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Title page

Involving patients and nurses in choosing between two validated questionnaires to identify Chemotherapy Induced peripheral Neuropathy before implementing in clinical practice – a qualitative study.

Short running title: To identify side effects from cancer treatment

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Conflict of interest

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Authors' contributions

MÆJ, MY and BP designed the original study. MÆJ and BP gathered and analyzed the data. They drafted the paper that was further refined in discussions with MY. All researchers revised and approved the paper that presents the results of our research.

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Aims and objectives

To explore from a nurse and patient perspective what questionnaire - “Functional assessment of cancer treatment gynecological group neurotoxicity” or “Oxaliplatin-Associated Neuropathy Questionnaire” - best describes chemotherapy-induced peripheral neuropathy and its influence on everyday life in a comprehensive and meaningful way, prior to implementation in daily practice.

Background

Patients experience chemotherapy-induced peripheral neuropathy during and after chemotherapy for colorectal cancer with Oxaliplatin. This neuropathy is difficult to describe for patients and to identify for nurses. To address the specific needs of patients and improve identification of neuropathy and its influence on everyday life, we wanted to implement a questionnaire in clinical practice.

Design

A phenomenological hermeneutic frame of reference was used.

Method

Semi-structured interviews with 15 patients and two focus groups with eight cancer nurses were used for data collection. Data was organized and interpreted by content analytical steps in a hermeneutical process. COREQ checklist was used in reporting of the study.

Results

The analysis resulted in two main-themes 1) 'To dig deeper' with sub-themes 'to identify the line between acceptable and non-acceptable chemotherapy-induced peripheral neuropathy', and 'searching for a precise description'. 2). 'When everything is interrelated' with subthemes 'to be aware of different perspectives and understandings' and 'recognize potential pitfalls'.

Conclusion

Involving patients and nurses in choosing between the two questionnaires revealed that neither alone was sufficient to describe the patients' experiences. Instead, it seems essential to implement both questionnaires, using the answers as a basis for a dialogue to address the patients' specific needs.

Relevance for clinical practice

Using patients and nurses perspectives in a complementary way may provide a solid foundation before starting an implementation process in clinical practice. However, attention must be paid to potential barriers and facilitators as well as the fact that a successful implementing process requires leadership and information sharing.

Keywords

Chemotherapy, neuropathy, colorectal neoplasm, questionnaires, implementing, nurses, patients, focus groups, individual interviews, content analysis

Introduction

This paper explores from a nurse and patient perspective which of two validated questionnaires best describes Chemotherapy Induced Peripheral Neurotoxicity (CIPN) in a comprehensive and meaningful way, as well as its influence on everyday life way before

implementing one of them in daily practice. Understanding and valuing patients' experience-based knowledge and applying their expertise in research processes may positively influence the outcome e.g. the patients' engagement and willingness in responding questionnaires (Duffett, 2017). In addition, involving patients in deciding a questionnaire may contribute to increasing quality and high compliance in follow-ups (Althubaiti, 2016; Schwappach, 2010). Moreover, involving clinical nurses in decision-making may contribute to tailoring a subsequent intervention to the clinical setting and take into account potential barriers and facilitators (Stacey et al., 2015). In this specific case, the questionnaire is meant to support patients in describing their experiences of CIPN and assist health care professionals (HCPs) to assess CIPN during and after chemotherapy for colorectal cancer (CRC) in a specific clinical setting. Thus, to take into account the priority of patients, the reality of clinical settings and facilitate the subsequent implementation of the questionnaire, patients and cancer nurses were involved in the study process.

Background

CIPN is one of the most common side effects to platinum-based chemotherapy like Oxaliplatin (Banach et al., 2016). CIPN is described as nerve damage that may develop during and after chemotherapy triggered by drug accumulation (Seretny et al., 2014). CIPN affects both the sensory and motor nerve system and includes dysesthesias, tingling and burning sensations and pain involving both lower and upper extremities and the head and neck area (Banach et al., 2016).

As early detection of it is a means to prevent persistent CIPN (Massey et al., 2014), it is important to encourage patients to report CIPN as soon as possible and monitor it closely (Banach et al., 2016). However, patients find it difficult to express how they experience CIPN as the symptoms are multifaceted and to some degree blurry (Miltenburg & Boogerd, 2014; Tanay et al., 2017). Accordingly, it is important to apply tools to identify CIPN that are acceptable and meaningful for the patients, which may be clarified through patient involvement.

According to Staley and Barron (Staley & Barron, 2019), patient involvement must be tailored for a purpose and be regarded as a conversation that supports learning for the involved parties (Staley & Barron, 2019). To learn from patients' perspectives before implementing a questionnaire in clinical practice, patients may participate as consultants, providing input and views on selected aspects of the research process (Duffett, 2017). Recent

literature highlights patients' increasing involvement in research and quality processes e.g. transforming guidelines into lay language (Boelens et al., 2014) and investigating acceptability and feasibility for a screening tool (Ristevski et al., 2015). However, no studies were found about involvement of patients with gastro-intestinal cancer in choosing a questionnaire for CIPN identification.

