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Reporting of paclitaxel-induced peripheral neuropathy symptoms to clinicians among women with breast cancer: a qualitative study

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Ethical approval: All procedures performed in studies involving human participants were in accordance with the ethical standards of the University of Michigan Institutional Review Board (HUM00086259 and HUM00099924) and University of Michigan Rogel Comprehensive Cancer Center (UMCCC 2014.002), and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent. Informed consent was obtained from all individual participants included in the study.

Data availability statement. The datasets during and/or analyzed during the current study are available from the corresponding author on reasonable request.

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Abstract

Purpose: Cases of chemotherapy-induced peripheral neuropathy (CIPN) under-reporting have been sporadically described in the literature, but no studies have focused on actively examining this behavior. Our primary aim was to identify women who purposefully under-reported CIPN, along with reasons for doing so. A secondary aim was to explore factors enabling or hindering communication of CIPN to clinicians.

Methods: Semi-structured interviews were conducted with women with breast cancer who had received paclitaxel in a prospective observational study. The interview guide was developed based on factors hypothesized to influence side effect disclosure to clinicians. Interviews were recorded, transcribed *verbatim*, and thematically content analyzed.

Results: Thirty-four women were interviewed. Three main themes emerged from the analysis: 1) enablers of CIPN reporting (e.g., positive relationships with the oncology team, sufficient appointment time, existence of alternative communication channels to office visits, expectation of CIPN as a side effect); 2) deterrents to CIPN reporting (e.g., perception of need to complete the full course of therapy, fear of treatment discontinuation, lack of knowledge of long-term consequences of CIPN); and 3) balancing survival *versus* functional impairment due to CIPN. Women prioritized efficacy over CIPN until physical functioning was meaningfully affected. No patients reported purposeful CIPN under-reporting, but three women admitted having considered doing so.

Conclusions: Despite the lack of evidence of CIPN withholding, women considered both the effectiveness and the toxicity of paclitaxel treatment, as well as beliefs about treatment and long-term consequences of CIPN and relationship with the oncology team, when deciding whether to report CIPN symptoms.

Keywords

Breast cancer; Chemotherapy-Induced Peripheral Neuropathy; Qualitative Research [MH]; Taxoids [MH]

Introduction

Chemotherapy-induced peripheral neuropathy (CIPN) is a common side effect from several chemotherapeutic agents, including platinins, vinca alkaloids, and taxanes [1,2]. Within the context of breast cancer treatment, taxanes are commonly used in the adjuvant setting and contribute to the development of CIPN in 20–60% of patients [3,4]. The experience of CIPN is multifaceted, with impairment at the sensory (numbness, tingling, pain, impaired

sensation and hearing), motor (cramps in feet, limb loss of strength) and autonomic levels (blurred vision, dizziness when standing from sitting or lying position) [5,6]. CIPN experience in previous qualitative work has been analogized to “fingernails on a chalkboard” [7], walking on “hot coals” [8], “sandpaper” [9], “a rock on the bottom of your feet” [8], “walking in mud” [9], or described as “pain like needle being stuck in my toes” [7], “severe burning in fingertips” [10], or “feet being asleep” [9].

CIPN can last several months past treatment discontinuation and can, in some cases, become permanent [6,11,12], thus significantly affecting patients’ quality of life [13,14]. Activities of daily living, such as dressing, cooking, sewing, performing household tasks or leisure activities, can become challenging or even impossible. In some cases, walking, climbing stairs, driving, exercising, and socializing are severely compromised [7–10]. Loss of balance, falls, and injury due to CIPN have also been described [7,8]. These symptoms lead to feelings of frustration, embarrassment, isolation, anxiety, depression and loss of purpose among cancer patients [8].

