

Patient Perceptions Associated With Chemotherapy-Induced Peripheral Neuropathy

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Peripheral neuropathies are a common side effect of certain types of chemotherapy drugs, including taxanes, platinum-based drugs, vinca alkaloids, and thalidomide. Neuropathies may last for months or years following treatment and can impact functional performance and quality of life. The purpose of this study was to explore the effects of chemotherapy-induced peripheral neuropathy (CIPN) and neuropathic pain on the lives of patients with cancer. Participants were recruited from an urban outpatient medical oncology clinic in West Central Florida. Semistructured, private interviews with 14 participants were conducted and transcripts were reviewed for symptoms and effects. Participants often had difficulty describing neuropathic symptoms but reported simultaneous pain or discomfort and loss of sensation in the upper and lower extremities. Injuries secondary to numbness, muscle weakness, and loss of balance were reported. Neuropathic symptoms interfered with many aspects of daily life and participants voiced feelings of frustration, depression, and loss of purpose as a result of having to give up enjoyable activities. The results of this study emphasize the importance of ongoing assessment and communication with patients about their experiences with peripheral neuropathies. Knowledge of what patients with CIPN experience will guide nurses in suggesting interventions to promote safety and help alleviate symptoms.

Neurotoxic chemotherapy drugs, such as taxanes and platinum-based agents, are prescribed to treat many of the 750,000 people diagnosed with breast, prostate, lung, or colorectal cancer each year (American Cancer Society, 2008). Neurotoxic chemotherapy drugs also are used to treat less common malignancies such as testicular or ovarian cancer and multiple myeloma. More than 30% of patients who receive paclitaxel, docetaxel, oxaliplatin, or cisplatin will develop chemotherapy-induced peripheral neuropathy (CIPN) (University of Florida Shands Cancer Center, 2009). CIPN causes a variety of unpleasant symptoms that are uncomfortable and difficult to manage (Bakitas, 2007; Wilkes, 2007). Severe peripheral neuropathies result in dose reductions, a change in chemotherapy regimen, or early cessation of chemotherapy, all of which compromise the success of cancer treatment (Mantyh, 2006; Visovsky, 2003). In addition, neuropathies can interfere with key aspects of quality of life, including physical, social, and role functioning and emotional well being (Bakitas, 2007; Ostchega, Donohue, & Fox, 1988). The purpose of this study was to explore the effects of CIPNs and neuropathic pain on the lives of patients with cancer. The following research questions

At a Glance

- ◆ Patients with chemotherapy-induced peripheral neuropathy (CIPN) report a combination of sensory and motor symptoms, both painful and nonpainful.
- ◆ CIPN negatively affects physical and emotional well-being. Patients report feeling significant personal loss when CIPN affects their ability to participate in usual activities.
- ◆ Oncology nurses can assist patients with CIPN by thoroughly and frequently assessing neuropathic symptoms and their effects on quality of life.

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were addressed in this study: (1) What are the most frequently reported symptoms of CIPN, and (2) what aspects of daily life do symptoms of CIPN affect?

Neuropathic Symptoms

The National Cancer Institute's (n.d.) Dictionary of Cancer Terms defined peripheral neuropathy as "a nerve problem that causes pain, numbness, tingling, swelling, or muscle weakness in different parts of the body. It usually begins in the hands or feet and gets worse over time" (p. 1). Peripheral neuropathy is characterized by sensory symptoms, which involve unusual or exaggerated responses to stimuli (painful symptoms) or loss of sensation (nonpainful symptoms). Motor symptoms, which affect the musculoskeletal system, also may be manifestations of peripheral neuropathy and can be classified as painful (i.e., arthralgias) or nonpainful (i.e., muscle weakness) (Backonja, 2003).

Ostchega et al. (1988) conducted interviews with patients who had received high doses of cisplatin and found that they often reported numbness, tingling, stiffness or tightness, and discomfort in the feet and also reported loss of balance. Postma et al. (2005) interviewed patients and health professionals and concluded that difficulty distinguishing differences in temperature, muscle cramps, muscle weakness, postural lightheadedness, hearing and visual impairments, and erectile dysfunction were associated with CIPN.

