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REVIEW

Patient empowerment: a systematic review of questionnaires measuring empowerment in cancer patients

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ABSTRACT

Background: There is an increased attention to and demand for patient empowerment in cancer treatment and follow-up programs. Patient empowerment has been defined as feeling in control of or having mastery in relation to cancer and cancer care. This calls for properly developed questionnaires assessing empowerment from the user perspective. The aim of this review was to identify questionnaires and subscales measuring empowerment and manifestations of empowerment among cancer patients.

Materials and methods: We conducted a systematic search of the PubMed, PsycINFO and CINAHL databases. Empowerment and multiple search terms associated with empowerment were included. We included peer-reviewed articles published in English, which described questionnaires measuring empowerment or manifestations of empowerment in a cancer setting. In addition, the questionnaire had to be a patient-reported outcome measure for adult cancer patients.

Results: Database searches identified 831 records. Title and abstract screening resulted in 482 records being excluded. The remaining 349 full text articles were retrieved and assessed for eligibility. This led to the inclusion of 33 individual instruments measuring empowerment and manifestations of empowerment. Of these, only four were specifically developed to measure empowerment, and two were originally developed for the cancer setting, whereas the remaining two were developed elsewhere, but adapted to the cancer setting. The other 29 questionnaires were not intended to measure the concept of empowerment, but focused on patient-centered care, patient competence, self-efficacy, etc. However, they were included because part of the instrument (at least five items) was considered to measure empowerment or manifestations of empowerment.

Conclusion: Our study provides an overview of the available questionnaires, which can be used by researchers and practitioners who wish to measure the concept of empowerment among cancer patients. Very few questionnaires were explicitly developed to explore empowerment, and the review brings to light a significant lack of questionnaires that measure patient empowerment comprehensively.

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Due to improved treatment options and increased survival rates, an increasing amount of cancer patients overcome their illness or live with it for long periods of time. A growing number of cancer patients are therefore involved in different kinds of follow-up programs [1]. In Denmark, approximately 38 000 are part of a follow-up program for cancer patients [2], among 267 000 cancer survivors [3] in a population of 5.6 million.

The follow-up programs in Denmark have recently been revised, and patient empowerment has been explicitly emphasized as essential [1,2,4,5]. This is in line with other parts of the Danish healthcare system that have similarly begun to realize the potential and importance of empowerment. Health researchers and other stakeholders in public health have begun to implement the concept of empowerment [5], and research has shown that interventions engaging and involving patients and supporting patient empowerment produce greater patient satisfaction, better health and lower costs [6–12].

To support the process of increasing patient empowerment, appropriate measures to monitor levels of patient empowerment and evaluate initiatives aimed to increase empowerment are essential [13]. In 2006, the World Health Organization therefore called for properly developed and tested questionnaires on patient empowerment [14].

This paper is a systematic review of questionnaires measuring empowerment in cancer patients. The review is part of a larger study, investigating empowerment in cancer follow-up programs. For the study we wanted to review questionnaires assessing empowerment in order to decide whether

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Supplemental data and underlying research materials for this article can be accessed here.

we could use an already existing questionnaire to collect data or whether we should develop a new questionnaire that could be used in future studies assessing empowerment in cancer patients [15].

Three systematic reviews of questionnaires assessing empowerment already existed. Herbert et al. (2009) [16] and Cyril et al. (2015) [17] both identified questionnaires aimed at measuring health-related empowerment, and they also both included questionnaires for non-patients. Barr et al. (2015) identified questionnaires assessing patient empowerment among all types of patients, as well as generic questionnaires, and did not exclude any questionnaires based on the condition of the target group [13]. However, none these reviews focused on cancer.

It is often argued that empowerment may be context-specific and may vary across different types of patients, different contexts and different times in the illness journey [18]. We therefore decided to conduct a review that exclusively investigated questionnaires developed for, adapted to or used in cancer patients. We considered this necessary to ensure that a questionnaire selected for cancer patients is indeed a relevant and sensitive measure for this group.

