managing CIPN symptoms.

Methods

A phenomenological approach was employed to understand real life experiences of individuals who had or still have symptoms of CIPN and to investigate the meaning of their experiences (Green and Thorogood 2018). The study was advertised once through cancer charity websites and social media accounts *e.g.* Wordpress™, Twitter™ and Facebook™ with permission obtained from charity gatekeepers. Purposeful, convenience sampling was employed and participants recruited if they met the study eligibility criteria (Table 1). The study information sheet and researcher's contact details were provided by either email or post to those who expressed a willingness to participate. We aimed to recruit up to 20 participants from across the United Kingdom. A total of 54 individuals responded within the first two weeks of recruitment and were all sent patient information sheets. Eighteen (n=18) of 34 individuals who responded

after being sent a patient information sheet agreed to participate and signed a consent form. Two were subsequently found to be ineligible and one participant was not interviewed for health reasons. Fifteen semi-structured audio recorded telephone interviews were conducted by the primary author (MT) at a time convenient to the participants between September 2015 and June 2016. Open-ended questions were used to explore their experiences (Patton 2002). For example, 'How was neuropathy explained to you?'; 'Describe how neuropathy affected your daily life and activities'; 'Describe how the information you received helped you to recognise the symptoms'; 'What support was provided to help you address the symptoms?'. These questions provided an opportunity to further explore participants' experiences (Patton 2002). Interviews lasted 20-54 minutes.

Data were analysed using interpretative phenomenological analysis (IPA) to explore how individuals made sense of their experiences (Smith and Osborn 2003). This approach allowed exploration of the participants' perspectives of their experience while permitting the researchers to conceptualise and interpret an individual's world (Smith *et al.* 2009). The interviews were transcribed verbatim. After repeated reading of the entire transcripts, preliminary themes were identified. Themes were grouped and clustered and main themes were organised across transcripts (Smith and Osborn 2003). Emerging key themes represented the nature of participants' experiences (Willig & Stainton Rodgers 2008). Both researchers (MT, JA) participated in the analysis process and confirmed the themes. Data were managed using Microsoft Excel© software. The study was approved by King's College London, Psychiatry, Nursing and Midwifery Research Ethics Subcommittee (HR-14/15-1759).

Results

Of fifteen female participants (*n*=15) recruited to the study, thirteen (*n*=13) were diagnosed with ovarian cancer. One participant was diagnosed with breast cancer and one was diagnosed with peritoneal cancer but was included because her initial diagnosis was ovarian cancer. The mean age was 62 years (range 50-76 years), and all participants described themselves as White-British or White-European ethnicity. At the point of data collection, the average time since participants completed chemotherapy treatment

was 4.4 years (range 0.5-18 years). Although all participants were still experiencing CIPN symptoms, intensity varied from mild to severe. Participants resided and received chemotherapy treatment across different regions of the UK; about 40% were treated in London. Table 2 shows participants' demographic profile and chemotherapy drugs they received. Data regarding modifications in chemotherapy schedules were not collected.

Four main themes emerged from the analysis: (1) struggle to process CIPN information, (2) information from and trust in clinicians are key, (3) experience of reporting CIPN symptoms and (4) challenge of managing CIPN symptoms. Table 3 provides examples of quotes illustrating the main themes and sub-themes while Figure 1 presents a thematic diagram of the four main themes.

Theme 1: Struggle to process CIPN information

Overwhelming information before starting treatment

Participants reported that information about CIPN was sandwiched between layers of information about cancer and chemotherapy which they received prior to starting treatment. They mentioned being given *'a whole list of side-effects'* (P-02, P-08, P-12, P-13, P-14) and having *'a big discussion about the treatment'* (P-01). For them, there was so much information that it was very hard to absorb everything that was said, especially so close to being diagnosed with cancer (P-06, P-08). Despite feeling bombarded by too much information, decisions had to be made quickly (P-01, P-03, P-06). They felt they were being *'swept along with what clinicians were saying'* (P-03) despite having difficulty understanding everything that was said about the treatments.

