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Living with chemotherapy-induced peripheral neuropathy: Uncovering the symptom experience and self-management of neuropathic symptoms among cancer survivors

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ABSTRACT

Purpose: The study aimed at uncovering the symptom experience of neurotoxicity, self-adopted approaches and perspectives in managing chemotherapy-induced peripheral neuropathic (CIPN) symptoms in a sample of Chinese cancer survivors.

Methods: A qualitative descriptive study was used to explore individual experiences. A purposive sample of 12 female participants experiencing CIPN was invited to semi-structured interviews who were part of a larger prospective observational study investigating the natural progression and risk factors of CIPN. Textual interview data were managed in NVivo. Content analysis was used.

Results: Participants were aged 41–64 years and experienced moderate to severe neuropathic symptoms from 5 to 23 months after completion of a six-cycle chemotherapy regimens at reported during the interviews. Four categories emerged from the qualitative data, namely, (1) experience come to reality: characteristics of CIPN symptoms, (2) disruptions and perceived threat: ability to perform activities and resume work, (3) re-establishing an 'at least satisfactory level of well-being', and (4) views of and approaches in managing neuropathic symptoms.

Conclusions: The characteristics of CIPN symptoms causing disruptions in functional and/or psychosocial well-being from the patients' perspectives and the self-help strategies used to manage symptoms showed a need to provide quality multidisciplinary supportive care, focusing on restoring functional and psychosocial well-being, and enhancing knowledge about symptom assessment and evidence-based strategies for empowering cancer survivors to cope with this complex symptom.

1. Introduction

Chemotherapy-induced peripheral neuropathy (CIPN) is a result of damage caused to the peripheral nervous system by chemotherapy. It affects the functions of sensory, motor, and autonomic neurons (Argyriou et al., 2014; Miltenburg and Boogerd, 2014), producing symptoms ranging from bothersome to disabling tingling, burning or numbness in the hands and feet, pain, muscle weakness, ototoxicity, ophthalmic changes, and sensations of dizziness (Miltenburg and Boogerd, 2014; Verstappen et al., 2003).

CIPN symptoms can disrupt the patients' daily activities, functions and behaviours across different aspects of domestic, work, social and leisure life (Speck et al., 2012). Patients express feelings of frustration, depression and loss of purpose because of having to give up enjoyable activities (Tofthagen, 2010). Patients coping with CIPN symptoms reported that they used prescription drugs (e.g. naproxen) or over-the-counter medications (e.g., ibuprofen), or adopted behaviours to deal with the changes resulting from CIPN such as the use of movement to reduce symptoms, logistics planning to simplify daily demands, and focusing on exercise, mindfulness, occupational therapy and environmental planning to reduce the impact of symptoms (Speck et al., 2012).

The prevalence of CIPN varies among studies. CIPN prevalence reported in a systematic review was 68%, 60% and 30% in the first month, at 3 months and 6 months (or more) after chemotherapy (Seretny et al., 2014). Ethnic differences in the incidence of neurosensory adverse events have been reported, prompting investigators to

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suggest that the cultural and environmental factors such as a patient's tolerance and care for neurological abnormalities might be relevant (Sugihara et al., 2012). In fact, the experience of CIPN and the strategies used to cope with drug-induced neuropathies among patients from the Chinese populations may be under-explored, in particular using a qualitative research approach adept at exploring individuals' experiences. Hence, the aim of this study was to conduct a qualitative study among the Hong Kong (HK) Chinese population to provide a descriptive, explorative account of the patients' experience of living with CIPN – the symptom experience and its management. This would add insights for health professionals to enhance symptom management and reduce the impact of post-chemotherapy neurotoxicity.

2. Methods

2.1. Design and participants

This was a qualitative descriptive study, using semi-structured interviews as the data collection method. Qualitative descriptive study was used to explore issues or phenomena by knowing the facts from cancer survivors' points of view and it entailed description and interpretation (Sandelowski, 2000). A purposive sample of participants experiencing symptoms of CIPN was invited for an individual interview from part of a larger prospective observational study investigating the natural progression and risk factors of CIPN among cancer patients receiving their first chemotherapy treatment in the oncology unit of an acute hospital in Hong Kong. To be included in the present study, the participants had to be: (1) experiencing CIPN symptom(s) developed after starting chemotherapy for at least three months in the upper or lower limbs (e.g. numbness, tingling, burning pain, pain, discomfort, and/or pins and needles); (2) receiving neurotoxic chemotherapy such as paclitaxel/carboplatin/vinorelbine/cisplatin or carboplatin/taxotere or cisplatin for the first time (3) diagnosed with (e.g. breast, ovarian, lung, or head and neck); cancer with or without metastasis; (4) at least 18 years old; (5) able and willing to verbalize their experience; and (6) able to give informed consent. Participants were excluded if they had previously been treated with neurotoxic chemotherapy, had documented neuropathy in their medical records before initiating neurotoxic chemotherapy, or discontinued neurotoxic chemotherapy after only one cycle for any reason.