In addition to patients, nurses play an essential role in meeting patients' concerns and needs when patients visit the outpatient clinic for chemotherapy. They follow up on information about the risk of developing CIPN and contribute to identifying early signs of it (Miltenburg & Boogerd, 2014). This requires that nurses have insight into and knowledge of the extent of CIPN and are able to take relevant actions that may prevent and/or alleviate CIPN. Likewise, they are responsible for the initial assessment of CIPN and for reporting to the physician if they evaluate CIPN to be serious and intervention to be required. Involving both patients and nurses to explore the meaningfulness and comprehensiveness of the questionnaires is therefore anticipated to facilitate the implementation process.

Choice of instrument

CIPN has been found to obstruct normal activities like driving, writing, picking up things, carrying out hobbies, household, duties and exercising (Bennett et al., 2012; Tofthagen, 2010). Besides, the experience of CIPN depends on its intensity, analgesic efficacy, self-care strategies, the level of pain increase, sleep disturbance, fatigue, and interference with valued activities (Bakitas, 2007). Multiple instruments have been developed to identify CIPN but no gold standard has been established, although it is common for physicians to use the scales of National Cancer Institute - Common Terminology Criteria Adverse Events (NCI-CTCAE) in their assessments of patients' adverse events. However, comparing a clinician-based grading system like the CTCAE scale with patient-reported outcome measures shows that professionals score patients' conditions lower than patient' themselves and thus identify fewer patients with CIPN (Molassiotis et al., 2019; Nyrop et al., 2019).

In addition to the NCI-CTCAE scale, the European Organization for Research and Treatment of Cancer developed a questionnaire CIPN20 (EORTC-CIPN20). This measures sensory, motor and autonomic and functioning in patients experiencing CIPN (Tofthagen et al., 2011). Although CIPN20 contains questions about side effects in upper and lower extremities and from the head area, it does not assess the grade of distress symptoms cause. Thus, according to Kieffer et al. (2017), CIPN20 is useful for a simple additive checklist.

Based on a review on CIPN tools, Haryani et al. (2017) recommend 'Functional assessment of Cancer treatment gynecological group neurotoxicity (FACT/GOG-Ntx) as this

questionnaire combines questions about quality of life and neurotoxic side effects. Patients are asked to answer questions about physical wellbeing (seven items), social wellbeing (seven items), emotional wellbeing (six items), functional wellbeing (seven items) and 11 items regarding neurotoxicity on a scale from 0 to 4. Although FACT/GOG-Ntx was developed for use among patients with gynecological cancer and other neurotoxic chemotherapy it is widely used in studies on CIPN among patients with different cancer diagnoses including CRC (Dault et al., 2016; Driessen et al., 2012; Mols et al., 2014; Vatandoust et al., 2014).

Moreover, there has been increased attention on widening the assessment of CIPN to include an examination of physical symptoms from the mouth and face and investigate to what extent the symptoms affect daily activities (Driessen et al., 2012; Gustafsson et al., 2016; Leonard et al., 2005). In 2005, Leonard et al. developed a questionnaire for assessing CIPN divided into three areas: the upper and lower extremities and orofacial areas with ten, nine and ten items respectively. First, the patient is asked to grade CIPN on a scale from one (almost nothing) to five (a lot) and next to grade how CIPN affects everyday life (Leonard et al., 2005). The questionnaire was later called OANQ, an abbreviation for Oxaliplatin-Associated Neuropathy Questionnaire (Gustafsson et al., 2016).

Based on this review of instruments to detect CIPN, FACT/GOG-Ntx contains questions about quality of life and OANQ about how CIPN affects daily activities. Thus, it seemed that one of these would be the most useful to implement. In addition, both questionnaires were translated into Danish and have undergone reliability testing in detecting CIPN (Calhoun et al., 2003; Driessen et al., 2012; Gustafsson et al., 2016).

Aim

The aim of this study was to explore, by involving patients and nurses perspectives, which of the two validated questionnaires - FACT/GOG-Ntx and OANQ - best describes CIPN and its influence on everyday life in a comprehensive and meaningful way before implementing one of them in daily practice.

Method

This qualitative explorative study was conducted in a phenomenological hermeneutic frame of reference, which is a mode of understanding in qualitative interviewing that aims to reveal interviewed subjects' perspective (Brinkmann & Kvale, 2015). To explore the patients' experiences of using the questionnaires, individual semi-structured interviews were used as

this kind of interviewing may provide detailed information in the respondents' own words and allow for supplementary questions (Brinkmann & Kvale, 2015).

To explore the nurses' perspective on the use of the questionnaires, Focus Groups (FGs) were used for data collection as discussions and interactions between participants in FGs may provide a platform for sharing and comparing experiences and opinions among participants (Groenkjaer et al., 2011; Halkier, 2003; Kitzinger, 1994; Krueger & Casey, 2009). The Consolidated Criteria for reporting Qualitative Research Checklist was used as a guideline for facilitating and securing a complete reporting of the study (Tong et al., 2007).

Participants

At the oncological outpatient clinic, at a Danish University Hospital, fifteen patients; eight males and seven females, mean age 62.7 years (range 53 – 72) were included consecutively when they attended the outpatient clinic for their chemotherapy (Table 1). Danish speaking patients receiving adjuvant or palliative treatment with the chemotherapeutic drug Oxaliplatin for gastro intestinal cancer were included independent of their treatment cycle. Patients with cognitive impairments, difficulties in speaking and understanding Danish were excluded. The first author, a development nurse (Master of Clinical Nursing) from the outpatient clinic unit who occasionally participated in patient care, approached the patients and gave them information about the project before their final consent. None of the patients declined to participate.

