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Development and content validation of a questionnaire measuring patient empowerment in cancer follow-up

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Abstract

Purpose

The aim of this study was to develop and ensure the content validity of a new patient-reported outcome measure, the Cancer Patient Empowerment Questionnaire (CPEQ), to measure the level and enablement of and desire for empowerment among cancer patients in follow-up.

Methods

An iterative process based on: (i) empowerment theories by Zimmerman and Tengland, (ii) a systematic review of questionnaires measuring empowerment or related concepts among cancer patients, (iii) qualitative data from 18 semi-structured interviews with Danish cancer patients in follow-up, (iv) input from a group of 8 cancer patients involved as co-researchers and from an expert steering-group, and (v) cognitive interviews with 15 cancer patients in follow-up.

Results

The items for the CPEQ were developed and revised and 12 versions of the questionnaire were evaluated. The final version consists of 67 items, covering three different dimensions of empowerment: (A) empowerment outcomes consisting of three components: (A1) the intrapersonal-, (A2) interactional-, and (A3) behavioral component, (B) empowerment facilitators (enablement), and (C) the value of empowerment.

Conclusions

This study documents the theoretical and empirical basis for the development of the CPEQ and its content validity. The CPEQ provides a tool for researchers to assess the level and enablement of and

desire for empowerment among cancer patients. The next steps will be to use the CPEQ in a nationwide study of empowerment in cancer follow-up and subsequently shorten the CPEQ based on psychometric methods in order to make it more relevant in clinical studies.

1. BACKGROUND

Patient empowerment is a term that is increasingly used in the health care setting. Preliminary evidence shows that involving and empowering patients may improve care experiences and enhance satisfaction, compliance and treatment effects [1-3]. Empowerment is a latent variable [4] and many definitions of the term ‘empowerment’ exist [5,6]. A broadly accepted definition in the psychological field relevant to our study is described by Zimmerman, who distinguishes between empowerment as a *process* and an *outcome*: “*Empowerment is a process by which people gain mastery over issues of concern to them and the outcome is having mastery and control of these processes*” [7,8].

Empowerment is closely related to other terms such as self-efficacy, health-literacy, shared decision making, cancer care experience etc., which we would argue are all indicators (either causal or reflective) of the empowerment concept. One of the strengths of the empowerment concept is that it is comprehensive and complex.

In this study, we focus on empowerment in relation to patients’ interaction with the healthcare system and their way of managing their health, which can be defined as ‘patient empowerment’.

Empowerment is a relevant concept in cancer follow-up [9-11]. The steady improvement in cancer treatment ensures that people with cancer are living longer, which also leads to cancer increasingly being considered a chronic disease [12]. It has been widely recognized that a cancer diagnosis and subsequent treatment often leave a significant mark on patients [12] and that support needs of cancer patients often do not cease immediately after treatment completion [12,13]. Many patients continue to struggle with significant issues, such as fear of recurrence, side effects, late complications, cognitive impairments, and challenges related to returning to everyday life after cancer, as it is a potential life altering experience [12]. Stakeholders have thus called for more focus on this specific

part of the cancer trajectory and emphasized the essential need for more individualized follow-up plans, taking the individual cancer patients' specific experiences, needs, concerns and well-being into consideration [12,14,15].

In many countries, including Denmark, cancer patients will be referred to a follow-up program after initial treatment [16,17]. In 2015, the follow-up program in Denmark was revised, and it was requested that at the beginning of the follow-up program every cancer patient must be involved in the development of a plan adapted to their individual needs for follow-up. Furthermore, patients should be supported in self-care and in how to monitor and act on their own symptoms [16]. However, this ideal may seem as an extensive demand to some patients and for patients to feel comfortable with taking on this role, there is an increased need for empowerment.

Our theoretical understanding of empowerment, based on Zimmerman's research and theory (for more details on the theory, please see results), assumes that empowerment takes different forms for different people and in different contexts and that it is a dynamic variable that may fluctuate over time. This call for an operationalization of empowerment manifested in the specific target population and setting. One may also argue that the operationalization will be dependent on the specific country and healthcare system, however, we believe that patients in cancer follow-up will share many similar challenges across health care settings. This is supported by the fact that for example the APECC questionnaire developed in the U.S. [18] measures some of the same aspects of cancer care as included in this questionnaire.

Few studies have examined empowerment in the context of cancer follow-up [19]. Thus, to investigate, understand and support empowerment among cancer patients in follow-up, there was a

need for a context and population-specific multidimensional questionnaire [7]. A review showed that four empowerment questionnaires have been developed for or adapted to the cancer setting, but none of these were developed for the follow-up context or covered our theoretical understanding of empowerment [20].