Little or no information about CIPN

Most participants mentioned that they did not get any information, did not remember getting information (P-01, P-06, P-15) or only received minimal information about CIPN (P-02, P-04, P05, P-12, P-14). They reported that although CIPN was listed on the written chemotherapy information, clinicians did not put enough emphasis on how CIPN could affect their quality of life (QOL) leaving them surprised when symptoms appeared and lingered for a long time (P-03, P-06).

Potential risk is uncertain

Participants mentioned that information about the potential risk of CIPN and potential severity of CIPN symptoms lacked clarity. Prior to chemotherapy, they were told that it *'may not affect them'* (P-04, P-013). One was told *'not to get too paranoid about the side-effects'* and felt *'the nurse was protecting her from becoming too anxious'* (P-13). Another participant said *'they [clinicians] don't want to talk about the side effects because they know that lots of people probably would query a lot more and possibly wouldn't go ahead with the chemo*' (P-04). When CIPN symptoms started to appear and the duration of CIPN symptoms were discussed, some participants were told it *'will probably clear up'*, *'may get better'*, or *'should not last for much beyond the end of treatment'* – participants said they did not find such comments useful or helpful (P-01, P-03, P-08, P-09). While many participants mentioned that their symptoms improved over time, all were still experiencing residual CIPN symptoms at the time of data collection. For some, symptoms were still severe and significantly diminished their QOL even after months or years from completion of treatment.

Theme 2: Information and trust are key

Those who reported receiving adequate information felt empowered as they knew what symptoms to look out for. They said that information helped manage their anxieties – *'I think that (information) is really important because you don't get anxious'* (P-08, P-09, P-10). One pointed out that having detailed information about CIPN had not deterred her from having chemotherapy (P-10). When decisions had to be made about treatment due to CIPN symptoms, those who received information trusted their clinicians and felt included in the treatment decision-making process (P-05, P-10, P-12, P-13). While participants acknowledged that *'not having chemotherapy'* was not a decision they would have made at the time, specific and ongoing information about CIPN would have better prepared them for its deleterious effect on their lives (P-01, P-03, P-09, P-10, P-12, P-15).

Theme 3: Experience of symptom-reporting

Reported but not followed-up

It was unclear to participants when assessment of CIPN symptoms should happen. Some were told that they must report CIPN symptoms as soon as possible, but those who did this were not followed-up by a clinician for a few weeks (P-09, P-11). Some were given further chemotherapy cycles without CIPN reassessment or discussion taking place; during which time their symptoms worsened (P-04, P-11). Participants who were enrolled in clinical trials and hence had regular follow-up with clinicians felt CIPN symptoms they reported were only collected for the trial purposes as nothing was done to help alleviate them (P-04, P-06). Similarly, participants seen by chemotherapy nurses prior to each chemotherapy cycle were asked about their CIPN symptoms but no further contact was made after *'data was collected'* (P-10, P-03).

Felt ignored

Some participants felt they '*were not listened to', 'dismissed'* (P-04) and '*ignored*' when they mentioned their CIPN symptoms (P-03, P-06-P-14); and as a result they learned not to report them (P-01, P-02, P-03). The impression they got was that they were *'misunderstood'* by clinicians and *'nobody was taking their symptoms seriously'* (P-03, P-15). There were several explanations participants suggested as reasons for clinicians' not taking notice of their CIPN symptoms. These included: clinicians are '*too busy'* (P-15), a notion that '*CIPN is so common and didn't surprise anybody'* (P-03, P-06, P-14), clinicians say *'symptoms are temporary'* (P-03, P-08, P-09) and that they only take notice when patients '*cannot cope with the symptoms anymore'* (P-10, P-11). A participant suggested that there should be *'more acknowledgment that CIPN affects many people, because it is a bit of a secret thing'* (P-14) and that *'clinicians should listen more to their patients'* (P-04). Having experienced how CIPN negatively affected their lives, participants, with hindsight, wished they had *'insisted for clinicians to take more notice'* (P-03, P-04) rather than *'not making a fuss'* despite *'suffering the symptoms'* (P-01).

Theme 4: Challenge of managing symptoms

Participants used metaphors to describe their symptoms, as highlighted in earlier qualitative studies (Tanay *et al.* 2016). Examples are: 'walking on fine gravel or sand', 'was like walking on needles', 'walking on marbles or pebbles', 'scrunched-up socks under my foot', 'feeling like nails coming off the nailbed', 'getting an electric shock', 'like wearing strange gloves' and 'like having an anthill on my feet'. CIPN had a profound disabling effect on their daily lives and everyday life became fraught with danger, even in their own homes.