Several studies conclude that there is a lack of consensus about the definition of empowerment [13,16,19,20], partly because the concept is closely related to and difficult to distinguish from other terms, such as self-efficacy, competence, participation in decision making, etc. As a consequence, questionnaires aimed at measuring these closely related concepts often involve empowerment-related items, even though they do not necessarily explicitly mention this concept. This means that relevant empowerment items can be found in questionnaires, which are described as measures of other concepts [13,21,22].

The aim of this review was therefore to identify questionnaires assessing empowerment in cancer patients including both questionnaires explicitly developed for this purpose and questionnaires containing items assessing empowerment.

Definition of empowerment

There are countless definitions of empowerment as a general concept, and definitions of patient empowerment in the health-related literature are similarly very diverse [13,16,19–21]. As a guideline for our search strategy and our inclusion and exclusion criteria, a specific definition of empowerment was needed, as well as an outline of related theoretical concepts that could contain empowerment-related information and therefore should be included in our search string.

Zimmerman's definition of psychological empowerment (drawing on Rappaport) [18] occupies a prominent position in studies of patient empowerment. In this review, we have defined the term empowerment on the basis of Zimmerman's definition of psychological empowerment: *'Empowerment is a process by which people, organizations, and communities gain mastery over issues of concern to them'* and *'PE (Psychological Empowerment) is a feeling of control, a critical awareness of one's environment, and an active engagement in it'*. Zimmerman distinguishes between two complementary uses of empowerment, for instance empowering processes and empowering outcomes. They state that psychological empowerment consists of three qualities, (1) intrapersonal; (2) interactional; and (3) behavioral components [18]:

1. *'The intrapersonal component refers to how people think about themselves'*. A keyword is perception; what people think they can do, as perception provides the initiative to engage in specific types of behavior in order to influence desired outcomes. It is unlikely that anyone would try to do what it takes to achieve something without believing in his or her own capability of accomplishing it [18]. This component therefore includes perceived control, self-efficacy, motivation to control, perceived competence, and mastery' [18].
2. *'The interactional component refers to how people think about and relate to their social environment'* [23]. This covers a person's ability to navigate in a specific situation or context, to learn and understand his or her options, and to assess what choices will make it possible to achieve his or her goal [18]. This component is closely related to knowledge and health literacy, which is often understood as being necessary in order to navigate the healthcare system and influence it [24].
3. '*The behavioral component refers to specific actions taken to change one's situation and influence outcomes*' [18] (e.g. participation in decision making and active coping).

Taken together the three components describe how an empowered patient believes that he or she is capable of influencing the context/situation (intrapersonal component), understands how the healthcare system works and how to act to achieve desired outcomes (interactional component), and engages in specific types of behavior to exercise control (behavioral component) [18]. Zimmerman emphasizes that all three components need to be measured to fully capture psychological empowerment [18].

However, drawing on another definition of empowerment provided by Tengland (2008), we would argue that empowerment is fundamentally a relational concept [25]. Patients can only become empowered if healthcare professionals offer them the opportunity to become empowered. The concept of empowerment thus needs to take the 'power balance' between the professional and the patient into account. In order to include this aspect of empowerment, we argue for the inclusion of the component 'Enablement' [26,27], in order to fully capture empowerment.

In the context of the healthcare system, enablement [27] is defined as the way in which the healthcare system/healthcare professionals create(s) opportunities for the patient to be informed and involved (e.g. providing relevant information, enabling the patient to take part in making decisions, listening, answering questions, etc.). As such, it measures facilitators rather than manifestations of empowerment.

However, we will argue that it is a necessary component, and needs to be included.

Methods

Search strategy

We followed the PRISMA guidelines in a modified version suitable for a qualitative review of questionnaires [28], and a systematic and comprehensive search of the electronic bibliographic databases PubMed, PsycINFO and CINAHL was conducted in October 2015.

We used multiple search terms and relevant MeSH terms associated with empowerment (see Table 1). The following combination of search terms was used for our search (slightly adapted to the different databases): empowerment theoretically related terms and manifestations (including the concepts: power, self-efficacy, self-advocacy, mastery, perceived control, patient-centered care, patient-focused care, patient participation, shared care, shared decision making, patient participation, personal autonomy, health literacy, personal control, enablement, adaptation, delivery of health care, integrated care, patient preference, collaborative care, self-care, self-management, patient education, etc.) were combined with search terms for instruments (e.g. questionnaire, patient-reported outcome, healthcare survey combined with validity, reliability, psychometrics, etc.), and search terms for cancer (e.g. cancer, neoplasm and carcinoma).