The symptom experience for patients with peripheral neuropathy is thought to vary widely among individuals depending on individual characteristics and the type of chemotherapy given (Bouhassira et al., 2004). Several studies have attempted to discover commonality between how patients describe painful neuropathy (Bouhassira et al., 2004; Krause & Backonja, 2003; Wilkie, Huang, Reilly, & Cain, 2001). In lung cancer, Wilkie et al. (2001) found that tugging, numb, penetrating, pulling, and pricking were descriptions used to describe neuropathic pain. Other signs and symptoms used to describe peripheral neuropathy in patients without cancer were burning (71%), tingling (66%), pins and needles (63%), squeezing (63%), pressure (61%), electric shocks (61%), and stabbing (60%) (Bouhassira et al., 2004). Krause and Backonja (2003) found that many patients complained of burning, shooting, numbness, electric-like tingling, squeezing, freezing, and being overly sensitive to touch as sensations associated with peripheral neuropathy. In addition, increased pain from touch and weather changes were significant (Krause & Backonja, 2003). Rasmussen, Sindrup, Jansen, and Bach (2004) also reported that patients with neuropathic pain were likely to have pain evoked from touch or cold.

Effects on Daily Life

CIPN has the potential to negatively influence many aspects of quality of life (Almadrones, McGuire, Walczak, Florio, & Tian, 2004; Bakitas, 2007). Patients who experience neuropathies in the upper extremities experience different functional limitations compared to patients with neuropathies in the lower extremities. Patients whose upper extremities are affected may experience difficulty with buttoning buttons or zipping zippers, writing, cooking, sewing, or any work or home activity

that requires manual dexterity. Patients whose lower extremities are affected may experience difficulty driving, walking, exercising, or engaging in any activity that requires mobility or balance. Even when patients do not perceive their symptoms as being severe, they may be highly distressed over the way that neuropathy affects their ability to carry out daily activities. Patients may experience depressed mood, anxiety, anger, frustration, and inability to cope. Because of functional limitations, relationships with family, friends, and coworkers may be adversely affected. Patients may choose to endure the distress and limitations caused by CIPN because of fears that their cancer will progress if their chemotherapy regimen is altered or discontinued (Bakitas, 2007).

Methods

Design, Sample, and Setting

This study is descriptive and uses data from semistructured, in-depth interviews with purposively selected participants (i.e., only patients experiencing symptoms of chemotherapy-induced peripheral neuropathy were selected). To be included in the study, patients had to be at least 18 years old, able to read and write English, and had to be experiencing numbness, tingling, or pain in the upper and/or lower extremities that developed after beginning chemotherapy. Participants must have received any of the following types of chemotherapy within the last three years: paclitaxel, docetaxel, oxaliplatin, vincristine, vinblastine, cisplatin, vinorelbine, or thalidomide. Patients with diagnoses of mental illness or cognitive impairment were excluded. Participants were recruited from a two physician medical oncology practice in central Florida.

The purposive sample consisted of 14 participants (8 men, 6 women) ranging in age from 42–84 years (see Table 1). Participants were primarily Caucasian and had lung, breast, or colon

Table 1. Characteristics of Study Participants

CHARACTERISTIC	n	%
Race		
Caucasian	13	93
African American	1	7
Gender		
Male	8	57
Female	6	43
Cancer type		
Breast	4	28
Lung	4	28
Colorectal	3	22
Multiple myeloma	2	14
Cholangiocarcinoma	1	7
Neurotoxic agent		
Paclitaxel	4	28
Oxaliplatin	4	28
Docetaxel	3	22
Thalidomide	2	14
Vinorelbine	1	7

N = 14

Note. Because of rounding, not all percentages total 100.