> *'Difficult to write, really difficult to hold a pen and control that, quite difficult to type on a computer. I'd drop things quite a lot'* (P-09).

> *'I ended up breaking a rather precious and expensive casserole because I, I didn't get the hold of it properly'* (P-10).

> '*I look at my lovely shoes sitting in the wardrobe that I can't wear any more'* (P-03)

Participants mentioned how CIPN symptoms restricted their movement, sometimes keeping them from going out of their homes. This was highlighted as a significant effect on their quality of life as they were unable to socialise, made worse by fear of falling and injury.

> *'I couldn't manage to do a length of a walk anywhere'* (P-05)

> *'I stopped going into my office and I had to pretty much stay put and work from my armchair. It also definitely affected my moving around the house. It's not as insignificant as people think perhaps'* (P-06).

> *'Sometimes my legs go numb and sometimes it starts when I'm walking, which means I have to stop because I can't feel the leg and I can fall. I want to say the quality of life has been severely affected. I have to think very hard before I go anywhere'* (P-15).

Dealing with symptoms with minimal clinician input

Most participants felt they were left to manage their symptoms on their own and were unsure where to seek help about CIPN symptoms, particularly after discharge (P-04, P-07, P-13). They felt clinicians were dismissive of their symptoms and that their attitude suggests that CIPN is a price worth paying to survive cancer, and is viewed as '*an acceptable and expected symptom*' (P-02, P-04, P-06, P-09, P-10, P-12). Further, some participants suggested that people who have not experienced CIPN will find it difficult to understand – this is why *'clinicians cannot relate to it all and so it [CIPN] is put on the backburner'* (P-04, P-09, P-14, P-15). Some mentioned that maybe *'they [clinicians] do not have the information on what to do or there is nothing to tell'* (P-03, P-04). Many participants no longer reported their CIPN symptoms as they were left to *'get on with it'* or *'put up with it'* (P-01, P-02, P-04-06), and '*would not want to trouble the doctor'* (P-01, P-02).

Lack of practical advice on self-management

Participants overwhelmingly suggested '*more practical advice to support self-management of CIPN symptoms'* was needed (P-01, P-02, P-05, P-09-11, P13-15). They felt clinicians focused on managing their symptoms using pharmacological approaches, mainly to manage the pain, until they ran out of drugs to prescribe (P-01, P-11). However, participants pointed out the usefulness of information about self-management approaches that could help minimise the severity of their symptoms, mitigate the effects of CIPN and possibly help them get back to doing the things that they enjoyed doing (P-04, P-07 and P-13). Many obtained self-management information from other cancer survivors rather than from members of the chemotherapy team. These include using hot or cold packs, wearing walking boots, choosing clothes that have no buttons, performing video calls rather than telephone calls, bringing poles when walking and wearing sufficient warm clothing during cold weather. Many participants mentioned how acupuncture, reflexology and massage also minimised symptoms.

Searching for elusive information

Various avenues were accessed by participants to obtain more information about CIPN such as on-line discussion groups and websites with CIPN content. The majority accessed a variety of cancer charity websites both in the UK and USA, as well as

medical sites including information about diabetic neuropathy. What participants found most useful were patient forums where cancer survivors shared their individual CIPN experiences and interventions they used to minimise symptoms. On the other hand, participants expressed frustration about there not being a single place available to obtain information about CIPN and the fact that they had to find the information themselves. Many compared some of their issues to those experienced by individuals with diabetic neuropathy but felt disappointed that neuropathy services for cancer survivors are not well established.

Interpretative analysis of our findings suggests that CIPN was not experienced as the minor or discrete symptom described by clinicians. Rather participants saw themselves as profoundly disabled and socially isolated as CIPN impacted every aspect of their day to day lives. Moreover many described how they suffered in silence because clinicians appeared to ignore or dismiss their reports of CIPN symptoms and so they were forced to seek alternative sources of information and support. This implies that clinicians lack understanding of the wide ranging and negative impact that CIPN can make on the quality of life of people treated for cancer. They seem blind to the notion that whilst the treatment has successfully eliminated the cancer, it has permanently disabled the person. This suggests the consequences of CIPN are 'hidden' from view and are shouldered in private by those who suffer from them.