To familiarize the patients with the questionnaires, they completed them three times during their treatment cycles (Table 1). Completion on three occasions was anticipated to provide information of potentially different experiences across time in the individual interviews.

To ensure that included participants are knowable informants and able to share their experiences about the topic under investigation, the nurses were included purposefully among nurses that had dealt with patients filling in the questionnaires. Eight out of 14 potential nurses working two specific days from the CRC team were included. Thus, the risk for selection bias was decreased. The nurses were also approached by the first author, the development nurse from the outpatient clinic. They were all females, mean age 41.1 years (range 37 – 49) and with oncological experience mean 6.5 years (range 1 – 11) (Table 2). None of the nurses declined to participate but one nurse was unable to attend the FG due to illness.

Ethics

In Denmark, the Danish Research Ethics Committee does not assess and register qualitative studies. However, the project observes all regulations concerning research ethics according to The Nordic Nurses Federation (Nordic Nurses, 2003) and the Helsinki Declaration (The World Medical Association, 2018) and is notified to the Danish Data protection Agency (journal number: ID 2018 150). The participants were informed about the project orally and in writing and signed informed consent. Participation was voluntary and the participants were informed about their right to withdraw from the study at any time without consequences.

Anonymity and confidentiality are ensured by coding data and exchanging names with ID numbers. The data is stored in a keyword-protected computer only accessibly for the researchers.

Data collection

By means of an interview guide (Table 3), the first author who has skills in interviewing patients from her master program and daily practice conducted the individual semi-structured interview. The interview lasted from 6 to 21 minutes (equivalent to 2.6 hours of total interviewing).

The FGs with four and three nurses respectively took place at the end of a working day. The last author (MSc in Nursing, PhD) who is skilled in interviewing and moderating for a scientific purpose, conducted the FG. In the discussion, the moderator posed the opening question, 'What questionnaire do you find most useful to describe the patients' experiences of CIPN and their influence on everyday life'. The participants answered the opening question one by one, thus creating a platform for further discussion. Afterwards they challenged each other about their current practice, advantages, and disadvantages regarding implementing a questionnaire. Questions from the moderator were only asked to clarify and elaborate on what was said during the discussion or to ensure consistency between the interviews and the FGs, asking the participants to discuss the same question posed to the patients but moderately transformed (Table 4). At the end of the discussion, a debriefing took place to ensure that everybody had had the opportunity to contribute from her experiences (Brinkmann & Kvale, 2015; Morgan, 1997; Redmond & Curtis, 2009). The FGs lasted 49 and 55 minutes.

The individual semi-structured interviews and FGs took place at the outpatient clinic in a room convenient for the purpose. All interviews were conducted in Danish, digitally recorded and transcribed verbatim for further analysis. The quotes were translated into

English with caution by the authors not to change the intended meaning. Data saturation was obtained in the individual interviews as well as in the FGs as conducting the second FG and the last three individual interviews provided no meaningful new insight regarding choosing between the two questionnaires. Thus, due to the data saturation, the interviews and FGs provided rich data to fulfil the aim of the study and supported the credibility of the study (Graneheim & Lundman, 2004).

Analysis

To get a sense of the whole, the authors read the texts several times. Subsequently, the analysis was accomplished in an interplay between the researchers (first and last author) and data in an iterative process of reading, analyzing and rereading (Brinkmann & Kvale, 2015). According to Brinkman and Kvale (2015), the analysis from a phenomenological hermeneutic approach aims to describe the manifest meaning from the transcribed text and next interpreting the latent meaning, that goes beyond what is said to a deeper understanding (Brinkmann & Kvale, 2015). Inspired by content analytical steps, essential meaning units from individual interviews and FGs were identified and further condensed into manifest and latent content and coded (Graneheim & Lundman, 2004) (Table 5). Thus, the analysis moved from ‘what was in the data’ to ‘what the data was about’, thinking interpretively (Morse, 2008). After coding, we combined and arranged the data from individual interviews and FGs in themes and sub-themes (Graneheim & Lundman, 2004) (Table 5). In the whole process the researchers’ pre-understanding was taken into consideration by questioning each other’s interpretations until consensus was reached.

Results

The analysis provided two main themes, each elaborated in two sub-themes. Both patients and nurses found it important to implement a questionnaire that helped them to ‘To dig deeper’ and thus improving their ability to ‘identify the line between acceptable and non-acceptable CIPN’ as well as ‘searching for a precise description’. However, it was a challenge to choose between the two questionnaires ‘When everything is interrelated’ and it was important to be ‘aware of different perspectives and understandings’ while ‘recognizing potential pitfalls’.

‘To dig deeper’

Identifying the line between acceptable and non-acceptable CIPN

As the main issue for the nurses was to prevent persistent CIPN, it was important to clarify the demands for whether the development of CIPN prompted a change in the chemotherapy. As a nurse said: *'Our responsibility is not to prescribe. We need a tool to proceed with'* (N7). Acknowledging their specific role as mediators between patients and physicians, the nurses explored CIPN in their own way but found it difficult to identify systematically. The nurses anticipated that a specific tool could support their responsibility to dissociate between acceptable and non-acceptable CIPN and provide data for the physician for dose maintenance or reduction of the chemotherapy'

'I think the questionnaires will help us to explore the side effects in-depth, to ask questions exhaustively and reveal details, which I do not do in my current practice so systematically' (N3).

