Measuring patient empowerment - a systematic review

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Abstract

Objective: The purpose of this systematic review was to identify generic instruments measuring patient empowerment and related concepts and analyse the main content and psychometric properties of these instruments.

Methods: A systematic search was conducted using empowerment and related concepts (enablement, activation, engagement, perceived control) as search terms. The main content of the instruments was analysed by classifying the subscales and items of the elements of empowerment into patient's capacities, patient's knowledge, patient's behaviour and support by others. Psychometric properties were analysed with the criteria of Terwee and colleagues (2007).

Results: Thirteen instruments were identified; **and out of them, five instruments covered all the four elements used to define of empowerment**. Psychometric properties were variable; none of the instruments contained all the evaluated psychometric properties.

Conclusion: There are generic instruments measuring empowerment and its related concepts. The instruments were heterogeneous in structure and psychometric properties. Empowerment is more wide-ranging and multidimensional than its related concepts.

Practice Implications: This review provides knowledge for healthcare professionals and researchers who want to support or evaluate patients' empowerment. With a generic instrument, it is possible to obtain comparable information from diverse patient groups. Further testing of psychometric properties of each instrument is recommended.

Keywords: Empowerment, patient empowerment, instruments, review

1. Introduction

Patient empowerment is increasingly recognized as a core value of high-quality patient-centred care [1–3]. In addition, many health policy programmes highlight patient empowerment [2,4,5]. Patient empowerment is generally used to refer to patients' ability to control their health as well as their ability to be more involved in their care [1–3,6]. Many earlier studies have shown that better patient empowerment is related to better health outcomes, e.g. well-being, self-management [7–9], health status [10], health-related quality of life [11] and cost-effectiveness [2]. In health care, it is therefore important to recognize and measure patients' level of empowerment because it guides health care professionals to support patients' empowerment through provision of tailored care and education for each patient. Additionally, empowerment is an outcome in itself [7], and it can be used to measure patient outcomes in health care services [2,4,12].

The concept of empowerment is rooted in social action and the civil rights movement during the 1960s and "self-help" perspectives of the 1970s to promote the rights of ethnic and sexual minorities [13–15]. In health care, empowerment has increased since 1980s, especially in patients' care and education with long-term conditions [7,16]. The concept is including psychological, community and organizational empowerment [17]. Psychological empowerment is a process which people create or they are given opportunities to control their own life and it involves intrapersonal, interactional and behavioural components [18]. Organizational empowerment incorporates both processes that enable individuals to increase their control within the organization, and the organization to influence policies and decisions in the larger community [19]. Community empowerment is a process that involves interaction between individuals and organizations to enhance community living, thus effecting changes in a larger social system [17].

The concept of empowerment is multidimensional, with many different definitions [5,7,13,14,20,21]. However, a consensus about the definition of empowerment is still lacking [4,5,16]. In the existing definitions include patients' capacity [5,7,13,14,20–21], power [6,7,15,22], knowledge [5,7,16,20], patients' activities/behaviours, e.g. rational decision, shared decision-making [5,7,13,20,21] and management of own

illness and own lives [4,5,7,16,21]. In addition, support by health care professionals has been highlighted in patient empowerment [7,22,23]. Patients have to empower themselves; health care professionals can only support patients in their empowerment process [16].

Several studies have attempted to clarify the concept of patient empowerment. They have found concepts that are related to empowerment, such as enablement, engagement, activation and personal control [4–6,24,25]. These concepts, with corresponding constructs as the concept empowerment, have been used in similar situations [4,5,25]. All these concepts highlight patients' important role in their own care [6,25]. Fumagalli et al. [25] have clarified boundaries between the concepts. Enabled patients understand their health conditions and they are able to participate in self-care or shared decision-making, but they have not necessarily the motivation and power. The concept can be considered as a subset of the more comprehensive concept of "empowered patient". Engaged patient has a strong motivation to become more knowledgeable and more powerful and he/she has a motivation for self-management but do not necessarily have already sufficient ability and power for self-care [25]. Patient activation emphasizes patients' ability and motivation to manage their health. This requires patients to have the knowledge, skill, and confidence to manage one's health and understanding ones' role in the care process [26]. Both concepts, patient empowerment and patient activation relate to an increased ability, motivation and power but patient empowerment has a larger connotation than activation [6,12].

The measurement of patient empowerment has increased over the years. We found four systematic reviews of instruments assessing empowerment: two focusing on health-related empowerment [27,28], one on patient empowerment [12], and one aimed at cancer patients [29]. The health-related empowerment instruments focused mostly on parents or family members, children, on community empowerment or on socio-political control including disease- and situation-specific instruments [27,28]. Barr et al. [12] identified 19 patient empowerment instruments but most of them were disease-specific; only six instruments they were assessed as generic, which two of them included empowerment only on subscale level, one evaluated empowerment in the context of drug therapy, one focused on hospital staffs' actions to empower patients, and two instruments focused none special diseases and they we assessed as generic [30,31]. In earlier reviews, the problem

with most instruments was low methodological quality and lack of comprehensive psychometric testing [12,29]. However, even though there has been noticed a need for generic empowerment instruments for use in evaluating healthcare [4,12,32] we did not find systematically conducted reviews of generic instruments of patient empowerment. Therefore, in this review, we were interested in generic instruments of patient empowerment which not focusing any specific disease, and which can be used in diverse patient groups. We included concepts related to patient empowerment such as patient enablement, patient engagement, patient activation and personal control, which correspond to the concept of patient empowerment based on earlier studies [e.g. 4,6,12].

The purpose of this systematic review was to identify generic instruments for adults measuring patient empowerment including its related concepts and to analyse the main content and psychometric properties of these instruments.