Discussion

Our findings highlight the negative impact of CIPN on those who experience them, which is consistent with previous studies (Boehmke & Dickerson 2005; Bakitas 2007; Tofthagen 2010b; Speck *et al*. 2012),. Functional limitations because of symptoms involving their hands and feet resulted in challenges performing household and work activities. Recent studies showed CIPN was associated with falls and injuries (Winters-Stone *et al*. 2017). Participants in our study described that they felt unsafe and worried that they may fall, with some who reported they had fallen because of CIPN symptoms. These effects compromise cancer survivors' road to recovery. Lack of confidence and fear of falling may prevent an individual from doing their usual activities at home. Falls and injuries could prolong inactivity, delay resumption of daily activities and

performance of social roles and can also delay return to work which can have economic implications. As previous cost analysis studies showed, CIPN also has financial implications for the health service as symptoms and lead to functional consequences of CIPN that may require additional pharmacological treatment and medical devices, extra outpatient appointments and longer hospital stays (Pike *et al.* 2012, Calhoun *et al.* 2001)

As severity of CIPN symptoms are dose-related, it is paramount that healthcare professionals and patients work together to restrict progression of symptoms by delaying or reducing treatment (Park *et al.* 2013). Clear information about CIPN will help patients recognise CIPN symptoms early. Evidence suggests that when individuals understand the benefits and risks of their treatment, they become more involved in their care (Ahmed 2012). If CIPN symptoms are recognised early, these can be reported as soon as possible so individuals can be offered appropriate support by their clinicians. However, despite the potential considerable impact on patient's quality of life, our findings showed that patients felt little or no information about CIPN risk was provided to them prior to start of treatment - similar to findings from previous research wherein participants felt inadequately informed about CIPN (Boehmke & Dickerson 2005; Bakitas 2007; Tofthagen 2010a).

The women in our study reported feeling overwhelmed when provided with large amounts of information about their treatment and potential side effects so close after the time of cancer diagnosis (Corner and Bailey 2009). This may explain their poor grasp or incomplete processing of important information. It was also clear that participants struggled to understand the relevance of CIPN risk at the start of treatment, and that when they reported CIPN symptoms to clinicians, the uncertainty of CIPN became magnified. Edwards *et al*. (2002) suggest using graphics to offer a visual representation to facilitate understanding and comparison of risks. Using easy-to-understand graphs can help explain incidence and duration of CIPN symptoms to patients. For example, Ozanne *et al*. (2014) developed a tool that provides risk assessment and decision support for both patients and clinicians to use collaboratively. Participants in our study felt their clinicians withheld some information to protect them from worrying or feeling anxious about their treatment. However, they (participants) suggested that they would have wanted more information about the risk of CIPN and how it may affect them. Participants also suggested that receiving clear information

from clinicians helped to develop trust, enhancing confidence in their clinicians especially when making difficult treatment decisions such as dose-reduction, delaying or discontinuing treatment. Previous research shows that trust and emotions affect individual perceptions and decisions about risks (Slovic *et al.* 2004) and may help to empower patients to involve themselves in decision-making. But it is unclear from our findings what CIPN information is adequate or too much for patients. Further research is needed to explore patients' perceptions about the amount and content of information, when CIPN information is needed and how CIPN information is best delivered to emphasise the risks. Strategies such as appropriate timing, gradual and continued reinforcement of information, particularly late onset or long-term side-effects of chemotherapy such as CIPN, may help patients to effectively process information.