Currently, limited therapeutic options for preventing or treating CIPN exist, with some evidence that duloxetine may be effective for treating painful neuropathy [15–18]. Thus, the strategy used in clinical practice to avoid progression of moderate CIPN symptoms to severe, life-altering CIPN consists of decreasing, delaying or discontinuing chemotherapy treatment, which happens in approximately one-quarter of patients with non-metastatic breast cancer receiving paclitaxel [19]. Treatment disruption is a decision made collaboratively between clinicians and patients by weighing the risks of CIPN progression, and its associated consequences, against the risk of compromising treatment effectiveness [20,21]. Therefore, patient-clinician communication is key, particularly because patients rely on clinicians to tell them how much CIPN they should endure before any treatment decisions are made [7]. Yet, some patients feel that health care professionals are skeptical or dismissive of their CIPN symptoms, and that they provide conflicting information with regard to CIPN severity and longevity [7,22]. This behavior causes feelings of anger and frustration among patients and may lead to symptom under-reporting [7,22]. Another aspect that may contribute to CIPN under-reporting is patients’ determination to complete the full course of treatment to maximize its effectiveness, at the risk of developing long-term or permanent toxicity [5,6]. CIPN has been regarded as an expected and accepted consequence of treatment [5,6], reflecting the trade-off between short-term dysfunction to avoid long-term regret of cancer recurrence [7].

No studies to date have assessed whether CIPN under-reporting is a common occurrence among women with breast cancer receiving paclitaxel. The primary aim of this study was to identify patients who purposefully under-reported CIPN symptoms to their oncologist, and if so, to explore their reasons for under-reporting. A secondary aim was to explore factors enabling or deterring communication of CIPN to clinicians.

Methods

Study Design

This was an exploratory descriptive qualitative study using semi-structured interviews. An interpretive phenomenological approach was selected because the focus was on understanding the lived experience of women who developed CIPN in light of the researcher's interpretation, as well as their thought process when reporting CIPN to clinicians [23]. This study was approved by the University of Michigan Institutional Review Board (HUM00086259 and HUM00099924) and the University of Michigan Rogel Comprehensive Cancer Center (UMCCC 2014.002).

Participants and recruitment

Women with breast cancer who had enrolled in a prospective observational study of paclitaxel treatment delivered in the adjuvant or neo-adjuvant setting for curative intent, and who had concluded their paclitaxel treatment, were invited to take part in this qualitative study [24]. The prospective study enrolled 60 women, aged 18 years or older, with early stage breast cancer scheduled to receive weekly paclitaxel 80 mg/m² infusions for 12 weeks at the University of Michigan Rogel Comprehensive Cancer Center. The primary objective of the observational study was to discover clinical and genetic predictors of paclitaxel-induced peripheral neuropathy ([ClinicalTrials.gov](https://clinicaltrials.gov/ct2/show/study/NCT02338115) registration number: [NCT02338115](https://clinicaltrials.gov/ct2/show/study/NCT02338115)). As part of the study, women completed a weekly patient reported CIPN questionnaire [25]. All 60 women who completed the prospective study were re-contacted (median=4.9, range 0.1–14.3 months after conclusion of paclitaxel) up to three times via e-mail or patient portal and invited for an interview with the researchers. This purposive sample of women represented information-rich cases due to their experience undergoing neurotoxic chemotherapy treatment and ability to provide the greatest insight into the research question [26]. Ultimately, 34 women were interviewed, with the remaining individuals not responding to the recruitment email or patient portal message. Informed consent was obtained from each participant prior to the interview.

Data collection

Individual face-to-face interviews were conducted in a private room at Michigan Medicine facilities, or via the telephone when in-person interviews were not feasible, between May and December 2016. No other individuals besides the participant and one of the researchers were present at the interview. Interviews were conducted by a PhD trained pharmacist with experience in qualitative research, who was a post-doctoral fellow at the University of Michigan, four doctor of pharmacy students at the same institution and a fellow who was a PharmD/MBA (all female). No relationship between individuals who conducted the interviews and participants existed prior to the study.