- Tell me about any of the following symptoms that you have experienced since starting chemotherapy: numbness, tingling, sharp stabbing or throbbing pain, a pins and needles sensation, or feeling like part of your body is asleep.
- What other words would you use to describe these symptoms?
- How have these symptoms affected your daily life?
- What things have these symptoms interfered with your ability to do?
- What do you find most troubling about these symptoms?
- Is there anything else you would like to share with me about these symptoms?

Figure 1. Interview Questions

cancer, multiple myeloma, or cholangiocarcinoma. The majority were treated with taxanes or oxaliplatin. Fifty-seven percent of participants had not yet had a dose reduction or discontinuation of treatment, whereas 43% had dose reductions or discontinuation of the neurotoxic agent at the time of the interview.

Procedures

The study was approved by the University of South Florida Internal Review Board and by the physicians who own the two medical oncology practices where data were collected. Eligible patients who were there for a regularly scheduled appointment were approached and invited to participate in the study. Informed consent was obtained and participants were taken by the researcher to a private examination room for the interview. Participants were given a \$10 department store gift card for participation in the study. Semistructured interviews were conducted with the participants while they were at the clinic, were recorded, and were professionally transcribed. Interviews ranged in length from 10–45 minutes. Patients were asked six questions related to their symptoms (see Figure 1). Demographic information was obtained from the medical record, including age, gender, cancer type, name, and cumulative dose of neurotoxic chemotherapy drug used and whether chemotherapy doses were altered or chemotherapy was interrupted as a result of peripheral neuropathy.

Data Analysis

Data analysis involved both a qualitative and quantitative approach using an ethnographic framework in which researchers attempted to get a detailed understanding of the experiences of the few participants being studied. Data saturation was apparent after 14 interviews (i.e., the information conveyed in the interviews had been expressed by earlier participants). Transcripts were reviewed numerous times for relevant content. The qualitative results were reviewed and validated by another researcher. Data were analyzed using SPSS® [v.16.0] and confirmed using Atlas TI.

Research questions 1 and 2 were each addressed using descriptive statistics, including frequencies and percentages, and by reviewing transcripts. For research question 1, each transcript was examined looking for neuropathic symptoms and descriptors. Each descriptor was entered as a variable into a database and coded. Terms that described similar concepts were combined. For instance, patients used a variety of terminology

to describe loss of balance including clumsiness, loss of balance, dizzy in the head, and not being able to walk. These were categorized together as “loss of balance.” To answer research question 2, each transcript was examined looking for aspects of daily life affected by CIPN. Again, each descriptor was entered as a variable into a database and coded; terms that described similar concepts were combined.

Results

Frequently Reported Symptoms

For research question 1, participants reported a combination of painful and nonpainful symptoms, both sensory and motor. Patients also frequently reported injuries as a result of neuropathic symptoms. Nonpainful symptoms, including numbness in the feet and loss of balance, were thought to contribute to injuries and falls.

Nonpainful symptoms: Patients reported a variety of nonpainful symptoms, including numbness, tingling, short-term memory loss, trouble concentrating, loss of balance, muscle weakness, clumsiness, loss of depth perception, lack of coordination, dizziness, and generalized weakness (see Table 2). Of these symptoms, numbness, muscle weakness, loss of balance, tingling, and generalized weakness were reported by at least 43% of participants. All of the patients reported numbness of the fingers and/or toes. Patients frequently described simultaneous pain and numbness.

Near or actual injuries were reported by almost 50% of patients, and were reported to result primarily from nonpainful symptoms. A patient with breast cancer, receiving docetaxel, previously treated with paclitaxel, reported having to go to the emergency room because of loss of balance and falling twice at home.

I hit my right arm and cut the heck out of it on the foot of the bed . . . but then the second time, I fell forward and hit my chest of drawers and it blackened my eye, my cheek, and my nose . . . well, in fact, it cracked my nose.