Inclusion and exclusion criteria

To qualify for inclusion the questionnaire had to be developed for, adapted to or used in cancer patients. Furthermore, studies were included if they described a questionnaire that either explicitly investigated patient empowerment or, according to the conceptual definition used in this review, contained at least five items measuring empowerment manifestations. The definition was operationalized as items assessing patients'; (1) perception of, motivation and perceived control in relation to their ability to obtain, find and understand relevant information, interact and communicate with the healthcare professionals and participate in decision making; (2) understanding of how to carry out the latter; (3) actual types of behavior relating to the above or (4) experience of the healthcare systems enablement in relation to these skills.

In addition, the questionnaire had to focus on the patients' meeting with the healthcare system or the patients' dealing with cancer, and focus on areas of empowerment affecting diagnosis, treatment, cancer care or follow-up.

Records were excluded if they did not focus on our target group of 'adult cancer patients', (e.g. focused on relatives, healthcare professionals, children with cancer, healthy people, people with other illnesses, screening or cancer prevention), were not related to this review's definition of empowerment, did not include at least five empowerment-related items, did not include a questionnaire, were not accessible in English, or were not published in a peer-review journal.

Abstracts were retrieved and screened for relevance to the research question. All potentially relevant articles were retrieved and read by at least one author. All potentially relevant questionnaires were discussed between the first and last author. Where relevant references did not include sufficient information about the instrument, efforts were made to contact the author to obtain a full copy of the questionnaire. Where relevant, references in the articles included were assessed as well.

Table 1. Search strategy in PubMed (performed October 2015). Filter: English language.

Area	Search terms
Cancer	Cancer OR cancers OR Neoplasms [MeSH] OR neoplasm* OR Carcinoma [MeSH] OR carcinoma*
Measurement tools	'Questionnaires' [MeSH] AND (validity OR validation OR reliability OR psychometrics [MeSH] OR Factor analysis, Statistical [MeSH]) OR 'Patient reported outcome*' AND (validity OR validation OR reliability OR psychometrics [MeSH] OR Factor analysis, Statistical [MeSH]) OR 'Health care surveys' [MeSH] AND (validity OR validation OR reliability OR psychometrics [MeSH] OR Factor analysis, Statistical [MeSH])
Empowerment	'Power(psychology)' [MeSH] OR 'Patient empowerment' OR empower* OR 'Self efficacy' [MeSH] or 'self-efficacy' OR 'Self-advocacy' OR Mastery OR 'Perceived control' OR 'Patient-centered care' [MeSH] OR 'patient centered care', OR 'patient focused Care' OR 'Patient navigation' [MeSH] OR 'Patient participation' [MeSH] OR 'patient involvement' OR 'patient activation' OR 'patient engagement' OR 'patient participation' OR 'Shared care' OR 'Shared decision making' OR 'Patient participation/psychology*' OR 'Personal autonomy'[MeSH] OR 'patient autonomy' OR 'Health literacy' [MeSH] OR' health literacy' 'Personal control' OR Enablement OR 'Adaptation, Psychological' [MeSH] OR 'Delivery of Health Care, Integrated'[MeSH] or 'integrated care' OR 'Patient Preference'[MeSH] OR 'collaborative care' OR 'Self Care' [MeSH] OR 'Patient Education as Topic'[MeSH]

Analysis

All questionnaires included were retrieved, and the scales, subscales, and items were described and categorized according to their content and measurement goals and entered into a table.

From each questionnaire the following information was extracted (if available): title of the questionnaire, aim of the questionnaire, original target population, country of origin, number of items in total, number of empowerment-related items, names of subscales or topics, definition of empowerment or reason for including the questionnaire (or parts of it) as measuring empowerment.

The items in each questionnaire were subsequently examined to determine which component of empowerment the majority of the relevant items measured. In this examination, the framing of the specific item was evaluated, for example an intrapersonal item could be; 'I feel confident that I can ask the doctor relevant questions', if it were instead to read, 'I ask the doctor relevant questions', it would be measuring the behavioral component. 'I know when to ask questions' would be measuring the interactional component and 'My doctor helps me ask questions' would be measuring enablement.