The interview guide was developed based on factors hypothesized to influence patient side effect disclosure to clinicians, namely: relationship with the oncologist and the oncology team; attitudes toward disclosure of side effects to clinicians; perception of risks and benefits of paclitaxel therapy and of continuing therapy after experiencing CIPN; characteristics of the CIPN experience during and after chemotherapy; and awareness of long-term

consequences of CIPN (Supplemental material). The interview guide was thoroughly discussed by the research team until agreement with the final version and subsequently pre-tested with two volunteers from the University of Michigan Rogel Comprehensive Cancer Center Breast Cancer Advisory Advocate Committee to establish face validity [27]. Minor changes to the wording of the questions resulted from pre-testing. The guide was iteratively modified following the first couple of interviews to better guide the discussion with participants as the study unfolded.

Our sampling strategy aimed to maximize the potential for achieving data saturation during analysis, indicated by the redundancy of the information provided by respondents and the emergence of no new content to identified themes or additional themes [28]. We were uncertain how many interviews would be required to identify a sample of under-reporters sufficient to reach saturation in response to our research questions. During analysis, we found that among the 34 women interviewed, we were able to reach saturation related to factors enabling and hindering CIPN symptom reporting but were unable to reach saturation regarding aspects related with under-reporting.

Data Analysis

Interviews were audio-recorded and transcribed *verbatim* by a professional external party. Transcription accuracy was checked for 10% of interviews. An inductive thematic content analysis using ATLAS.ti version 7.5.18 was performed, where the themes emerged directly from the data rather than being imposed *a priori* [29]. An initial version of the codebook was created by a qualitative data analyst after reviewing the transcripts. The codebook was thoroughly discussed with one of the researchers who is a PhD trained pharmacist and modifications were made accordingly. A sample of five transcripts were then independently coded by the two researchers and discrepancies were discussed and reconciled through a consensus process. After final adjustments were made to the codes and respective definitions, a third research team member who is a Doctor of Pharmacy candidate coded the remaining interviews based on the updated codebook. Weekly meetings were held during the coding process to discuss coding-related questions. Whenever changes to the codebook resulted from these discussions, all transcripts previously coded were reviewed for accuracy. A process of analysis and comparison back to the original transcripts ultimately resulted in codes being grouped into major themes. The research team debated the major themes and subthemes, and reached consensus as to their organization and relationship, ensuring the reliability of the analysis.[30] The importance of a concept or theme identified during qualitative analysis is not directly related to frequency of coding. However, in reporting results below, we use phrases such as “most participants”, “the majority of participants” or “patients overwhelmingly reported” to indicate a high prevalence of the discussed idea among research participants, usually among greater than 50% of respondents.

As a means to ensure rigor and trustworthiness [31,32], the analysis was upheld to the following principles: 1) triangulation, by having multiple independent researchers analyze the data and discuss theme interpretation; 2) reflexivity, by having individuals from diverse backgrounds analyze the data, thus reducing bias stemming from investigators prior assumptions and experiences (a CIPN expert, a PhD trained pharmacist with prior oncology

experience, a qualitative data analyst not familiar with the topic); 3) thick description, by presenting a thorough description of the methods used and the participants in the sample; and 4) attention to negative cases, by including subjects with a wide range of CIPN experiences. Exemplar quotes were extracted to support the analysis and to illustrate themes and subthemes. All quotes were used *verbatim*, with the exception of the word “taxol” which was replaced with “paclitaxel”. Study reporting followed the consolidated criteria for reporting qualitative research (COREQ) checklist [33].

Results

A total of 34 women were interviewed, of whom 30 reported experiencing various degrees of CIPN during treatment and 22 reported still experiencing CIPN at the time of the interview. Four women decreased or delayed paclitaxel dose and nine discontinued treatment before completing their 12 scheduled doses due to CIPN. Demographic and clinical characteristics of interview participants are presented in Table 1. Participants were representative of the overall cohort and there were no significant differences between interview participants and non-participants. The interviews lasted on average 33 minutes (range 9–70, shorter interviews corresponding to women who did not experience CIPN). Three main themes related to CIPN reporting emerged from the analysis: 1) enablers of CIPN reporting; 2) deterrents to CIPN reporting; and 3) balancing survival *versus* functional impairment due to CIPN. Figure 1 and Table 2 summarize the main findings and present exemplar quotes for each theme.