Thus, applying a questionnaire could reveal problems that normally were not articulated in the relationship with the patient and dig deeper into the experience of CIPN. Furthermore, it could assist the nurses to obtain comprehensive details from the patient and in this way 'get a shovel deeper' (N2). Not only the nurses found implementing questionnaires important, the patients also did so.

'Using the questionnaire makes me think differently and more than before. I admit that. The questionnaire forced me to be aware of what happens in my body. How did I manage, what did I experience – before the questionnaire I did not reflect on it' (P6).

Answering the questionnaire could push to a deeper reflection and provide additional words for the patients' experiences. From this perspective filling in a questionnaire could be a benefit and contribute to exploring CIPN more deeply and to identifying the line between acceptable and non-acceptable CIPN. Thus, both the patients and nurses were motivated in using questionnaires to explore CIPN.

Searching for a precise description

In general, the patients considered the questionnaires were easy to fill in although some preferred FACT-GOG/Ntx and others OANQ. However, testing the questionnaires revealed that some patients were able to answer them independently of guidance, whereas others needed additional help to understand the grading and structure of the questionnaires.

'It is important that you read the questions properly. Some I read more than once. What did the question mean? You also have to be aware of the division of hands and arms and on the next page feet and legs. It could be a good idea that

the nurses helped us to pay attention to this' (P2).

'I did not know how to describe my prickly sensation in hands and arms. I chose three – it was very unpleasant when it appeared but it disappeared quickly.

Whether it was almost nothing or a lot, I could not tell' (P9).

The quotes illustrate the request for a heightened awareness of patients' ability to understand and reply to the questionnaires and point to the importance of information and guidance from the nurses before filling in the questionnaire for the first time. Without information and guidance about filling in the questionnaires, the answering could lose trustworthiness and leave the patient alone with misunderstandings.

'I saw he graded five, but he had just said he had no side effects. Then I read the question again 'oh no, that was wrong' he said. It is a matter of understanding, that grade one is no side effects and five is a lot' (N1).

Although the nurses were interested in knowing '*how the side effects are right now*' (N1), as a point of reference for the next chemotherapy, they also attached significance to whether CIPN increased in intensity and persisted between the chemotherapy sessions.

'I find it difficult....the patient can experience pain in the jaw....but for how? Answering 'almost none or quite a lot' tells nothing about how long it has lasted, which we also need to know' (N5).

Neither of the questionnaires depicted how long CIPN persisted in between the chemotherapy sessions, which was a part of the investigation and assessment of CIPN. In the FACT-GOG/ntx, the patients were asked to recall their side effects during the last week, whereas OANQ did not suggest a specific time point. Thus, searching for precise description would require continuous attention to the development of CIPN in between the scheduled chemotherapy sessions to compensate for this missing information. Consequently, a potential disadvantage for implementing the questionnaire was the risk of losing the real description of CIPN, which could be minimized if the answers from the questionnaires were used as a starting point for a dialogue.

When everything is interrelated

Awareness of different perspectives and understandings

In the nurses' current practice, their starting point in the conversation with the patients was what was prevailing for them. Implementing a questionnaire, they were aware that the starting point from the patient's perspective could be restricted in favor of a more

comprehensive exploration of physical sensations and functionality or a one-sided focus on questions from the questionnaire.

'Normally, the conversation starts naturally on what the patient feels is urgent right now – contrary to using a questionnaire that covers everything (about neuropathy). It is a matter of exploring what is urgent for the patients as well as all neuropathic side effects' (N1).

Being attentive to the interrelatedness of symptoms and everyday life, the nurses strove not to overlook worries that were important for the patient and their everyday living. Exploring the influence of CIPN on everyday life felt more natural using FACT-GOG/Ntx. Likewise, filling in this questionnaire could support the patients' vocabulary to describe their own experiences. A patient said, *'I could have used the questionnaire (when I started the treatment) to put into words how I feel. What is normal, how much is it okay to be affected' (P3).*

Implementing a questionnaire may affect the patients psychologically because filling in the questionnaires forced the patient to recognize side effects they did not understand, overlooked or repressed. This could be a positive effect as, *I found out Okay my discomfort may originate from the chemo. It is the reason for my condition (P14).* Another patient said the questionnaires covered almost everything and that FACT-GOG/Ntx hit the emotions in an uncomfortable way, *'These questions (...) are coming close to you when you are sitting here alone (...). In addition, you suddenly consider 'can I get these side effects as well (P2)'. Thus, being confronted with questions from the questionnaires seems to require attention to how patients during and after chemotherapy cope and enter into learning processes.*

Caring for patients' potential defense mechanisms, acknowledging the risk for talking past each other and not recognizing their perspectives, the nurses currently *'encourage the patients to use their own words' (N4).* In their efforts to reach a shared language, they furthermore tried to increase and complement the patient's vocabulary with other patients' descriptions of CIPN and use their experience from former situations to explore the present patient's experience.

'You can describe it with words from another patient, 'Is it like walking on cotton wool? No, it is not like that. Is it like walking on needles? Yes, it seems like this'.

(...). Asking questions and explaining symptoms in different ways to reach understandings; suddenly one patient may say 'Oh that is what it means' (N7).

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These statements reveal how the nurses currently pay attention to the patient that may understand information and report CIPN differently. To reach the patient's perspective and provide the best data for decision on the dose of chemotherapy the questionnaires can contribute to a more complete reporting style. However, it seems still important to take into consideration the difference between patients' and professionals' perspectives, pre-understandings and language.