Another said,

I looked down at my toes one day and I had a purple toe and I didn't know how I had a purple toe. I didn't remember

Table 2. Frequency of Nonpainful Symptoms Among Study Participants

SYMPTOM	n	%
Numbness ^a	14	100
Loss of balance	8	57
Muscle weakness	8	57
Tingling	7	50
Generalized weakness	6	43
Lack of coordination	2	14
Short-term memory loss	2	14
Trouble concentrating	2	14
Loss of depth perception	1	7

N = 14

^aTen of the 14 participants (71%) who reported numbness also reported pain.

dropping [anything on it], obviously I dropped something pretty hard and I literally had a purple toe. . . . And you don't feel it; I mean, I don't feel the pain.

A patient with breast cancer, who was in her 40s and heavily treated with docetaxel and paclitaxel, said,

I always take baths and slowly I noticed I was having a hard time getting myself to stand up to get out of the bathtub. I cannot get out of the bathtub by myself. Sometimes I do it, but I know one of these days I'm going to end up probably knocking my teeth out or knocking my face off or something because I'm trying to push on the side of the tub to get up and it's slippery.

Forty-three percent of patients (n = 6) who were completely ambulatory before starting chemotherapy required assistive devices, such as a cane or walker, because of neuropathic symptoms. One patient with lung cancer receiving paclitaxel said,

I don't have any feeling, so I lose my balance. But, I get a lot of weakness in my legs and my thighs. Sometimes, when I'm on the cane, sometimes I'll lose my balance and . . . like my leg will give way, just for a short period.

Painful symptoms: The most commonly reported painful symptoms were burning, muscle aches, and sensitivity to cold (see Table 3). These symptoms were reported in at least 36% of patients. Although 10 participants used the word "pain" to describe their uncomfortable experiences, four participants did not use the word "pain" in their description. Patients described a host of unpleasant sensations, including feelings that their feet were "ice cold," that they were "walking on hot coals," "walking on a rock on the bottom of your feet," or with "sandpaper on the bottom of your feet." They often had trouble describing these symptoms succinctly and struggled to put words to their experience. One woman with breast cancer treated with taxanes described her experience in the following way: "Yeah, it feels like . . . I think I've got something crawling on me; I reach down and there's nothing." Another woman undergoing treatment with docetaxel for breast cancer responded to a question

Table 3. Frequency of Painful Symptoms Among Study Participants

VARIABLE	n	%
Cold sensitivity	7	50
Pain	10	71
Burning	6	43
Muscle aches	5	36
Pins and needles	4	29
Soreness	3	22
Tremors	3	22
Jaw pain	2	14
Joint pain	2	14
Sharp pain	2	14
Shooting pain	2	14
Electric-like pain	1	7
Pressure	1	7
Stabbing pain	1	7
Trampling pain	1	7

N = 14

about how neuropathic symptoms had affected her life with the following.

With my husband and I, intimately, you know, as far as my sex life, I'm hurting. I just . . . I hurt, and my legs really hurt, and it's been very dragging on my quality of life.

Patients who did have pain described it using a variety of terms. Although burning was the adjective most often used to describe pain, several other descriptors, including sharp, shooting, pins and needles, muscle aches, soreness, trampling, stabbing, electric-like, and pressure, were used. The location of pain was generally the upper and/or lower extremities, but two participants described jaw pain and two participants described joint pain. The patients who described jaw pain had received oxaliplatin and the patients who described joint pain had received taxanes.

Patients occasionally reported muscle tremors. Sensitivity to cold temperatures was not limited to patients receiving oxaliplatin but also occurred in patients receiving other neurotoxic chemotherapies. No specific pattern in timing of painful symptoms was identified.

Effects on Daily Life

For research question 2, patients described a variety of ways in which neuropathic symptoms interfered with manual dexterity, general activities, activities of daily living, driving, writing, picking things up, work, sleep, walking, hobbies, household duties, and exercise (see Table 4). They voiced feelings of frustration, depression, and loss of purpose as a result of having to give up enjoyable activities.