Theme 1: Enablers of CIPN reporting

1.1. Internal and external motivation to disclose all symptoms—Most women believed that it was critical to be completely honest about their CIPN and other side effects, in order for physicians to provide the best possible care. For those aware of the long-term consequences of CIPN, fear of permanent functional impairment was also an internal motivator to disclose symptoms.

The oncology team and family members were important external motivators to disclose symptoms. Patients were frequently warned that CIPN could become highly debilitating and were asked about CIPN during visits, to the extent that some women considered there to be too much emphasis on CIPN in detriment of other side effects (e.g., pain). In addition, family members who had prior knowledge of the long-term effects of CIPN, insisted that CIPN be reported.

1.2. Positive relationship with clinicians—Patients overwhelmingly reported a positive relationship with their oncologist during treatment. Reasons cited included a sense of openness, comfort, encouragement, caring, listening to the patient, availability to answer questions, and explaining the process using patient-friendly terms. Patients trusted their oncologists’ expertise and judgement.

A few exceptions felt that, at times, their concerns were not given full consideration – “I think sometimes some of my concerns were kind of not pushed off, but it was like oh don’t

worry about that, don't worry about that kind of thing" –, or that oncologists focused more on the cancer itself than on the impact of treatment on patients' quality of life.

Positive relationships with other members of the healthcare team were also widely reported. Women highlighted that the team worked unified and communicated effectively, allowing patients to experience continuity of care without having to constantly repeat their medical history. The positive attitudes of all members of the team and the stress-free atmosphere of the clinic and staff were also emphasized. Nurse practitioners were often perceived as more available than oncologists, thus contributing to the strong patient-nurse relationship voiced by many women.

1.3. Sufficient appointment time for discussion—The majority of interviewees perceived their appointment time with the clinicians to be adequate and conducive to asking questions, without feeling rushed or dismissed. For some, the visits with the oncologist were less frequent, which made them more conscious of the oncologist's time. Despite feeling that all their questions were answered, women found that nurse practitioners often had more time to speak with patients.

1.4. Ability to communicate outside of clinic appointments—To contact the oncology team in-between appointments, patients called the office, messaged through the patient portal, or emailed specific members of the team. Most patients were pleased with both the answers received and the response time. Problems were also escalated, if necessary, by the team member receiving the question through practices, such as consulting the oncologist or scheduling an in-person meeting.

1.5. Knowledge of CIPN as side effect of treatment—All except one of the participants were aware that CIPN was a side effect from treatment with paclitaxel. At the initial appointment, clinicians provided patients with a description of common CIPN symptoms such as 'numbness' or 'tingling'. In some cases, the description tended to be simplistic with no mention of possible effect on function, which could have affected women's understanding. In other cases, clinicians used allegories, such as 'walking on marbles', that resulted in patients not being able to recognize CIPN symptoms and thus not reporting them.

Theme 2: Deterrents to CIPN reporting

2.1. Perception of need to complete the full course of therapy—Most patients agreed that completing all 12 paclitaxel doses was critical to maximize therapeutic success and minimize risk of cancer recurrence, and women felt very strongly about completing the full course of therapy. Over a third (n=9) were not aware that treatment discontinuation was an option, even in the case of severe CIPN. Patients voiced that they preferred to have known upfront that discontinuation was an option.

2.2. Fear of treatment discontinuation—When faced with the need to discontinue treatment due to CIPN severity, women expressed concern and fear that not receiving the 12 doses would jeopardize long-term survival. Some women also perceived treatment

discontinuation as a sign of weakness and giving up. In these cases, oncologists played a critical role explaining the risk/benefit relationship of paclitaxel.

Despite some resistance to accept treatment discontinuation, several women experienced a sense of relief for not needing additional treatment.

2.3. Lack of knowledge of long-term consequences of CIPN—While a majority of women were aware of the long-term consequences of CIPN prior to starting treatment, having received information from the oncology team and other patients or from searching the web, others were unaware altogether that CIPN could be permanent. For those who experienced CIPN during treatment, they expected symptoms to go away once treatment was concluded.