To assess the psychometric properties and the quality of the questionnaires explicitly measuring empowerment we used criteria developed by Terwee et al. (2007) [29]. We assessed the following criteria: content validity, internal consistency, construct validity, reproducibility, responsiveness, floor and ceiling effects, and interpretability. Questionnaires were rated as positive (+), intermediate (?), negative (-) or no information available (0) [29]. We did not assess criterion validity, because there is no gold standard comparison for measures of empowerment [13,29]. Following the advice of Terwee et al. we did not present the results as an 'overall quality score', as this would assume that all measurement properties are equally important.

Results

Studies included

Our search strategy identified 551 articles in the PubMed database, 309 articles in the CINAHL database and 112 articles in the PsycINFO database, totaling 972 records. After removing duplicates, 831 records remained.

The inclusion of records can be seen in the PRISMA flow chart (Figure 1). The title and abstract screening resulted in the exclusion of 482 records. Of these, we excluded 221 records because they were not focused on our target group, 232 because they did not relate to empowerment, 19 because they did not include a PROM (e.g. qualitative studies), six because they were not published in English, and four because they were not peer-reviewed articles (e.g. dissertation abstracts, chapters of books, etc.).

The remaining 349 full text articles were retrieved and assessed for eligibility. Of these, 305 records were excluded (see Figure 1).

When potentially relevant questionnaires were mentioned or used, but the specific items were not available in the article, we searched the reference list of the article or elsewhere to retrieve an example of the questionnaire. In some cases we found more detailed development articles on questionnaires included in the review and used these instead or in addition. This led to the inclusion of an additional 12 articles, whereas no additional questionnaires were included.

In total, 56 articles remained and were included, representing 33 individual questionnaires measuring empowerment manifestations according to the definition of this review.

Table 2 provides an overview of the measures included explicitly assessing empowerment among cancer patients and supplemental Appendix A provides an overview of the measures included involving at least five items assessing empowerment according to the definition of this review.

Questionnaires explicitly assessing empowerment in cancer patients

Two of the four questionnaires explicitly measuring empowerment were originally developed for the cancer setting: the Patient Empowerment Scale (PES) [38] and the Cyber Info-Decisional Empowerment Scale (CIDES) [39]. The remaining two were initially developed for other patients, but have been adapted to the cancer setting: the Cancer Empowerment Questionnaire (CEQ) was originally developed for mental health patients [23] and the Health Education Impact Questionnaire (heiQ) for chronically ill patients in general [40] (Table 2).

The topics in and focus of the items in the four questionnaires are quite diverse, even though they claim to measure the same construct among the same type of patients.

The CIDES is different from the other three questionnaires because it only focuses on the support of the digital environment. None of the other three questionnaires cover this aspect.

The other three questionnaires (the CEQ, PES and heiQ) overlap in regard to some themes, but the heiQ and the CEQ have no questions related to patients' involvement in decision making, their access to knowledge or the sufficiency of information in relation to their illness, which the PES has.

Furthermore, the CEQ differs from the other questionnaires as half of the CEQ consists of two subscales with a focus that is not mentioned in the two other questionnaires; 'Personal strength' measures the patient's general self-esteem and 'Community' assess the patient's feelings of being accepted and respected in society.

All of the four questionnaires entail empowerment items according to the definition of this review. The CIDES entails seven items of which all can be categorized as enablement (i.e. cyber support is here considered comparable to the support given by the healthcare system), the PES has approximately seven items covering enablement, the intrapersonal and interactional component, the CEQ has approximately five items covering the intrapersonal and enablement