The aim of this study was to develop and carry out the content validation of a new patient-reported outcome measure, the Cancer Patient Empowerment Questionnaire (CPEQ), measuring levels of empowerment, enablement of empowerment and desire for empowerment among cancer patients in follow-up.

The CPEQ was developed with the initial practical aims to investigate the level of and the opportunity and desire for empowerment in the Danish cancer follow-up in a nationwide survey. The purpose of the survey was to understand the current picture of empowerment and additionally to support in tailoring and evaluating new follow-up plans. Subsequently, psychometric testing of the CPEQ will be performed to determine the number of subscales, possible elimination of items, and shortening of the questionnaire, in order to ensure that the CPEQ could also be a candidate outcome measure in clinical trials and intervention studies.

The target population of the questionnaire (and this study) are persons who have or have had a cancer diagnosis and who are now in follow-up stage in the health care system. They will often be referred to as cancer survivors, but here will be referred to as cancer patients.

2. METHODS

Overall design

The development of the CPEQ was inspired by best practice for the development of patient reported outcome measures (PROMs) as described by Patrick et al. [21,22] and builds on i) empowerment theory [7,23], ii) a systematic review of questionnaires measuring empowerment or related concepts among cancer patients [20], iii) qualitative data from interviews with Danish cancer patients during follow-up [8], iv) input from a group of cancer patients involved as co-researchers and from an expert steering-group, and v) cognitive interviews with cancer patients in follow-up. The process consisted of four phases of which phase one “conceptualization” has been reported previously [8], and phases two and three are described in this article (see Figure 1). Phase four, psychometric testing, will follow in a later publication.

(Figure 1. Phases of the development process of the CPEQ)

Participants and materials

In phase one, 18 interviews were conducted with 16 patients with different cancer diagnoses in follow-up recruited from Zealand University Hospital and Copenhagen University Hospital. For further details on the recruitment and participants, see [8]. Data from these interviews were also used in phases two and three, and thus reported in this paper.

A project steering group of experts, consisting of two anthropologists, a psychologist, three medical doctors, a nurse, and a cancer patient was formed and participated in all phases. They contributed with expertise in cancer, cancer follow-up, questionnaire development, validation, etc. The

conceptual framework and various versions of the questionnaire were presented to the project steering group either via emails or face-to-face meetings for discussions and feedback throughout the entire process.

A group of patient co-researchers was formed and participated in all phases. These were cancer patients who were recruited via mailing lists and advertisements on the webpages of patient organizations. In total, 8 of these patient co-researchers were involved in phases two and three. Of these, 7 were female and one male. They had breast cancer, prostate cancer, kidney cancer, melanoma, multiple myeloma, ovarian cancer or childhood cancer. Some of the patients had had more than one cancer diagnosis, some were cancer free, while others had incurable cancer. Time since diagnosis varied substantially: one co-researcher was diagnosed as a child (32 years ago), while others were diagnosed for the first time shortly before being involved in the project. All patient co-researchers had started their follow-up when invited to join the project. Some of the co-researchers experienced relapses during the project period. For further details on the process of recruitment and the characteristics of the patient co-researchers, see [24,25].

In phase three, reported here, cognitive interviews were conducted. We used ‘purposive sampling’ [26] to ensure diversity among the participants in relation to age, gender, diagnosis and socioeconomic status.

A nurse and the first author (NBE) recruited 11 participants from the Danish Knowledge Centre for Rehabilitation and Palliative Care and two from the department of Surgery at Zealand University Hospital. Additionally, two participants were recruited through the investigators’ personal network.

The first 14 interviews were performed from May to July 2017, with two additional interviews in March 2018. One patient was interviewed twice. The duration of the interviews varied from 37 to 150 minutes (average 75 minutes). Patient characteristics are presented in Table 1.

(Table 1. Characteristics of cognitive interview participants.)

Finally, for the development process, we used the Danish Health Authority's standardized descriptions of patients' trajectories from suspicion of cancer, to diagnosis, treatment, follow-up, and rehabilitation [16]. These are called 'Cancer packages' ('Kræftpakker') and 'Follow-up programs' ('Opfølgingsprogrammer'). The first of the new follow-up programs (OGF) was implemented in 2015 [16]. Elements of these guidelines with relevance for empowerment were used in the questionnaire development.