Theme 3: Balancing effectiveness versus functional impairment due to CIPN

3.1 CIPN tolerability associated with symptom reporting—When deciding whether to interrupt paclitaxel treatment (delay or discontinuation) due to CIPN, patients prioritized efficacy over CIPN until physical functioning was affected to a certain degree, at which point patients prioritized avoiding further worsening of CIPN. The effect of this phenomenon on symptom disclosure depended on patient prioritization at the time: prioritizing efficacy would likely discourage symptom reporting, while prioritizing adverse effect mitigation would likely encourage reporting.

When asked to think back at what they would have done differently, women currently experiencing long-term CIPN articulated that they would have asked to discontinue treatment early, had they known that it was an option, or asked for CIPN preventative measures.

3.2 Potential CIPN under-reporting—No patients in our study admitted to having purposefully under-reported CIPN to their clinicians. Three patients suggested circumstances in which they contemplated under-reporting CIPN symptoms to their clinicians but, ultimately, decided not to. The main reason for considering an incomplete disclosure of symptoms was fear of treatment discontinuation, which could compromise long-term therapeutic success.

An inclination to conceal side effects was also identified in a patient who experienced a severe rash – *I did have that feeling where I don't want anybody to you know say anything or notice anything that's going to make them have to stop the treatment, because I really didn't want to do that.*

Discussion

Women in our study did not purposefully under-report CIPN to their clinicians, but three admitted they considered doing so. Factors enabling full symptom disclosure included positive relationships with the oncologist and the oncology team, sufficient appointment time to discuss treatment and side effects, existence of alternative communication channels to office visits, and expectation of CIPN as a side effect from chemotherapy. Factors

potentially contributing to incomplete symptom reporting were the perception of need to complete the full course of therapy, fear of treatment discontinuation, and lack of knowledge of long-term consequences of CIPN.

Treatment effectiveness and avoidance of cancer recurrence was an absolute priority for these patients. As reported in our study and elsewhere, women expected and accepted CIPN as a side effect from treatment [7,34]. While participants in other studies considered CIPN to be of minimal importance within the context of a cancer diagnosis [7,8], referring to it as “background noise” [7], women in our study prioritized survival over functional impairment, only up to a certain threshold. Despite not having observed CIPN under-reporting in our sample, women held many of the same concerns that lead other women to not disclose symptoms, including fear of cancer recurrence and wanting to complete the full course of therapy. Under-reporting can also result from changes in patients’ motivations and tolerance of CIPN over time. What may be considered a side effect in the beginning, may be perceived as a “new normal” later on, as described in patients with colorectal cancer receiving oxaliplatin [35]. This underscores the importance of iterative, rather than one-time, patient-clinician discussions to account for a shift in CIPN reporting priorities over time.

All patients in our study reported having a positive relationship with the team, but this may not be true for patients receiving care at different institutions. In previous studies, patients worried that the healthcare team would not understand or believe them [7]. Similarly, some women in our study felt that their concerns were not completely addressed and that there was a greater emphasis on treating the cancer than on the impact of treatment on patients’ quality of life. Previous research suggests that patients must reach a “threshold trust” in their physician before they seek relief for an immediate concern [36]. Likewise, the way a physician communicates with patients also impacts how willingly patients participate in the interaction, including reporting symptoms and concerns [37]. Our findings show that patients had positive interactions with and easy access to the oncology team, both during and outside clinic visits.

Although it was only a minority, some women did not understand that CIPN could continue long-term. When weighing long-term treatment effectiveness against long-term toxicity, patients with a lack of understanding of long-term CIPN could be heavily leaning toward prioritizing effectiveness and, thus, be less prone to report CIPN. Consequently, treatment continuation could result in further CIPN progression and increased risk of long-term/irreversible symptoms. In a previous study, rectal cancer survivors articulated that knowledge of the long-term effects of symptoms on function prior to starting treatment might have altered their initial treatment decisions [38]. In our study, women voiced that they would likely hold different perceptions of the risk/benefit of treatment had their CIPN severely impacted long-term function. More rarely, women were not aware that CIPN could be a side effect from chemotherapy, which has also been previously reported [7,10,34,39].