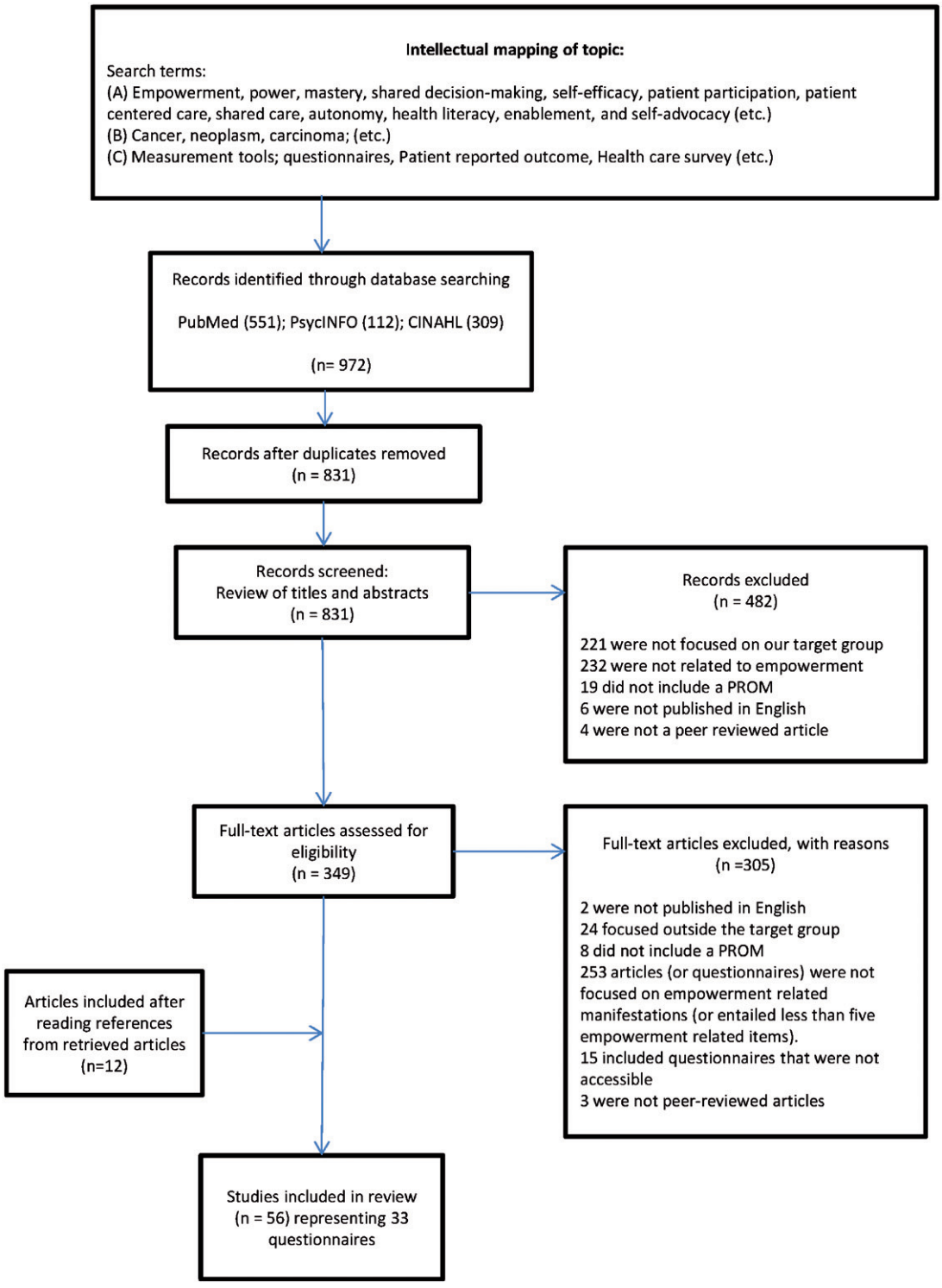

Figure 1. Prisma flow chart. *An additional five questionnaires were not assessed because it proved not to be possible for us to obtain them [e.g. The Stanford inventory of Cancer Patient Adjustment (SICPA) [30], The Psychosocial Adjustment to Illness scale (PAIS) [31], the threatening Medical Situations Inventory (TMSI) [32], Cancer Knowledge [33], and the Lewis Cancer Self-efficacy Scale (CASE) [34] it was not possible to determine whether they should be included or excluded from the information that was available. **Two questionnaires were not included even though they in all probability were relevant, because the precise framing of the items were not accessible in English [35,36]. ***One questionnaire was not included even though it explicitly measured empowerment in cancer patients, because only the items were accessible in English [37].

Table 2. Questionnaires explicitly measuring empowerment.