The challenge of CIPN assessment does not lie solely on the lack of patient's recognition of symptoms. As highlighted in earlier American studies (Tanay *et al.* 2016), women in this study felt ignored when they reported CIPN symptoms to clinicians and highlighted a lack of further or proactive assessment of CIPN symptoms by nurses and doctors. This may be due to a lack of consensus as to the most appropriate assessment tool for CIPN (Curcio 2016) and because treatments options are limited (Arygyriou *et al.* 2012), possibly making CIPN difficult to discuss if clinicians cannot offer other interventions. Further, assessments such as nerve conduction studies, Rydel-Seiffer tuning fork and 10 g monofilament (Cavaletti *et al.* 2012) are time-consuming to conduct and require specialist skills. There is also evidence in our study that the potential severity and impact of CIPN symptoms were somewhat downplayed by clinicians. Clinicians' attitudes that leant towards the temporary nature of CIPN symptoms rather than long-term, coupled with ignoring behaviour when patients report their symptoms, may prevent early CIPN management. Patients can become discouraged and disinterested in reporting CIPN symptoms if their symptoms are ignored or downplayed.

Findings in our study strongly indicate that participants wanted more information about how they could better cope with CIPN on a day to day basis. Mirroring findings from previous studies (Tanay *et al.* 2016), participants in our study described CIPN symptoms using metaphors and analogies. This may be their way of emphasising that CIPN is a different experience, not merely 'pins and needles', a term commonly used

to explain the symptoms. They highlighted that the experience of CIPN will be difficult to understand for those who have not experienced the symptoms. Thus, research studies using questionnaires with limited choices to describe neuropathy symptoms should also allow patients to describe their symptoms in their own words. During clinical assessment, individuals should also be encouraged to describe their CIPN symptoms and explain how these affect their daily activities.

CIPN affects various aspects of daily living such as work, social, leisure and domestic activities (Tanay *et al.* 2016). The women in our study mentioned how CIPN symptoms affected their lives resulting to social isolation, safety issues and difficulties in performing tasks at home and at work. Information about social/family roles, occupation, lifestyle and activities during patient-clinician dialogue may be necessary, taking into account the realities of how CIPN affects patients and cancer survivors in their daily lives. Without guidance, coping with functional consequences of CIPN symptoms can be challenging for individuals as they try to minimise the impact on their lives.

Most participants obtained CIPN information from other sources. As a result of receiving information from clinicians, a small number of participants felt empowered. This supports findings from a study by Yates *et al.* (2005) in which an educational intervention showed potential to empower women to cope with cancer fatigue. Participants also highlighted the usefulness of practical suggestions from other cancer survivors which they accessed through charity events, health forums and chatrooms. There is evidence to suggest that group education improves patients' knowledge about their specific illness and self-care (Steinsbekk *et al.* 2012, Plow *et al.* 2011). Various self-management interventions have been developed for other conditions and symptoms such as HIV/AIDS (Nicholas *et al*. 2007), arthritis, diabetes, COPD and cancer-related fatigue and were proven effective (Barlow *et al*. 2002; Foster *et al.* 2016). Bearing in mind the benefits of obtaining information from both clinicians and fellow patients/cancer survivors, a self-management educational intervention for CIPN co-designed by both patients/cancer survivors and clinicians, may be an effective approach (Robert *et al*. 2015).

A few limitations of our study are worth noting. Although recruitment using social media was relatively easy, only those with access to such platforms were able to obtain information about study participation. Thus those interviewed were more likely to be technologically savvy individuals who obtain information via the internet. It is also possible that these participants were more likely to have severe CIPN, were persistently exploring CIPN information from various sources and therefore were more motivated to participate. Our recruitment approach may have excluded those with limited IT skills or limited means of finding information and, indeed, may have different experiences of getting CIPN information. Telephone interviews may also have affected participants' responses. Some participants mentioned difficulty holding their phones for a long time due to existing CIPN symptoms, and they may have unconsciously limited their answers to shorten the interview. Most participants were diagnosed with ovarian cancer; all were Caucasian females, and over the age of fifty. The researchers learned at a later stage of the recruitment that the study webpage was shared in an ovarian cancer support discussion forum bv a participant. This may explain the response received from ovarian cancer survivors. The experience of CIPN may be different for those with different cancer diagnoses, are male, younger s and individuals from ethnic minorities. The experience of CIPN among these populations should be explored in future research.