As implications for practice, our study highlights the need for further work to optimize the communication between clinicians and patients about CIPN at the start of and throughout treatment. It is important that clinicians convey that CIPN can have long-term consequences and that paclitaxel treatment can be modified or discontinued to avoid causing severe,

potentially irreversible, CIPN. Despite existing evidence that early discontinuation decreases effectiveness [20,21,40], conversations about the benefits/risks of treatment are necessary. Furthermore, there is a need for clinicians to describe CIPN symptoms considering its multifaceted nature [5,6] to avoid misinterpretation of CIPN symptoms by patients, as verified in our sample. Perhaps incorporating peer-to-peer education where patients share, first-hand, their CIPN experience with newly diagnosed patients as they begin treatment could be beneficial [41,42]. Patients appreciate serving in supporting and advocacy roles [43]. Further analysis of how the dialogue between patients and clinicians unfolds when discussing CIPN throughout treatment, by recording these interactions in a clinical setting, would be insightful to unveil further details about the communication flow and style.

Our study has some limitations. First, our sample was very homogenous with regard to education level (high) and race (White), and originated from a single institution; thus, the experience with care received and access to specific resources (e.g., nurse line, patient portal) was similar across participants. The lack of diversity among patients and oncologists may also have accounted for similar perspectives – previous research showed that racial bias among oncologists results in shorter interactions with patients and less patient-centered and supportive communication [44]. Therefore, investigating potential under-reporting in a more diverse sample is imperative. Patients in the prospective study completed weekly patient-reported CIPN questionnaires, which may have made them more aware of symptoms and prompted them to report during the clinic visit. We also included only cases of adjuvant/curative breast cancer, so their perspectives may differ from those of patients with metastatic breast cancer or other tumor types with different efficacy/toxicity balance. Even though our study focused on CIPN, under-reporting can be an issue for other symptoms as well. Some interviews were conducted over the telephone, rather than face-to-face, which could have affected rapport building between participants and the interviewers. Additionally, the amount of information obtained from participants who were willing to be interviewed for a long period of time differed from those whose interviews were brief. Finally, data saturation is a theoretical concept and for that reason the chance of misinterpretation of the saturation point should be acknowledged.

In conclusion, we did not find evidence of CIPN symptom withholding, but women had considerations on both the effectiveness and the toxicity of paclitaxel treatment, as well as other factors that make CIPN reporting to clinicians more or less likely. Future work should focus on identifying true CIPN symptom withholders and understanding their rationale, so that patient-clinician communication and treatment outcomes can be improved. Another avenue for research may encompass the creation of a survey instrument based on these findings to be used in a larger, more diverse sample of patients from multiple clinic sites (including community-based practices).

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Conflict of interest.

Syverson owns stock in Pfizer Inc. and AbbVie Inc. Farris is a consultant and received remuneration from Quio Technologies. Henry received support to her institution for pharma-sponsored clinical trials from Abbvie, Pfizer, and Innocrin Pharmaceuticals. All other authors declare that they have no conflict of interest.