Measurement tool and authors	Target population and country	Number of items	Focus of scale	Description of subscales or themes	Definition of empowerment
The Patient Empowerment Scale (PES) [38]	Cancer patients Potentially relevant to be used among patients with chronic illnesses Australia	15 Likert-type scale	The scale aims to assess empowerment among cancer patients To be used in clinical settings to help assessing patients' ability to adapt to their illness and engage proactively with treatment	No subscales presented Themes mentioned in the article: 1) Access to relevant and timely information about their illness 2) Social support networks 3) Open and positive communication between health professionals themselves and with the patient 4) Decision making involvement 5) Adjustment to acceptance of their illness 6) Use of complementary therapies 7) Religion and/or spirituality 8) Feeling useful in terms of paid/unpaid employment Statements indicate different aspects of empowerment (e.g. I am capable of handling my illness) – patients were asked whether they 'strongly agreed' to 'strongly disagree'	Empowerment understood as both coping strategies and self-efficacy It is unclear whether empowerment is viewed as a process or outcome
The Cancer Empowerment Questionnaire [23]	Mental health patients Adapted to and validated in breast cancer patients The Netherlands	40 Likert-type scale	To operationalize cancer empowerment as an outcome measure	1) Intrapersonal aspects of empowerment: personal strengths 2) Interpersonal strengths: social support, community, health care Original subscales: 1) health care, 2) social support, 3) self-esteem, 4) feeling connected, 5) self-management, 6) community support Measures empowerment as an outcome with a 5-point Likert-type scale from 'strongly disagree' to 'strongly agree'	The scale is constructed according to Zimmerman's definition of psychological empowerment. A broad construct that comprehends intrapersonal, interactional and behavioral components The questionnaire measure the intrapersonal (how people derive strength from themselves) and the interpersonal (how people derive strength from their social surroundings) aspects of PE
The Health Education Impact Questionnaire (heiQ) [40]	Patients with a chronic illness Validated in cancer patients Canada	25	Assess the effects of health education programs among individuals with chronic conditions	5 factors: 1) Social Integration and Support 2) Health service navigation 3) Constructive attitudes and approaches 4) Skill and technique acquisition 5) Emotional distress Patients were asked to indicate their agreement with statements from 'strongly disagree' to 'strongly agree'	The authors understand empowerment as a positive, contextually defined, dynamic multidimensional construct: 'It refers to an individual's feelings of being able to manage the challenges of the cancer experience and of having a sense of control over one's life' 'Defined both as a social process by which individuals gain mastery over their lives and as an outcome resulting from this process' Their definition is inspired by Zimmerman's definition of empowerment including both intrapersonal, interactional and behavioral components The authors argue that the scale covers the intrapersonal, interactional and behavioral component
Cyber Info-Decisional Empowerment Scale (CIDES) [39]	Cancer patients USA	7	The instrument is developed to measure cyber informational and decisional empowerment It aims to measure perceived empowerment benefits of digital health and medical peer support	The respondents were asked to report the extent to which cyber support helped them with different aspects of information and knowledge seeking and helped them with different decisions Each item was measured on a five-point Likert scale (from 'not at all' to 'very much')	The authors do not define their use of the term empowerment

component, and the heiQ entails about 10 items with few items covering each of the four components. Taken together, only one of the questionnaires (the heiQ) captures all four components of empowerment as defined in this review.

Quality of instruments

Table 3 provides an overview of the assessment of the quality of the psychometric properties of the four questionnaires explicitly measuring empowerment. It shows that content validity was assessed in three out the four questionnaires, and both the PES and the heiQ received positive ratings. Internal consistency was tested in all four questionnaires, with all positive ratings. Construct validity was assessed in two questionnaires (CEQ, heiQ) with positive ratings. Only one study assessed reliability (PES) and similarly only one study assessed floor and ceiling effects (heiQ) both with positive results. No information was found on reproducibility agreement, responsiveness or interpretability. The quality of the included questionnaires explicitly assessing empowerment was found to be poor to fair.

The best performing questionnaire identified in this review was the heiQ, receiving positive scores for content validity, internal consistency, construct validity and floor and ceiling effects.

None of the included questionnaires has been fully tested on all criteria.