Informed consent

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

PHASE 1: Conceptualization

The conceptualization process has been reported previously [8]. To guide our development of the CPEQ, Zimmerman's theory of psychologic empowerment (PE) was used [7]. Zimmerman's PE theory is comprehensive and describes a 'nomological' network, which provides a solid basis for the development of a questionnaire [7]. However, since PE is both an abstract theory and a dynamic and contextually driven concept [7], we included qualitative data to qualify the theory in the relevant context. The qualitative interviews and interview guide were based on a review investigating facilitators and barriers to empowerment among cancer patients during follow-up [19].

As empowerment as an outcome is a latent variable, the goal of the conceptualization phase was to find manifestations (or reflective indicators) that could be used to measure the level of empowerment [4]. In addition, we included manifestations of empowerment possibilities and desires (see results section). As soon as the indicators of the latent variable is measured it is referred to as an outcome. For further details on phase one, see our previous publication [8].

PHASE 2: Development and revision of an initial item pool

An initial item pool was created based on the conceptual framework, evaluation of other empowerment related questionnaires [20], qualitative interviews, and official guidelines for cancer follow-up. We attempted to cover all areas in the conceptual framework with all relevant manifestations.

The evaluation of other empowerment questionnaires was used to make the authors more precise on delimiting the construct and how phrasing of items were important to distinguish between components. In the final version of the questionnaire, some items cover aspects also included in other questionnaires (e.g. “has the doctor used an understandable language”). However, in these cases, as for all other items, they were developed based on the qualitative interviews, the cognitive interviews or discussions with the patient co-researchers as shown in Table 4.

The initial items were reviewed at a workshop with the patient co-researchers to reduce the number of items whilst reformulating and producing new items. These revised items were then presented at another workshop with the patient co-researchers who were asked to rate the items, select the two most important and the two least important items in each theme and explain their choices. At the third workshop, the patient co-researchers were asked to interview each other using cognitive interview

techniques. At a final workshop, the patient co-researchers were presented with a close to final version of the CPEQ and invited to discuss and comment on the questionnaire.

PHASE 3: Initial validation and revision based on cognitive interviews with patients

The cognitive interviews were planned, conducted and analyzed using the methods described by Willis [27] to investigate whether items were understandable, relevant, suitable and sensitive regarding the target group and whether the items generated the intended information.

The first author (NBE), a trained anthropologist, conducted all cognitive interviews at the preferred location of the participants. At the beginning of the interviews, the participants were introduced to the purpose of the interview and were instructed to fill out the questionnaire. Two approaches were used to gain insight into the validity of the questionnaire - *think-aloud* and *probing* [27]. The cognitive testing was conducted partly during the completion of the CPEQ (mainly after each page) and also with additional summative and clarifying questions after the full CPEQ had been completed. With these methods, we gained insight into the patients' understanding of the items, including the participants' understanding of central terms (such as follow-up, relapse, control, involvement, decisions, information etc.), elaborations on how the participant constructed their answers, etc.

Furthermore, general and specific probes were used to investigate the response process when the participant hesitated, changed an answer or skipped an item. Finally, if the participant at some point during the interview told stories that led the interviewer to expect different answers to items than those given by the participant, this was further explored in a dialogue between the participant and the interviewer.

All interviews were recorded and detailed notes summarizing the results for each item in the CPEQ were added to a table. The interviews were conducted in three waves (of 9, 5 and 2 interviews), and the questionnaire was revised according to the participants' comments, reactions and answers between each wave.

The steering group and the patient co-researchers participated in the discussions and revisions of the questionnaire.

PHASE 4: Psychometric testing

A psychometric testing of the CPEQ has not yet been conducted. However, the questionnaire has been sent out as part of a nationwide questionnaire survey in Denmark and these data will form the basis for later psychometric testing.

3. RESULTS

DEVELOPMENT PROCESS OF THE QUESTIONNAIRE

Versions of the CPEQ

The CPEQ went through 12 different versions (See Figure 2). The number of items both decreased and increased throughout the process (from 239 to 40 and then up to 67 items), which might not follow a usual trajectory in a questionnaire development process. However, there are several reasons for this. First, as some items continuously caused problems despite different attempts to rephrase them, it was decided that the most appropriate solution was to split some of these items into several items (e.g. items 8-13 started out as one item aiming to assess the patient's insight into decisions during their follow-up). Second, some items had been excluded too early in the process and were considered relevant later after a comprehensive rephrasing. Third, the deliberate aim to continuously involve patients to maintain a qualitative focus and stay close to the lived experiences of the patients led to the development of new insights during the process, which in some cases had to be included as additional manifestations.