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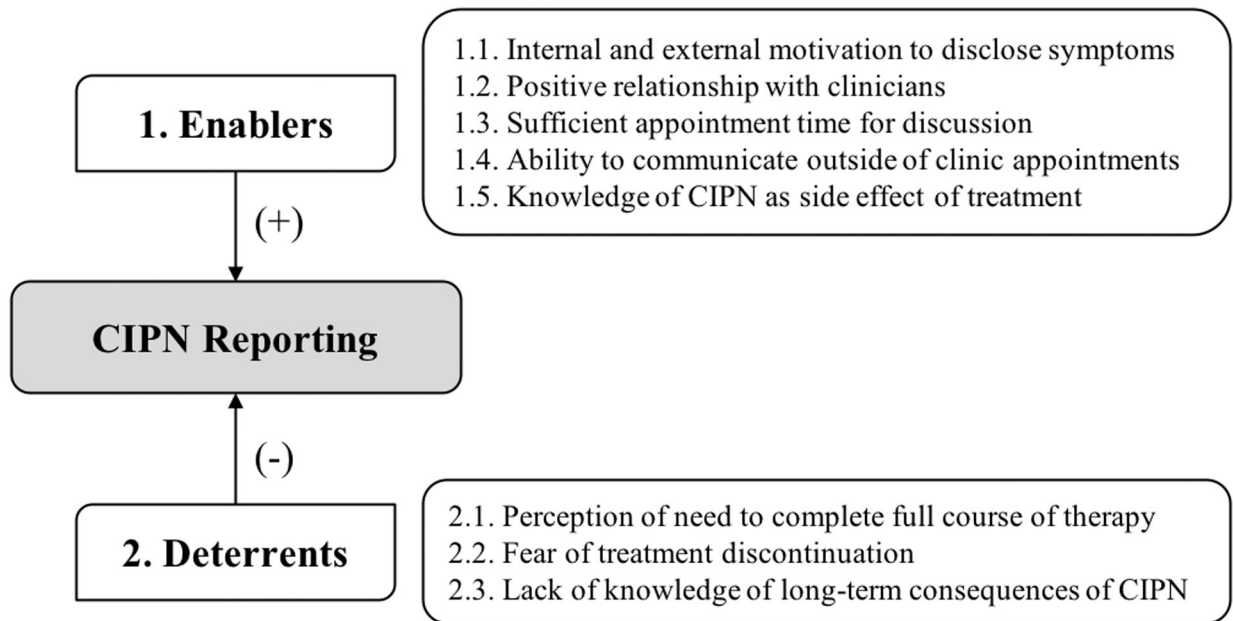


Fig. 1. Summary of enablers and deterrents of CIPN reporting to clinicians. *CIPN*, chemotherapy-induced peripheral neuropathy.

Table 1

Demographic and clinical characteristics of interview participants.

Characteristic	Participants n=34
Age [Mean (SD), range]	56.9 (8.8), 39–71
Race [n (%)]	
Caucasian	31 (91.2)
African American	1 (2.9)
Other	2 (5.9)
Diagnosis of diabetes [n (%)]	1 (2.9)
Chemotherapy setting [n (%)]	
Adjuvant	25 (73.5)
Neoadjuvant	9 (26.5)
Receipt 12 doses paclitaxel [n (%)] ^a	22 (64.7)

^aFour women decreased (range between doses 7 and 12) or delayed (range between doses 3 and 11) paclitaxel dose; nine women discontinued treatment before completing their 12 scheduled doses (range between doses 6 and 10).

Table 2

Summary of themes and sub-themes identified from the qualitative analysis, along with exemplar quotes.