Recognizing potential pitfalls

Initially the nurses assessed OANQ as appropriate for the exploration of CIPN but they were aware of potential pitfalls if they just focused on the items in this questionnaire.

Acknowledging that exploring the grade of CIPN was their primary aim, the 'soft' information and helping the patients with everyday concerns came next. Nevertheless, they paid attention to the interrelatedness between physical sensations and impairment and their influence on physical, emotional, socially, and functional wellbeing in everyday life, which was explored to a higher degree using FACT- GOG/Ntx

'Initially, information and action regarding neuropathic side effects come first everyday life comes after. Although OANQ focuses on CIPN, we should talk about quality of life as well. Overwhelming fatigue may prevent one from leaving the house (...). What does it mean to them? Regarding FACT-GOG/Ntx; if you struggle hard with side effects without having any network, it can be difficult. On the other hand, if our goal is to identify patients suffering from CIPN, OANQ is more relevant' (N1).

In the FGs, the nurses moved between which questionnaire was deemed most suitable regarding its focus mainly on CIPN and whether the data obtained from the questionnaires also should depict how patients were influenced in their everyday living in a broad sense. The initial assessment of OANQ illustrated that this questionnaire could indirectly reveal the effect on everyday living but limited to functioning and symptoms from the hands, arms, feet, legs and face areas. Thus, implementing this questionnaire alone would lead to missing information about everyday concerns. Although OANQ also was deemed suitable regarding the attention to the development of CIPN by patients and nurses, they articulated this inter-relatedness.

'OANQ is best if you focus on facts, but you cannot use it if you need to know something about my social life. If I lived alone without nearby friends and family FACT-GOG/Ntx helps you to express pain, loneliness etc.' (P6).

'I think FACT-GOG/Ntx is good because it asks questions about nausea and energy, which you may also suffer from. On the other hand, OANQ asks questions about all odd thing appearing in your hands. They are good, both of them' (P3).

It became clear how the two questionnaires complemented each other and how the application of both could contribute to a nursing perspective that incorporates the patient's physical state and functioning as well as quality of life. Thus, implementing both questionnaires could support the nurses in the clinical practice, where they stress the importance of talking about what could be important for the patient and at the same time getting valid information on the patient's CIPN to prevent it from becoming consistent.

Discussion

This study aimed to explore which of two validated questionnaires best describes CIPN and its influence on everyday life in a comprehensive and meaningful way before implementing one in daily practice. As there is no gold standard regarding which questionnaire is most comprehensive in identifying CIPN, it was reasonable to involve patients and nurses in the decision. To take into account potential barriers and facilitators that may enhance implementing the questionnaire for daily use prospectively (Stacey et al., 2015), patients' and nurses' priorities and opinions would be essential to integrate in the implementing process.

Although involving patients in research is often met with skepticism about their ability to contribute to the process, this opinion is changing and the interest in patient-reported outcomes is increasing (Duffett, 2017). In addition to choosing the questionnaire, engaging patients and clinical nurses sought to tailor the subsequent intervention. However, it may be discussed on which level the patients were involved. De Wit et al. (2019) define patient involvement according to the role the patient takes in the researching process. In accordance with Duffett's (2017) description of the consulting role, de Wit et al. (2019) discuss patient involvement where patients contribute with their individual experience and the information flows from patient to the researcher often by means of a kind of interviewing (de Wit et al., 2019). Thus, the consulting role was evident in our study. They also took an implicitly advising role when they displayed their opinion about the questionnaires. Even though the patients were experts in their disease and experiences of CIPN, they were not involved as collaborators, which would have meant participation in the planning and executing of the

study (de Wit et al., 2019). Anticipated to take an essential role in the subsequent implementation process, the nurses were involved as well as consultants and advisors.

In agreement with Harvey and Kitson (2016), successful implementation relies on the recipients, those who are affected by and influence implementation at the individual as well as at the collective team level. Involving the recipients makes it possible to take into account their motivation, values and beliefs, skills and knowledge, etc. (Harvey & Kitson, 2016). The recipients in our study were patients and nurses. All of them put a positive value on implementing a questionnaire that helps them to 'To dig deeper', to identify the line between acceptable and non-acceptable CIPN and ensure a precise description. According to Weiner (Weiner, 2009) it may indicate that both patients and nurses were ready to adopt the changes and willing to participate in the implementing process in a positive way. However, our findings showed that we needed to consider the nurses' current practice, patients' potential difficulties in understanding the questionnaire, as well as emotions appearing among the patients. Failing to consider these potential pitfalls in the implementing process may obstruct a successful implementation (Harvey & Kitson, 2016).

According to Stacey, it is of great value to address potential barriers when changing professional practice and find a way to resolve them before starting the process (Stacey et al., 2015). In our study, some barriers seemed to be associated with the risk of missing exploration of the patients' experiences, which required awareness of different perspectives and understandings among the patients. Although the patients filled in both questionnaires three times, they still displayed difficulties due to trouble in understanding the questions and the grading, which did not correspond with their everyday language. A discrepancy between patients' and HCPs' languages and understanding is pointed out by Clark (Clark, 2008). Not taking care of these pitfalls and barriers may subsequently prevent a precise description and provide insufficient data for assessment of the dose of chemotherapy. To gain insight into the patients' concerns and reach a shared understanding, Clark talks about different horizons that need to fuse. In this process, the patient and HCP increase their common understanding of a certain topic (Clark, 2008) in this case, identification of CIPN and its influence on everyday life.