(Figure 2. Flowchart of the CPEQ development process)

Challenges and solutions when developing the CPEQ

In the development process of the CPEQ, we encountered several challenges which needed to be addressed. In Table 2, our main challenges and solutions to these, based on discussions and experiences from the cognitive interviews and meetings with patient co-researchers, are presented.

(Table 2. Challenges and solutions when developing the CPEQ based on cognitive interviews and involvement of patient co-researchers)

Seven main challenges were identified in the process (Table 2). These included difficulties defining the most relevant context of the CPEQ, how to keep patients' focus on follow-up, how to avoid making empowerment the responsibility of the patient, the relevance of assessing the value of empowerment and how to define healthcare professionals. Finally, narrowing down the relevant factors in relation to enablement was discussed.

THE FINAL QUESTIONNAIRE

Overview of the questionnaire

The CPEQ developed in this study is a multidimensional questionnaire that consists of 67 items and 11 open entry questions. It covers three different parts: (A) empowerment outcomes consisting of three components: (A1) the intrapersonal, (A2) interactional, and (A3) behavioral, (B) empowerment processes/facilitators (enablement), and (C) the value of empowerment. The three parts of the CPEQ thus cover five theoretically driven components.

Furthermore, the CPEQ is arranged in five themes, which are based on our qualitative data collected from the patient interviews, the patient co-researchers and cognitive interviews, to ensure they were contextually relevant and specific in relation to empowerment among cancer patients in follow-up. These five themes were; 1) Information/knowledge, 2) Navigation/overview, 3) Questions/communication, 4) Decisions, and 5) Self-care. These five themes are to some extent cross-cutting with the components (i.e. information/knowledge, decisions and self-care covering all five components).

Table 3 presents an illustration of the conceptual framework of the CPEQ.

(Table 3. Conceptual framework of the CPEQ)

Theoretical and empirical rationale for the items

In Table 4 all items are shown alongside theoretical and empirical arguments for their inclusion and empirical examples of their manifestations. The examples came from 18 qualitative interviews, meetings and discussions with the patient co-researchers and the project steering group, the official guidelines on cancer follow-up and the 16 cognitive interviews.

(Table 4. Theoretical and empirical rationale for CPEQ items)

Part A covers empowerment outcomes in three different components.

- A1) The interactional component covers patients' critical awareness, insight into and ability to navigate their follow-up, which requires that patients have knowledge of possible options, choices or resources in the given context, enabling them to exert control and achieve their goals [7]. This component is closely related to knowledge and health literacy, which are often considered essential/necessary to navigate the healthcare system and influence it [7].

Sub-components: 'Knowledge about context', 'Knowledge of resources, information, and possibilities of navigation', 'Security and satisfaction', and 'Awareness of choices and possibilities'.

- A2) The intrapersonal component covers how patients think about themselves and their possibilities of control. It resembles self-efficacy [7] and is central to engagement in behaviors that influence desired outcomes. According to Zimmerman, a person will more likely engage in actions aimed at achieving a specific goal, if they believe they are capable of succeeding [7].

Sub-components: ‘Perceived ability to understand and handle information’, ‘Perceived ability to practice self-care’, and ‘Perceived ability to interact with health care professionals’.

- A3) The behavioral component covers actions taken to directly influence outcomes [7], such as actual types of behaviors relating to finding and understanding relevant information, interacting and communicating with healthcare professionals and participating in decision making.

Sub-components: ‘Participating in decision making’, ‘Active communication and collaboration with the healthcare professionals’, and ‘Actively seeking additional support’.

According to Zimmerman, these three components are empowerment outcomes [7].

Part B – Empowerment facilitators: Enablement from the health care system.

- Empowerment is a relational concept [23] where central actors, such as healthcare professionals (HCPs), hold a significant part of the power. Therefore, we want to assess to what degree patients experience support from and feel enabled by healthcare professionals, in relation to enacting the elements represented in the three components above.

Sub-components: ‘Adequate information and support’, ‘Being listened to and taken seriously’, and ‘Support of relatives’.

Part C – The value of empowerment.

- Covers to what degree the empowerment components are important to patients.

The five themes were:

1) Information/knowledge

- covering patients' knowledge on how to get access to information, confidence in understanding, identifying and assessing quality of information, the adequacy of the information provided by HCPs, patients' own actions to retrieve information, and the value of specific information.