One patient, a physician who completed six months of treatment with oxaliplatin for colon cancer over two years before the interview, described how neuropathies have interfered with his ability to perform his job.

Both the combination neuropathy and the sciatic nerve problem forced me to close my medical practice. When I finished with the chemo[therapy], the neuropathy really prevented me from doing the endoscopic procedures that I had done previously or standing for long periods of time. In my specialty of gastroenterology, you have to stand for hours at a time. I had to close the office. So, for me, that's been a major personal effect. It's changed my whole life.

Unfortunately, he also reported that his neuropathic symptoms had worsened, rather than improved, since he completed his chemotherapy. One woman who had received thalidomide for multiple myeloma said, "I just get discouraged and down and . . . 'cause I was always a doer, a person that was on the go doing things and I can't . . . can't do any of that." Another patient, an attorney who also is disabled as a result of advanced lung cancer, reported,

I didn't realize how much I used my hands. My writing is shot; it was never very good to begin with and even typing . . . I've even quit fooling around with e-mail because it's just too painful. I'm not driving very much anymore; driving feels weird, too. I can barely feel the pedals.

Another patient with colorectal cancer who previously enjoyed restoring antique automobiles was distraught over the fact that

Table 4. Frequency of Neuropathic Symptoms' Interference With Usual Activities

INTERFERENCE WITH	n	%
Activities of daily living	8	57
Walking	7	50
Picking up things	6	43
Driving	5	36
Hobbies	5	36
Relationships	4	29
Household chores	3	22
Manual dexterity	3	22
Work	3	22
Writing	2	14
Exercise	1	7
Sexual activity	1	7
Sleep	1	7

N = 14

he no longer has the manual dexterity to work on his cars. When asked about how neuropathic symptoms have interfered with his ability to participate in this activity, he said,

I can wax them, that's about it. As far as working on them, no. I get my son to do that. It's because my fingers are numb and, I mean, if I go to pick up a screwdriver, I don't know it's there. I have to watch and make sure I have it. It ain't like you can feel it when you pick it up. And when I walk, it just feels like I'm dragging dead feet with me and, if my shoe comes off, I don't know it until it's off, so I can't do things. I have to depend on my son if I need to change an alternator or something; I have to get him to do it, but I want to do it 'cause I want to get my hands greasy. I want to pull a motor out or something, put another motor in. I can't do it. I hate to ask people for help. I have been around trucks and cars all my life. So now the brakes are put on.

Discussion

This study highlights which neuropathic symptoms are reported most frequently in patients receiving chemotherapy, how patients describe their symptoms, and how these symptoms affect their daily lives. Patients should be viewed as experts on their own experiences with CIPN.

Several limitations exist in this study. The sample size was small, limiting the generalizability of the results. The sample was selected from a single geographic location where patients tend to be of above-average education and socioeconomic status, although no data on these variables were collected. Minority populations were not adequately represented. Results may differ based on racial or ethnic variations. Perhaps the most significant limitation is the possibility of bias in the study. The dual role of the researcher as healthcare provider may have caused patients to withhold information that may influence healthcare decisions. It also is possible that the pre-established rapport between participants and researcher allowed for more honest and straightforward discussion. The selection of participants was not random but purposive and, therefore, the experience of these patients may differ from those in a random sample.

Several of the patients had completed chemotherapy as many as three years prior to the interview, yet were still experiencing neuropathic symptoms. Because of the significant lapse in time from onset of symptoms, their descriptions may not be entirely reflective of their actual experience. In addition, no objective or systematic assessment of neuropathic symptoms was conducted. Patients were free to report any neuropathic symptoms they chose to discuss in any amount of detail they were comfortable with. They may have experienced additional neuropathic symptoms that were not discussed in the interview. Conversely, patients may have reported symptoms during the interview that do not have an underlying neuropathic etiology. Ability to differentiate cause of symptoms varies from person to person. The opportunity to speak of their symptom experience in an open-ended discussion may have caused some individuals to report symptoms that were distressing but not necessarily of neuropathic origin.