Themes	Exemplar Quotes	
Theme 1: Enablers of CIPN reporting	1.1. Internal and external motivation to disclose all symptoms	<p>Internal motivators</p> <p><i>I don't understand why someone would hide any of their symptoms. [...] if you don't tell the doctors they aren't going to be able to help you.</i></p> <p>(Participant 26)</p> <p><i>I was definitely prepared to report if it [CIPN] got worse because of, you know, the fear of permanent [damage]...</i></p> <p>(Participant 48)</p> <p>External motivators</p> <p><i>... they [oncology team] said if we find out later that you had these symptoms earlier, we're not going to be happy. So, I knew I had to be letting them [oncology team] know each week what was going on.</i></p> <p>(Participant 52)</p> <p><i>... without my son pushing me or telling me mom you could end up with a walker [...] I probably would have hidden the beginning of the neuropathy.</i></p> <p>(Participant 21)</p>
	1.2. Positive relationship with clinicians	<p><i>She [oncologist] was just open, comfortable, calm, receiving, you know not telling, receiving, responding. [...] in my state of total chaos, she was my rock. [...] Whatever was in my head and my heart, I had to talk to her because she was my physician, my lifeline, and my connection to any support service.</i></p> <p>(Participant 02)</p> <p><i>I think a lot of times they [oncologists] are more centered on, you know, treating the cancer and not the quality of life of the people that are involved, and I mean even little things like [...] losing your nails...you know that's really important too if you're living the life.</i></p> <p>(Participant 58)</p> <p><i>The physician's assistants were excellent, the nursing care was always excellent. Everybody was on point in terms of knowing my case. [...] So, it was heartening to see that kind of attention to detail as a cancer patient.</i></p> <p>(Participant 22)</p>
	1.3. Sufficient appointment time for discussion	<p><i>I never felt rushed at all. I felt like that they [oncology team] were there for the time I needed to be there [...]. The length was probably more determined by me than them [oncology team].</i></p> <p>(Participant 30)</p>
	1.4. Ability to communicate outside of clinic appointments	<p><i>Well if I couldn't do it [communicate] in the office, you're plugged into the breast care phone system, so you call and they put you directly through to either the PA [physician assistant], the nurse, or whatever. And if they can't directly call you, I'm called within 24 hours, generally that same day. So, I felt reporting and getting an answer was [...] very efficient and I felt very comfortable.</i></p> <p>(Participant 2)</p>
	1.5. Knowledge of CIPN as side effect of treatment	<p><i>...even though they [clinicians] say you're going to have numbness and tingling, you're like okay. Well it's numbness and tingling and not having said you won't be able to walk. I think folks would make a different decision, you know.</i></p> <p>(Participant 43)</p> <p><i>I have a little tingling in my fingers, but that's basically a 'no' because what they're [clinicians] looking for is walking on marbles. [...] I told my M.D. that I was having no neuropathy, because the way they were describing the neuropathy I wasn't having it.</i></p> <p>(Participant 10)</p>
Theme 2: Deterrents to CIPN reporting	2.1. Perception of need to complete the full course of therapy	<p><i>I didn't think it was an option [discontinue treatment] actually. I thought I needed 12 and even if I was super sick, I was going to go through with my 12. I had a countdown on my wall with 12 on it and I never thought of doing any less.</i></p> <p>(Participant 26)</p>

Themes		Exemplar Quotes
	2.2. Fear of treatment discontinuation	<p><i>I was nervous and I was afraid that I needed 12 [doses], and I wasn't going to get 12 [doses], and how was that going to affect my long-term outcome, which was scary.</i> (Participant 50)</p> <p><i>I needed the oncologist's actual permission and recommendation that I quit it when I did because I felt I was giving up or wasn't getting everything that I should have.</i> (Participant 21)</p> <p><i>I was a little scared at first because, like I had said, I thought I needed all 12 [doses] to actually complete the whole process. But I was so relieved when she [the oncologist] said no you just do as many as you can.</i> (Participant 37)</p>
	2.3. Lack of knowledge of long-term consequences of CIPN	<p><i>Well I think believing that it [CIPN] was only temporary, you know, and that once I was off of the paclitaxel that I would begin to get back to normal. Now, if they had told me that this was a permanent thing, I probably wouldn't have taken it [paclitaxel]</i> (Participant 43)</p>
Theme 3: Balancing effectiveness versus functional impairment due to CIPN	3.1 CIPN tolerability associated with symptom reporting	<p><i>...if it [CIPN] ever increased to a great degree, I had in the back of my mind that I was going to tell her, because every week it was like okay if it doesn't get any worse than this, I can live with this the rest of my life, if this is permanent.</i> (Participant 48)</p> <p><i>I didn't really want to have to stop, because I wanted to get it [treatment] over with... But again, if it's so debilitating that I can't function, and I was pretty close to not functioning, if it had been worse than that, I guess I probably would've done what my doctor felt was correct.</i> (Participant 02)</p> <p><i>...knowing now that I could've skipped a few of them [treatments] near the end, [...] I probably would've stopped the paclitaxel at like number 8 or 9 [...], if my doctor felt confident that it [paclitaxel] [...] was doing its job enough.</i> (Participant 37)</p>
	3.2 Potential CIPN under-reporting	<p><i>It [under-reporting] crossed my mind somewhere after the neuropathy started, around the fourth week... [...] maybe I can get away with it if I don't tell her... Just let me get through all my treatments because I want to get it done in the right order.</i> (Participant 41)</p>

CIPN, chemotherapy-induced peripheral neuropathy