In addition to using a questionnaire, the nurses in our study stressed the need to maintain their current practice and talk about the patients' primary concerns first and not to overlook what was urgent for them. This indicated attention to the patients' perspectives although this did

not ensure the patients' understanding of filling in the questionnaire. On the other hand, we found that implementing a questionnaire could support the patients in revealing urgent care needs associated with CIPN in a time-limited unit in a more systematic way. This is in accordance with Mooney et al. (2017) who demonstrated that using a questionnaire may contribute to intensifying symptom care and improve quality of life among the patients (Mooney, Berry, Whisenant, & Sjoberg, 2017). However, the outcome may rely on the ability to narrow or close the gap between the patients' and the professionals' estimation and grading of symptoms, a gap which in other studies is articulated as a crucial problem (Molassiotis et al., 2019; Mooney et al., 2017; Nyrop et al., 2019). Thus, closing the gap and dealing with different perspectives and understandings when everything is interrelated, the nurses need finely tuned communication to help the patients' to express their fundamental care needs (Bundgaard, 2019). As CIPN may affect sleep disturbance (Hong, Tian, & Wu, 2014), normal daily activities (Bennett et al., 2012; Tofthagen, 2010) and lead to depression (Miltenburg & Booger, 2014) etc., the dialogue about physical and psycho-social side effects that potentially may lie outside the scope of the questionnaire may be essential to get an understanding of the patients' preferences. Consequently, using their communicative skills, the nurses may support a fusion of horizons as stressed by Clark (Clark, 2008) and thereby accommodate the patients' needs and deliver nursing care at a high quality, as shown in the study of Bundgaard et al. (2019). In addition, combining questionnaires with the dialogue about what is of concern for the patients may prevent the inherent risk when using a standardized communication form of producing care which is dehumanized and unaccompanied (Jørgensen, Kastrup Jensen, & Brogaard, 2019).

Bearing this in mind, it appeared difficult for patients and nurses to choose one of the questionnaires 'because everything is interrelated'. Although they agreed that OANQ (Gustafsson et al., 2016) seemed meaningful and comprehensive for assessing CIPN, this questionnaire lacked the opportunity to explore the patients' quality of life with CIPN, which could increase the nurses' understanding of the patients' fundamental care needs. Focusing on grading CIPN alone could also imply a one-sided bio-medical perspective, which is not in accordance with nursing care that emphasizes the integration of the patients' bio- psychosocial needs (Feo, Kitson, & Conroy, 2018). On the other hand, choosing FACT-GOG/Ntx (Haryani et al., 2017) alone was not sufficient to explore CIPN in depth. Thus, implementing both questionnaires from the perspective of patients and nurses would contribute to making the right decisions and ensuring a focus on what values most to the patients (Staley & Barron, 2019).

Strengths and limitations

Analyzing the data with content analytical steps, illustrating the structure for the analysis and presenting the findings related to quotes, makes it possible to follow our reasoning through the study (Erlingsson & Brysiewicz, 2017). Staying close to the data, continuous discussions in the research group and thorough revisions of the material limited the risk for confirmation bias in the research group (Althubaiti, 2016). Additionally, this makes it easier for the reader to assess the rigor of the study and supports the trustworthiness of the study (Erlingsson & Brysiewicz, 2017). Including patients consecutively may lead to slight variation in the sample. However, the patients displayed a variation in age, sex, diagnosis and treatment schedule, which enabled nuanced information (table 1) although some of the interviews were very short. This may have depended on whether the patient had experienced no or low-grade CIPN or had experienced increasing side effects. The latter case may have forced them to reflect deeper on how to fill in the questionnaire, which contributed to more data.

To decrease selection bias, nurses who had dealt with patients filling in the questionnaires on two specific working days were purposefully included in FGs. Although Morgan (Morgan, 1997) recommends three to six groups with six to ten participants when conducting FGs alone, he stresses that fewer participants also can be productive. However, the two FGs with fewer participants, revealed that the nurses were able to challenge each other's opinions and discuss the benefits and disadvantages of the two questionnaires. Thus, combining the perspectives of 15 patients and 7 nurses on the same topic contributed with rich material, which supports the credibility of the study (Graneheim & Lundman, 2004). The transferability of the findings to other context depends on the reader (Graneheim & Lundman, 2004). However, involving patients and nurses to participate in a study before selecting an instrument, seems appropriate and transferable to every setting where new questionnaires are intended to be implemented. Combining the two specific questionnaires supports the opportunity to explore CIPN as well as its influence on everyday life in a comprehensive and meaningful way. However this seems only transferable to settings where patients are challenged with CIPN due to treatment with oxaliplatin.

Conclusion

The study provided insight into the importance of involving the patients and nurses in choosing between two validated questionnaires. This involvement made it possible to obtain knowledge of what values the most to the users of the instrument and contributes to tailoring

the intervention to the clinical setting and taking into account potential barriers and facilitators before planning the implementation process. Individual interviews with patients and FGs with nurses pointed to the need to choose both questionnaires to ensure the identification of CIPN and the influence on patients' quality of life. In addition, the study revealed the requirement to focus on the patients' preferences in an attempt to maintain essential values in nursing when improving the assessment of CIPN.