While neurotoxic chemotherapy drugs remain a main treatment modality for treating cancer and as more and more individuals survive cancer, the incidence of CIPN among cancer survivors is likely to also increase. CIPN symptoms may linger years after chemotherapy treatment had finished. It is important to consider strategies to empower patients from the start of treatment to identify CIPN symptoms early, to proactively report their symptoms to clinicians and to effectively self-manage their symptoms. Research focused on developing interventions to address gaps in practice is essential to improve patient experience and to achieve as healthy and optimum patient quality of life as possible for patients who develop CIPN following treatment of cancer.

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Table 1. Sample eligibility criteria

Inclusion criteria	Exclusion criteria
Individuals who: • were diagnosed with ovarian, breast or colorectal cancer; • had experienced or are still experiencing symptoms of chemotherapy-induced peripheral neuropathy; • had received neurotoxic chemotherapy drugs for cancer treatment, • were 18 years old and above, • were willing to provide consent, • were UK-residents.	Individuals who: • had peripheral neuropathy caused by other conditions such as diabetes or caused by cancer treatments other than chemotherapy; • were unable to speak and understand English due to lack of translation resources; • were unwilling to have their interviews recorded.

Table 2. Participant profile

Study ID	Cancer diagnosis and stage	Chemotherapy drugs	Completed chemotherapy at the time of interview (Year and Month)	Age	Gender	Ethnicity	UK Region	Still experiencing CIPN symptoms
01	Stage 3 ovary	Paclitaxel and Carboplatin	2Y and 2M	60	Female	White-British	Devon	Yes
02	Stage 3c peritoneum	1st line: Paclitaxel and Carboplatin 2nd line: Carboplatin then Cisplatin	10Y	75	Female	White-British	Suffolk	Yes
03	Stage 1c ovary	Carboplatin	2Y	58	Female	White-British	Nottingham	Yes
04	Stage 2c ovary and right fallopian tube	Paclitaxel and Carboplatin	2Y	74	Female	White-British	Cambridgeshire	Yes
05	Stage 2a ovary	Paclitaxel and Carboplatin	18Y	76	Female	White-British	Glasgow	Yes
06	Stage 3c ovary	Paclitaxel and Carboplatin	2Y and 6M	50	Female	White - European	Windsor	Yes
07	Stage 3c ovary	Paclitaxel and Carboplatin	1Y and 6M	51	Female	White - European	London	Yes
08	Ovary (stage unknown)	Paclitaxel and Carboplatin	15Y	70	Female	White - European	London	Yes
09	Stage 2c ovary	Paclitaxel and Carboplatin	1Y	51	Female	White-British	Hertfordshire	Yes
10	Stage 3c ovary	Paclitaxel and Carboplatin	3Y	69	Female	White-British	Lincolnshire	Yes
11	Stage 1c ovary	Paclitaxel and Carboplatin	5Y	54	Female	White-British	Staffordshire	Yes
12	Stage 2 breast	5FU, Epirubicin, Cyclophosphamide and Docetaxel	9Y	53	Female	White-British	Cambridgeshire	Yes
13	Stage 3 ovary	Paclitaxel and Carboplatin	5M	67	Female	White-British	Devon	Yes
14	Stage 3 ovary	Paclitaxel and Carboplatin	2Y	69	Female	White - European	London	Yes
15	Stage 1c ovary	Paclitaxel and Carboplatin	9Y	54	Female	White - European	London	Yes