2) Navigation/overview

- covering patients' awareness and knowledge of their follow-up and opportunities, their efforts to turn to additional help, and the value of influencing their follow-up plan.

3) Questions/communication

- covering patients' confidence in expressing their challenges, the HCP's responsiveness, the patients' questions and role in the communication with HCPs, and the value of specific information.

4) Decisions

- covering patients' awareness of possible decisions, confidence in decision making, the HCP's support in decision making, patients' actions in decision making, and the value of knowledge and involvement in decisions.

5) Self-care

- covering patients' awareness of selfcare, confidence in selfcare, HCP's support in selfcare, selfcare actions and the value of being supported in selfcare (such as keeping an eye on symptoms or doing things that are good for physical or mental well-being etc.).

5. DISCUSSION

This study developed a questionnaire - the CPEQ - because the available questionnaires measuring empowerment did not target empowerment in cancer follow-up, and we believed that a context specific measure was needed, and because previous questionnaires were not based on Zimmermann's theory [20]. The CPEQ consists of 67 items measuring empowerment in cancer patients attending follow-up. The content of the questionnaire has with this study been initially validated among the target group to ensure content validity and face validity of the items.

The CPEQ was developed with the initial practical aims to investigate the level of and the opportunity and desire for empowerment in the Danish cancer follow-up in a nationwide survey and is detailed and comprehensive. In future studies, the questionnaire will be shortened based on psychometric methods and the scale-structure investigated. This in order to ensure that the CPEQ could also be a candidate outcome measure in clinical trials and intervention studies [28].

Four other questionnaires have previously been developed to measure empowerment in cancer. The first of these, the CIDES (Cyber Info-Decisional Empowerment Scale), assesses how cancer patients use and feel supported by digital environments (cyber support), and covers areas, such as access to knowledge, questions to healthcare professionals, decision making, knowing when to consult oncologists, and being critical in relation to decisions and treatment [29]. Most of these overlap with themes covered in the CPEQ, but in the CIDES all items are specifically assessing support by the digital environments.

The CEQ (Cancer Empowerment Questionnaire) covers four different subscales, 'Personal Strength' (incorporating perceived control, self-esteem/self-worth, and post-traumatic growth), and 'Social

Support’, ‘Community’, and ‘Health Care’ [30]. The questionnaire is an adapted version of an empowerment questionnaire developed for patients with mental health problems and the issues and challenges of the original target group is still apparent in the specific manifestations in the CEQ [30]. Several of these manifestations were not considered as relevant challenges for our target group when interviewed about pertinent issues in relation to the context of their illness (e.g., the ‘Community factor’ consisting of items, such as ‘The society respects my rights as a citizen’) and were therefore not covered in the CPEQ.

The PES (Patient Empowerment Scale) is well-founded in qualitative data among cancer patients in Australia, but was developed with the aim of also being useful in a context beyond cancer [31]. Several items in the PES represent similar themes and concerns as the CPEQ (e.g. items related to enablement from healthcare professionals or items about trusting one’s abilities of handling one’s illness, making decisions etc.). However, the PES has no items covering the behavioral component or the value of empowerment, which were considered important in our theoretical framework.

The heiQ (Health Education Impact Questionnaire) was not developed as an empowerment questionnaire, however, five subscales from the heiQ were validated as key dimensions of empowerment among cancer patients [32]. The heiQ has several items overlapping with the CPEQ, but no items covering the value of empowerment, which were considered important in our theoretical framework.

In addition to lacking some of the components that were central to our conceptual model of empowerment, the PES and heiQ mainly cover facilitators of empowerment and not empowerment outcomes, which is a main focus of the CPEQ. The CPEQ deliberately only covers facilitators of

empowerment from the health care system (and not for example facilitators such as family support or religion), because a delimitation was needed and challenges with the health care system seemed of especially high relevance to cancer patients. Further, because the purpose of the CPEQ was to be able to measure the effect of interventions in the healthcare system.

Even though there is a convergence of components and themes across the four empowerment questionnaires and the CPEQ, the differences between these five questionnaires are striking when they purport to assess the same construct among the same patient population. This emphasizes the essential importance of paying attention to the specific understanding and interpretation of the construct in the context. Furthermore, these differences support the main aim of this article, namely a fundamental need for detailed and thorough descriptions of the rationale and conceptualization when developing or choosing a questionnaire.