2.2. Data collection procedures

Ethical approval from the university and hospital research ethics committees was obtained prior to study commencement. From June to December 2016, patients in the larger study fulfilling the eligibility criteria were identified and invited to participate through phone invitation or direct approaching them in the oncology unit by a research assistant. In order to facilitate a successful recruitment of participants, the research assistant would provide participants with several options of timeslots for conducting the interviews. Written informed consent was obtained from each participant who voluntarily agreed to be interviewed, and a convenient time and venue for conducting the interview were then arranged. Interviews were conducted in the participants' homes or an interview room at the university. Each participant received a supermarket cash coupon of HK$100 (US$13) to compensate them for their time and any travel expenses incurred.

All interviews were conducted by the first author; they lasted 18–49 min and the average length of the interviews was 35 min. Interviews were audio-recorded. Participants' names were not mentioned during the audio-taped interviews, and their anonymity and confidentiality were assured at all times. Field notes were used to record pertinent information during each interview. Open-ended, semi-structured interview questions were used to explore the participants' symptom experience, the impact of CIPN symptoms on them, coping strategies with CIPN or methods used to alleviate CIPN symptoms. Interviews were continued until data saturation was apparent. After 12 interviews with the female participants, data saturation was reached as no new information/categories emerged; and recruitment was then closed.

Socio-demographic and health-related information were also collected from the patients or their medical records, consisting of age, cancer history including type and stage of cancer, CIPN toxicity grade measured by the National Cancer Institute-Common Toxicity Criteria for Adverse Events (NCI-CTCAE) (Postma and Heimans, 2000), and cancer treatment regimens.

2.3. Data management and analysis

Descriptive statistics were used to summarize the sample socio-demographics and clinical data. Semi-structured interviews were transcribed into Chinese verbatim and then translated into English. Transcripts were carefully reviewed for semantic accuracy by the author who conducted the interviews. Pertinent field notes were added to maintain and preserve the participants' emphasis and meaning. Consensus was maintained by team discussion and reviewing of audio-taped interviews if any discrepancy existed.

Transcripts were loaded as Microsoft Word document into NVivo software for management and qualitative analysis (QSR International, 2008). Content analysis was used to analyse the qualitative data; data were coded, constantly compared, revised and examined for similarities and differences in categories and subcategories across interviews (Berg, 2007; Sandelowski, 2000). Coding was initially performed according to the pre-identified topics in the interview questions, and codes were generated from the data (Sandelowski, 2000). Initial open codes were identified; further, similar codes were grouped together according to common elements into a labeled category reflecting the words and experiences of the participants. During the analysis, all categories were compared with the other categories to maximize their unique and non-overlapping qualities. Data analysis, by two of the authors began with critical reviewing of the English interview transcripts. Thereafter, authors ensured that data were reliably interpreted, and that analysed data gave a valid representation of participants' experience of CIPN. Further, the analysis of data followed discussion by authors to ensure that the findings were reflecting the meaning purported by the patients and interpretation was consistent (Berg, 2007). The audio-taped interviews and verbatim quotes from the participants were also used as evidence to confirm the trustworthiness of the qualitative data. The final categories that emerged from the qualitative findings were reviewed, with consensus reached by all research team members.

3. Results

Twelve female participants were approached and they voluntarily agreed to be interviewed. The mean age of the participants was 56, ranging from 41 to 64 years. According to the NCI-CTCAE grading scale, 50% of the participants had severe CIPN toxicity grade 3 (sensory/motor peripheral neuropathy) and 50% had moderate CIPN toxicity grade 2 (sensory/motor peripheral neuropathy). Most of them (83.4%) were diagnosed with breast cancer, and 16.6% were with a diagnosis of ovarian or nasopharyngeal cancers. Of the participants with breast cancer, 30%, 20% and 50% were in cancer stage I, II, and III, respectively. All participants had received 6 cycles of cancer treatments, including a combination of taxane- and platinum-based chemotherapy.

The categories emerging from the textual qualitative data included (1) experience come to reality: characteristics of CIPN symptoms, (2) disruptions and perceived threat: ability to perform activities and resume work, (3) re-establishing an 'at least satisfactory level of well-being', and (4) views of and approaches in managing neuropathic symptoms.