Table 3. Themes, subthemes and text examples of participant quotes

Main themes	Sub-themes	Text examples
The struggle to process CIPN information	*Overwhelming information before starting treatment*	"I think because you're so overwhelmed with the information about the fact that, one, that you've got cancer and two, that you need to have chemotherapy treatment" (Participant 1) "I wasn't in a position to think about side effects" (Participant 15)
	Little or no information about CIPN	"I don't remember receiving any direct information from the nurses or anything." (Participant 6) "There was a brief mention of the fact that sometimes carboplatin can cause pins and needles and a bit of numbness but this should wear off after treatment. And that's pretty much all that was there. There was no warning that it could be a serious effect or that it could be long term." (Participant 1) "I was probably given like an information sheet at the time… that was really it." (Participant 12)
	Risk is uncertain	"I told everybody. I said, 'Look, this is bothering me now because it's still there. My feet feel odd.' And they just said, 'Oh yeah, that it is probably a bit of nerve damage. Don't worry. It will *probably* clear up,' and that was pretty much it. But it didn't and it got worse. (Participant 3) "I did speak to the consultant who was my oncologist but they just said that - I mean that was, you know, that was because of the treatment I was having and that they - well, both of the therapies did cause that and it *may improve* after I'd finished treatment." (Participant 1) "I don't know that I identified the neuropathy as, as being a particular concern because I think I'd been told repeatedly that it will improve, it will get better." (Participant 9) "Well, I asked how long and, and quite rightly they would reply that everybody was individual and, you know, they couldn't really say, but that it shouldn't last for much beyond the ending of treatment." (Participant 8) 'But when you say, 'Well, I'm a bit worried about peripheral neuropathy,' 'Well, we don't think you'll get that.' So you are dismissed.' (Participant 4)
Information and trust in clinicians are key	*Information*	"I couldn't feel anything at all. And that's when he came and said to me, 'I'm sorry, but we're not prepared to give you your last one.' And I think I burst into tears at that point because I was so excited this was my last one. And, this will kill anything that's there…It took me a wee while to get my head round that. I took charge of it so that I made the decisions." (Participant 5) "I don't think any of the information I was given deterred me from going into chemo to get the maximum benefit for myself and then I just thought, 'Well, I'll cope with the side effects and when I'm not coping, I'll chat to somebody and we'll make a decision'" (Participant 10) "But I think maybe that sometimes they ought to give you the information because, at the end of the day, you're the one who's got to live with it afterwards. I think they're so keen to get you to have the treatment because they know you need it to save your life they forget that … when they've saved your life you've got to live with the consequences of what they've done. So I would rather have known. I would still have probably had it." (Participant 3)
	Trust	"I don't think it was my decision. It was the consultant, the oncologist. You know, I was happy to go along. Well, because I very much trusted what he was saying." (Participant 2) "I've been asked for my opinion as has my husband as well, he was involved in all the consultations. So I think because I had confidence in them, well not that you don't question but you accept more I think." (Participant 13)
The experience of symptom-reporting	*Reported but not followed-up*	"I think that if you start noticing it halfway through chemotherapy there should be a point where you can discuss all of this." (Participant 14) "I think as well there just needs to be some sort of assessment, I was never assessed after, I was never given any, it was only because I raised the subject, it was never mentioned during or after treatment, it was because I raised the subject later on after the treatment finished." (Participant 11) "I reported it quite quickly, but it wasn't followed up for several weeks, so I'd had then one more cycle of chemo before I had the opportunity to speak to my oncologist about it." (Participant 9)
	Felt ignored	"…it's just push the chemo, push the chemo and not thinking about the person. And I think they have to think about the person. I think oncologists should listen more to their patients." (Participant 5) "I think she should have picked up more when I raised my concerns." (Participant 4) "It would have been nice to be - to have been taken seriously at the time. I think for cancer patients and certainly for those who suffer these different side effects that are long lasting, if not permanent, is being taken seriously." (Participant 3)
The challenges of managing symptoms	*Lack of practical advice on self-management*	"They always ask – so they track, for the purposes of the trial, the side effects. So I am always asked, without fail, about – about peripheral neuropathy, but no proactive information given, no." (Participant 6) "And I think that's the sort of thing they should be looking at is 'What can we do when people have these effects, these side effects?' Whether they're permanent, long term, short term or whatever, we need somebody that can talk to them and explain to them what their options are, what they can do, how they can help. Advice on how to deal with it." (Participant 3) "I didn't realise there were things that might have helped." (Participant 11)
	Patients actively looking for information	"You kind of have to accept that if there isn't very much anyone can do for you that you're a bit on your own. That's why you go to the forums, to find out if anyone has got a secret that helps them." (Participant 14) "Just so really I went to places where I thought I could get help and advice and I've worked round it on that basis." (Participant 6)
	Dealing with symptoms with minimal clinician input	"You were just left to get on with it." (Participant 6) "No, there was no discussion about what can be done about it at all. It was very much it's just one of the side-effects you might get. There was nothing about how you could ameliorate it or – nothing that I recall." (Participant 7) "I didn't make a fuss so they weren't aware that I was suffering as much as I was" (Participant 1)

Figure 1. Thematic map illustrating four main themes