Relevance to clinical practice

The results can build upon existing literature on how involving users of the healthcare system and HCPs can be essential for the outcome of an implementing process. Involving patients in research processes may be a benefit of the study (Duffett, 2017). Patients have expertise based on their experiences while the HCPs have expertise in the specific disease, diagnosis and relevant actions. Using these perspectives in a complementary way may provide a solid foundation before starting an implementation process in clinical practice.

Although the nurses in the study displayed readiness for the changes, attention must be paid to potential barriers and facilitators as well as the fact that a successful implementing process requires leadership and information sharing (Weiner, 2009). Firstly, an information sheet will be developed about how the nurses are expected to introduce and help the patients in filling in the questionnaire the first time either on paper or with electronic devices. This aims to take care of the risk of information bias, which may be a common one when patients are self-reporting (Althubaiti, 2016). Additionally, by doing this the nurses will be able to identify patients that are unable to fill in the questionnaire electronically and provide the patient with another solution to describe their side effects. Secondly, and in accordance with fundamental values in nursing, attention must be paid to using the answers as a starting point for a dialogue that also explores the patients' essential concerns and take care of their potential defense mechanisms. Thirdly, to recognize the nurses' need to identify how long CIPN lasted, this additional question is added to the OANQ questionnaire, which was deemed best to identify the grade of CIPN.

How does this paper contribute to the wider global clinical community?

- To take care of patient's needs in accordance with essential values in nursing, the findings raise awareness of the importance of involving users of an instrument before implementing it in daily practice
- To provide the HCPs valid information for further assessments, the patients need guidance before filling in the questionnaires the first time.
- Combining first person perspectives from patients and nurses promotes an awareness of potential barriers and facilitators and thus the possibility to tailor the intervention for all concerned.

Legends

Table 1. Participants - individual interviews

Insert section Participants

Table 2. Participants - focus groups

Insert section	Participants
Table 3.	Semi-structured questionnaire – the patients’ perspective
Insert section	Data collection
Table 4.	Focus Group questions – the nurses’ perspective
Insert section	Data collection
Table 5.	Stepwise Content Analysis
Insert section	Analysis

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Table 1. Participants - individual interviews

ID	Age	Sex	Type of cancer	Treatment	Chemotherapy	Questionnaires filled in treatment cycle no.
1	72	Female	Rectum	Palliative	Folfox and bevacizumab	3, 4 and 5
2	59	Male	Rectum	Palliative	Folfox and bevacizumab	3, 4 and 5
3	61	Female	Colon	Adjuvant	Folfox	2, 3 and 4
4	73	Female	Pancreas	Palliative	Folfox	7, 8 and 9
5	55	Female	Colon	Palliative	Folfox -iri	2, 3 and 4
6	60	Male	Rectum	Adjuvant	Folfox	6, 7 and 8
7	53	Male	Colon	Adjuvant	Folfox	4, 5 and 6
8	57	Male	Rectum	Palliative	Folfox and bevacizumab	7, 8 and 9
9	70	Male	Colon	Adjuvant	Folfox	5, 6 and 7
10	53	Female	Colon	Adjuvant	Folfox	2, 3 and 4
11	60	Male	Rectum	Adjuvant	Folfox	5, 6 and 7
12	72	Female	Colon	Adjuvant	Folfox	2, 3 and 4
13	65	Male	Rectum	Adjuvant	Folfox	3, 4 and 5
14	59	Male	Colon	Adjuvant	Folfox	2, 3 and 4
15	69	Male	Colon	Palliative	Panitumumab and folfox	2, 3 and 4

Table 2. Participants FGs

Participant ID	Age	Sex	Graduated (year)	Oncological experience
FG 1				
1	38	Female	2007	1
2	34	Female	2008	10
3	49	Female	1997	6
4	37	Female	2006	4
FG 2				
5	45	Female	1998	10
6	45	Female	2001	3
7	45	Female	2005	11

Table 3. Semi-structured questionnaire - the patient's perspective

How was your overall impression of filling in the questionnaires?

How did the questionnaires support your possibility of describing your symptoms?

Did the construct/set up of the questionnaires support or inhibit your opportunity to describe your symptoms?

Did you need help from the nurse to fill in the questionnaires?

Which one of the questionnaires did you prefer? Please explain why.

Table 4. Focus Group questions – the nurses perspective

The opening question:

‘What questionnaire do you find most useful to describe the patients’ experiences of CIPN and their influence on everyday life’.

Potential probing questions:

How was your overall impression of patients’ ability in filling in the questionnaires?

How did the questionnaires support the patients’ possibility of describing their symptoms?

Did the construct/set up of the questionnaires support or inhibit the patients’ ability to describe their symptoms and concerns?

Did the patients need you help when filling in the questionnaires?

Which one of the questionnaires did you prefer? Please explain why.