Questionnaires including at least five items assessing empowerment-related manifestations

The remaining 29 questionnaires are not specifically intended to measure empowerment but focus on concepts/themes such as competence in communication, patient self-advocacy, information received, health literacy etc.

These 29 questionnaires are included in this review because part of the questionnaires (at least five items) was considered to measure empowerment manifestations (supplemental Appendix A). Twenty of the questionnaires were developed for cancer patients (either specific types of cancer or cancer patients in general), and four of them for specific types of cancer (testicular, breast, prostate cancer). The remaining nine questionnaires were developed for older patients, chronic disease patients (3 questionnaires), influenza immunization, breast cancer screening, or patients with diabetes, musculo-skeletal disease, HIV/AIDS or chronic back pain. These nine questionnaires have subsequently been used in one or more studies with cancer patients.

The total number of items in each of the 29 questionnaires ranges from 10 to 124, of which approximately 5–20 items are empowerment-related.

The questionnaires were categorized according to whether they primarily address the intrapersonal (4), interactional (5), behavioral (6), or enablement component (14). None of the questionnaires captured the full concept of empowerment as defined in this review (i.e. all four components).

The APECC [41] is the only questionnaire identified that explicitly has cancer patients in follow-up care as the

Table 3. Quality of psychometric properties evaluated according to Terwee ratings [29].

Questionnaires and Authors (Year)	Content validity	Internal consistency	Construct validity	Reproducibility		Responsiveness	Floor and ceiling effects	Interpretability
				Agreement	Reliability			
Patient Empowerment scale (PES) Bulsara et al. (2013) [38]	+[a]	+[b]	0	0	+[c]	0	0	0
Cyber Info-Decisional Questionnaire (CIDES) Seçkin (2011) [39]	0	+	0[d]	0	0	0	0	0[e]
Cancer Empowerment Questionnaire (CEQ) Van den Berg et al. (2013) [23]	?	+	+	0	0	0	0	0
Health Education Impact Questionnaire (heiQ) Maunsell et al. (2014) [40]	+	+	+	0	0	0	+[e]	0

Rating: + = positive, ? = intermediate, - = negative, 0 = no information available. For further detail see Terwee et al. [29].
[a]Some information extracted from an earlier development article [22];
[b]Tested in a Rasch model [22];
[c]Other reliability tests were performed. Tested in a Rasch model [22];
[d]In another review by Barr et al. (2015) [13] did the scale receive a? for construct validity;
[e]In another review by Barr et al. (2015) [13] did the scale receive a? for interpretability;
[f]Four subscales were + and one subscale was –.

target group. The empowerment-related items mainly cover the enablement component. Three other questionnaires state that they have a subscale focusing on follow-up; follow-up care (QPCCC) [42], monitoring after treatment (PCQ-P) [43] or care at the end of treatment (CQI) [44]. All three subscales related to follow-up include at least four empowerment items, according to the definition of this review, all covering the enablement component.

For examples of excluded questionnaires see Supplemental Appendix B.

Discussion

This review has identified questionnaires that explicitly measured empowerment in cancer patients or included at least five items capturing empowerment when using the definition contained in this review.

Four questionnaires explicitly assessing empowerment in cancer patients were identified. These questionnaires pose very different questions, even though they claim to be measuring the same construct among the same type of patients. We are not able to conclude with certainty whether this is due to different theoretical definitions, different understandings or use of the theories, or that some of them were originally developed for a different target group and context.

The quality of the included questionnaires explicitly assessing empowerment was found to be poor to fair for the PES, CEQ and CIDES. The best performing questionnaire identified in this review was the heiQ. The heiQ was here assessed according to the article by Maunsell et al. [40], but several additional testing and validation articles are accessible [45–50], although these were not used here because of slight alterations in the questionnaire, different versions and use of the questionnaire in different languages.

Although the heiQ is a comprehensively tested and validated questionnaire, it also slightly differs from the conceptualization of empowerment used in this review, which indicates that one should also pay attention to the specific conceptualization of the term. This difference could also point to a challenge with the empowerment theories being too abstract and not specific enough, which could lead to very different interpretations and operationalizations.