Additionally, a systematic review identified 29 questionnaires measuring parts of empowerment (e.g., health literacy, self-efficacy, shared decision making, enablement, competence in communication, etc.) among cancer patients [20], but none of these were found suitable for our purpose, since none of them covered the full concept of empowerment (e.g. all components), which is emphasized by theories to be of central importance to be able to measure empowerment at all [7]. E.g., the APECC [18], which does have some content overlap with the CPEQ, mainly in the enablement and behavior component, also covers several other areas than empowerment, and not the full concept. However, the content overlap between the APECC and the CPEQ could point to the potential usability of the CPEQ in other contexts than the Danish.

Strengths and limitations

We believe that the iterative development process of the CPEQ has ensured a high content and face validity and that the CPEQ has a solid foundation in both theoretical and empirical arguments. To meet the broadly accepted demand on including patient perspectives in PRO development [21,28,33], we continuously searched for rationales and arguments in qualitative data and in discussions with the involved patients to ensure the relevance of the manifestations. Furthermore, the CPEQ was repeatedly evaluated in cognitive interviews and meetings with patient co-researchers to reduce problems regarding comprehension and to refine items, avoiding ambiguity etc.

Thorough efforts were made to conduct a project with patient and public involvement [24], and the involvement of different groups of cancer patients throughout the development process has undoubtedly contributed to the CPEQ covering more relevant manifestations in a subtle manner. However, since there is no such thing as an objective conceptualization and manifestations of empowerment the CPEQ is of course affected by the different people involved in the process, both patients interviewed, patient co-researchers and the steering group.

An expected but interesting observation was that the co-researchers did not always agree with each other. On the one hand, this led to discussions qualifying the process further. On the other hand, it shows that when involving patients in the development process, they contribute to the process with several different truths.

However, while the co-researchers and other patients involved in the project added to the diversity, our general goal to achieve diversity among all patients involved in the questionnaire development process may not have been entirely fulfilled. For the cognitive interviews, there was an overrepresentation of patients with breast cancer and a relatively high level of education. This was also the case among the co-researchers. We believe this may have been somewhat counterbalanced by the diversity in the sample for the qualitative interviews. However, there is a chance that our

questionnaire tends to express the wishes of the more educated population and of women than those of the less educated and men. In addition, we did not include ethnic minorities in this initial stage of development.

The CPEQ is a context specific questionnaire focusing on the follow-up of cancer patients in Denmark. However, the term context is an abstract and diffuse theoretical construct that is challenging to delimit and define. The main context of the CPEQ is the follow-up for cancer patients supported by several studies identifying follow-up for cancer patients as a distinct temporal and experiential context with distinct issues [12,13,34,35,14]. However, the way follow-up is carried out in practice is fairly diverse between different departments and hospitals and to some degree seemed to be more of an administrative term. Furthermore, the segregation of treatment and follow-up as two clearly distinct experiences was in some instances challenged by patients' more wholesome experience of being a cancer patient. Additionally, the great diversity in the patients' trajectories (e.g. some patients hardly ever felt sick or affected while others were impacted for life etc.) has an impact on patients' experiences of and actions in follow-up. Among others this complicates and challenges defining the most appropriate and relevant context.

However, we consider our deliberate choice of narrowing down our focus to address issues specifically urgent to follow-up and cancer to be a strength, but this might also preclude the CPEQ from being appropriate for use in other contexts (e.g., in other patient groups, at different time points in the cancer trajectory etc.). One may also question, if it will be relevant in other countries and other health care systems. As mentioned in the introduction, we believe it will be relevant in other settings too, since the international literature points to many similarities in the experiences of patients in follow-up (e.g., [18]). However, before the questionnaire is used in other parts of the worlds, it should be tested for its appropriateness in that context.

4. CONCLUSION

This article documents the theoretical and empirical basis for the development of the CPEQ and its content validity. The CPEQ is a patient reported outcome measure and is a tool for researchers and clinicians to assess the level of and the opportunity and desire empowerment among cancer patients in follow-up. The next steps will be to use the CPEQ in a nationwide study of empowerment in cancer follow-up and subsequently shorten the CPEQ based on psychometric methods.

Compliance with Ethical Standards

Disclosure statement: The authors declare that they have no conflict of interest.

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Research involving Human Participants and/or Animals: The study was granted exemption from requiring ethics approval by The Regional Committee on Health Research Ethics (VEK) (reference number: H-15000936). In Denmark, Interviews and questionnaires studies do not require ethics approval. All procedures performed in studies involving human participants were in accordance with the ethical standards of the Regional Committee on Health Research Ethics (VEK) (reference number: H-15000936) 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.

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