Table 5. Example structure analysis

Quotes from the text – meaning unit	Condensed manifest content close to the text (what is in the data)	Condensed interpretation of the latent content (what the data is about)	Code	Subtheme	Theme
Our responsibility is not to prescribe. We need a tool to proceed with (N7).	The nurses' responsibility is to assess side effects.	A tool is needed to assess side effects as a basis for the physician's prescription.	Benefit of a tool	The line between acceptable and non-acceptable CIPN	To dig deeper
I think the questionnaire will help us to explore the side effects in-depth, to ask questions exhaustively and reveal details, which I do not do in my current practice so systematically (N3).	Using a questionnaire can help nurses to explore side effects in depth.	Applying a questionnaire can challenge the nurses' current practice and support them in working more systematically.	Benefit of a tool	The line between acceptable and non-acceptable CIPN	To dig deeper
Using the questionnaire makes me think differently and more than before. I admit that. The questionnaire forces me to be aware of what happens in my body. How did I manage, what did I experience – before the questionnaire I did not reflect on it (P6).	Answering the questionnaire force the patient to reflect on bodily sensations.	Answering the questionnaire force the patient to realize bodily changes and think about her body in a different way.	Benefit of a tool	The line between acceptable and non-acceptable CIPN	To dig deeper
I did not know how to describe my prickly sensation in hands and arms. I chose 3 – it was very unpleasant when it appeared but it disappeared quickly. Whether it was almost	It can be difficult to grade prickly sensations because they are very unpleasant when they appear but	The questionnaire does not take into account the complexity of sensory disturbances and the patient	Risk for misunderstanding	Searching for a precise report	To dig deeper

nothing or a lot I could not tell (P9).	quickly disappear.	must choose the best answer.			
It is important that you read the questions properly and not in a hurry. Some I read more than once. What did it this question mean? You also have to be aware of the division in hands and arms and on the next page feet and legs. It could be a good idea that the nurses helped us to pay attention to this (P2).	Patients may read the questionnaire (OANQ) properly and pay attention to the division in upper and lower extremities. May need help to recognize this.	It can be difficult to recognize the structure of OANQ, which can lead to misleading answers. Information and guidance from the nurse may be required.	Risk for misunderstanding	Searching for a precise report	To dig deeper
I find it difficult...the patient can experience pain in the jaw...but for how long time? Answering 'almost none or quite a lot' tells nothing about how long it has lasted, which we also need to know (N5).	The questionnaires tell nothing about for how long time the CIPN has lasted between the treatments.	The nurses are aware that implementing questionnaires do not take into account all the information they need to prevent persistent CIPN.	Risk for misunderstanding	Searching for a precise report	To dig deeper
You can describe it with words from another patient 'is it like walking on cotton wool? No, it is not like that. Is it like walking on needles? Yes, it seems like this'(...) Asking questions and explaining symptoms in different ways to reach their understandings; suddenly one patient may say 'Oh that is what it means' (N7).	To reach the patients perspective, nurses use words from other patients and try to ask questions and explain symptoms in different ways.	To improve the patients understanding, the nurses use everyday language in the attempt to identify CIPN. Using trial and error, they can be lucky to hit on the patients preunderstanding.	Improving understanding	Awareness of different perspectives and understandings	When everything is inter-related
I could have used the questionnaire (when I started the treatment) to put into words how I feel. What is normal, how much is it okay to be	The questionnaire can help the patient to put side effects into words.	Without inspiration from the questionnaires it can be difficult to articulate and	Improving language and understanding	Awareness of different perspectives and	When everything is inter-related

affected (P3).		asses the seriousness of the side effects.		understandings	
These questions can (...) are coming close to you, when you are sitting here alone (...). In addition, you suddenly consider 'can I get these side effects as well' (P2).	Question in FACT-GOG/ntx can come close and visualise the amount of possible side effects.	FACT-GOG/ntx confronts the patient with possible side effects and outcomes that could be difficult to handle emotionally.	Confronting one's defense	Awareness of different perspectives and understandings	When everything is inter-related
OANQ is best if you are much focused on facts, but you cannot use it if you need to know something about my social life. If I lived alone without nearby friends and family FACT-GOG/ntx helps you to express pain and loneliness etc. (P6).	OANQ is focused on facts, but tells nothing about social life, pain and loneliness, which FACT-GOG/ntx helps you to express.	Neither of the questionnaires is sufficient to use alone, they have to be combined.	OANQ versus FACT-GOG/ntx	Recognizing potential pitfalls	When everything is inter-related
I think FACT-GOG/ntx is good because it asks questions about nausea and energy, which you may also suffer from. On the other hand; OANQ asks questions about all the odd thing appearing in your hands. They are good, both of them (P3).	Both questionnaires are good but ask questions in different areas.	Using both questionnaires supports the opportunity to describe CIPN as well as everyday life concerns.	OANQ versus FACT-GOG/ntx	Recognizing potential pitfalls	When everything is inter-related
Initially, information and action regarding neuropathic side effects comes first, everyday life comes after. Although OANQ focuses on CIPN, we should talk about quality of life as well. Overwhelming fatigue may prevent one from leaving the house. (...). What does it means to them? Regarding FACT-GOG/ntx, if you	If the patient struggles with side effects without a support network FACT-GOG/ntx is appropriate. OANQ is more suitable to identify patients suffering from CIPN. Questions	To take care of the unique patient, choosing one of the questionnaires does not fulfill the requirements of caring in a nursing context. Nursing is concerned with observations and actions to	OANQ versus FACT-GOG/ntx	Recognizing potential pitfalls	When everything is inter-related

struggle greatly with side effects without having any network, it can be difficult. On the other hand, if our goal is to identify patients suffering from CIPN, OANQ is more relevant (N1).	about wellbeing have to do with how they influence everyday life and not grading CIPN.	help the individual patients' with fundamental care needs and everyday living.			
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