None of the included questionnaires has been fully tested on all the criteria and both the CIDES and the CEQ have a substantial lack in their conceptual framework. There is still much work to be done, which also makes it difficult to judge the most appropriate questionnaire. However, all the questionnaires are rather newly developed (the oldest is the heiQ from 2006), which can have affected the lack of quality assessment.

In addition, 29 questionnaires containing at least five items that measured empowerment according to the definition applied in this review were identified. None of these questionnaires comprehensively measure all dimensions of empowerment given the multidimensional nature of the concept. Fourteen of these questionnaires primarily addressed the enablement component, followed by the interactional component (n = 6), the behavioral component (n = 5) and the intrapersonal component (n = 4).

We did not assess the psychometric properties of the 29 questionnaires that were not developed to measure empowerment, because this review is only concerned with a minor number of items from each of the questionnaires and all these questionnaires are developed and validated according to a construct other than empowerment.

Nine questionnaires were included although they were developed for a target group other than cancer patients. They were included because they had been used in at least one study with cancer patients implying that the researchers have considered the nine questionnaires suitable for the specific target group, but it is still important to pay attention to their adequacy when considering using them in a cancer population, as they are not validated in this patient group.

A specific theoretical model, including related and overlapping concepts

A challenge encountered in this review and in research aimed at measuring empowerment is defining and delimiting empowerment. Several studies and systematic reviews have emphasized the lack of a clear definition of the concept and have either tried to examine others' use of the concept, conceptualized the concept or discussed and defined it in relation to other closely related and overlapping concepts [13,16,17,20,21,26,51].

Due to the vague conceptualization of empowerment and its frequent overlap with other similar concepts [16], several questionnaires involve items capturing elements of the concept. One of the strengths of this review is that we have not only included questionnaires that explicitly measured empowerment but also those that assess related concepts, including at least five items according to an a priori definition, a definition that guided our search process, inclusion criteria and presentation of results. This process has increased the chances of finding multiple empowerment relevant items for our further development work.

Also, it has been a challenge to capture all the relevant, related concepts that are at least partially interchangeable with empowerment, as elements of empowerment can be found in many related concepts. No firm lines can be drawn, and relevant concepts which could have been drawn from questionnaires, may have been overlooked.

Empowerment as a context and population-specific measure

In their review, Barr et al. argue that it is relevant to develop a common theoretical approach to the concept of empowerment, as well as a generic, validated measure of empowerment that is usable among all types of patients. In contrast, Zimmerman illustrates that empowerment is not static, but a dynamic and contextually driven concept [18], and emphasizes that empowerment takes different forms for different people (e.g. according to age, socioeconomic status, gender, etc.), in different contexts (e.g. the context of treating cancer

can be quite different from that of treating diabetes and demands different types of skills, knowledge and actions), different spheres of life (e.g. work, family, recreation), and at different times (i.e. empowerment is a dynamic variable that may fluctuate over time). According to Zimmerman, these characteristics of empowerment mean that a universal and global measure is not an appropriate goal [18].

An examination of empowerment scales used outside the field of cancer supports the idea that empowerment is context-specific, for example there is a different focus in the Diabetes Empowerment Scale (DES) [52] compared to the measures included in this review. It can therefore be considered a strength of this review that we have limited our search to a condition-specific context, namely cancer. We are, however, aware that there are more than 100 different types of cancer [53], and studies show that patients have different experiences at different points in their disease trajectory (e.g. studies have found differences in coping strategies between early- and advanced-stage cancer patients [53]) and in relation to different treatments. It is therefore possible that empowerment manifestations also differ within the broad category of cancer patients.

Although, on the one hand, we have found many relevant questionnaires and items, on the other hand, it is possible that we have overlooked some important items, either in general or in relation to specific contexts.

Conclusion

This review may serve as a guideline for clinicians and researchers who wish to measure the concept of empowerment in cancer patients, as the results provide an overview of relevant scales and questionnaires and what components of empowerment they cover, which can help guide the choice of questionnaire. There is still a need for further evidence to support the reliability and validity of the existing questionnaires, and clinicians and researchers should pay attention to the specific conceptualization of the term when using these.

We believe that the lack of adequate questionnaires makes it relevant to develop a questionnaire that is based on a theoretical definition of empowerment and developed specifically for the target group to ensure that it is sensitive and relevant.

Disclosure statement

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