Conclusions

CIPN is a common complication of chemotherapy that negatively influences quality of life by producing unpleasant symptoms, limiting functional performance, and causing distress. The experience varies widely from patient to patient based on individual characteristics, perceptions, chemotherapy drug, and cumulative dose. Patients may have trouble describing their experiences to healthcare providers, but their symptoms put them at high risk for falls and other injuries. In fact, 7 of the 14 participants in the study had experienced falls or injuries caused by reduced sensation. Numbness in the upper and/or lower extremities was universally reported by participants. Discomfort in the upper and lower extremities was frequently reported, although patients' descriptions of their discomfort were quite varied and some denied any type of pain.

Patients in this study had been coping with neuropathic symptoms for as many as three years and believed that their quality of life had been adversely affected. Emotional distress was primarily attributed to neuropathic symptoms interfering with their ability to perform activities considered to be important to their physical and emotional well-being. These findings are supportive of previous research indicating that CIPN negatively affects functional, social, and emotional well-being (Almadrones et al., 2004; Bakitas, 2007).

Nursing Implications

An interdisciplinary approach to CIPN is warranted. Discussing the patient's symptoms and performance level with the oncologist will help ensure that the decision to continue with the chemotherapy, reduce the dose, or discontinue the regimen is made. Referrals to occupational therapy, physical therapy, and social services may help patients maintain independence and maximize quality of life.

Conversations with patients who are experiencing CIPN are vital to patient advocacy. Patients should be given the opportunity to articulate their experiences and to explore methods of relieving or coping with their symptoms. Assessment of

pre-existing neuropathic symptoms and lifestyle (e.g., occupation, roles, leisure activities) should be conducted before treatment with neurotoxic chemotherapy begins. Anticipatory guidance aimed toward preparing patients for possible changes in physical, social, and emotional function can be provided and alternative treatment options should be discussed. Ongoing assessment of symptoms should include evaluation of symptom intensity, distress, frequency, and interference with physical, emotional, and role functioning (Lenz, Pugh, Milligan, Gift, & Suppe, 1997; Lenz, Suppe, Gift, Pugh, & Milligan, 1995). Reliable and valid assessment tools that systematically address neuropathic symptoms, emotional distress, and neuropathic interference with functioning are needed (Bakitas, 2007; Dunlap & Paice, 2006; Wilkes, 2007). In the absence of a gold standard assessment tool, nurses may wish to use one of the existing validated self-report tools, such as the Peripheral Neuropathy Scale (Almadrones et al., 2004; Ostchega et al., 1988), the Chemotherapy-Induced Peripheral Neuropathy 20 (Postma et al., 2005), or the Functional Assessment of Cancer Therapy and Gynecologic Oncology Group neurotoxicity subscale (Huang, Brady, Cella, & Fleming, 2007) to assess changes in symptoms throughout treatment. Additionally, neuropathy should be routinely assessed in cancer survivors.

Patients should be questioned about painful and painless neuropathic symptoms because painless symptoms (e.g., numbness, muscle weakness, loss of balance) are frequently present in patients with CIPN and contribute to impaired physical performance and increased risk of falls and injuries. Patients also should be asked whether they feel unsteady on their feet and whether they have had any falls or near falls. Nurses can help patients identify potential safety hazards in their environment and suggest safety measures to help patients avoid injury (Wickham, 2007). Evidence-based interventions aimed at preventing or relieving neuropathic symptoms, as well as preventing injuries, are needed (Visovsky, Collins, Abbott, Aschenbrenner, & Hart, 2007). Nurses wanting to learn more about specific nursing interventions for CIPN may wish to refer to *Putting Evidence Into Practice: Evidence-Based Interventions for Chemotherapy-Induced Peripheral Neuropathy* (Visovsky et al., 2007) and *Chemotherapy-Induced Peripheral Neuropathy: A Review and Implications for Oncology Nursing Practice* (Wickham, 2007).

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