2. Methods

2.1. Search strategy

A literature search was undertaken according to the guidelines of the PRISMA statement for systematic reviews [33]. Computerized searches were conducted using the databases MEDLINE (PubMed), CINAHL, PsycINFO, ERIC and Web of Science from the date of inception of each database until 31.10.2018.

The literature search was performed using a combination of the following search terms:
((patient* OR "Patients"[Mesh]) AND (empower* OR enable* OR activation* OR engagement* OR perceived control* OR "Power (Psychology)"[Mesh]) AND (instrument* OR measure* OR scale* OR score* OR questionnaire* OR tool* OR "Surveys and Questionnaires"[Mesh]) AND (validit* OR validat* OR reliabilit* OR psychometric*)). Search terms were modified for each database. The search was supplemented with manual search of the reference lists of reviews and included articles.

2.2. Inclusion criteria

Studies were included if they: (1) described generic instruments for adults measuring patient empowerment or a related concept (patient enablement, patient activation, patient engagement, perceived control) from patient's viewpoint; (2) were self-reported instruments for adult patients aged 18 years or older; (3) reported psychometric properties of the instrument; (4) were empirical studies; (5) were published in the English language and (6) were published in peer-reviewed journals.

2.3. Exclusion criteria

Studies were excluded if: 1) they reported on disease-specific instruments measuring patient empowerment; 2) empowerment was included only on subscale level of the instrument; 3) the instrument was not described in the article; 4) they were reviews or 5) theoretical papers (e.g. conference abstracts, commentaries).

2.4. Literature search

A literature search was performed in November 2018, identifying 3674 records, of which 1176 were duplicates. A total of 2499 records were screened by title and abstract level by two reviewers (AP, SE). Eligibility of each of the remaining full-text articles (n = 89) was assessed by three reviewers independently (AP, SE, MS). Discrepancies were solved by discussion and consensus was achieved.

A total of 58 articles were excluded after full-text inspection because the empowerment instrument was disease- or situation-specific (n = 35, e.g. diabetes, rheumatic disease, genetic counselling), the instrument was not described in the article (n = 5), or did not focus on patient empowerment, patient enablement, patient activation, patient engagement or perceived control (n = 15) or empowerment was only included in the subscale level in the instrument (n = 3). Finally, 31 studies met the inclusion criteria and within these studies, 13 different instruments were identified and included in this review (Fig. 1).

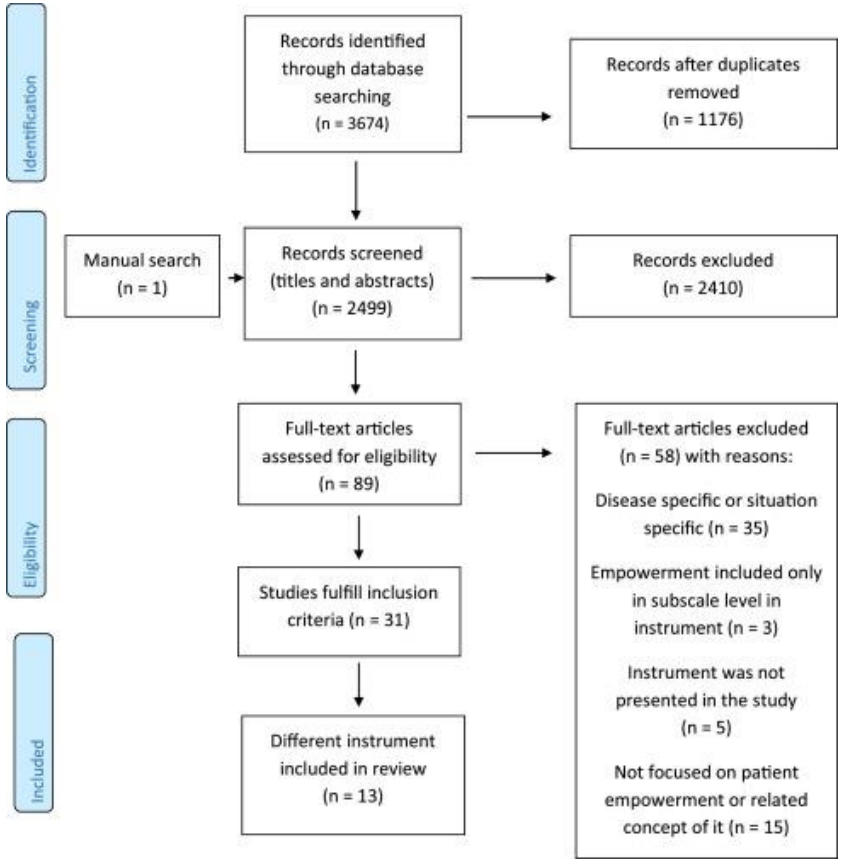

Fig. 1. Database search on PRISMA guidelines.

2.5. Data analysis

At first, each instrument the following descriptive details were extracted (Table 1): name of the instrument, author, year, measurement aim, name of the subscales, number of items of the instruments, population included, sample size, response scale and definition of the concept of the instrument.

Table 1. Characteristics of the instruments included in the review

Name of the instrument	**Study, year**	**Measurement aim of the instrument**	**Participants**	**Subscales (number of items)**	**Response scale**	**Definition of the concept of instrument**
Patient empowerment						
1. Patient perceptions of Empowerment Scale (PPES)	Lewin & Piper 2007 [35] UK	Measure patients' perceptions of their degree of empowerment.	n=103 patients, in coronary care	no subscales (17)	5-point Likert Scale (strongly disagree – strongly agree)	Empowerment as a technology used for practical, day-to-day and face-to-face encounters with patients. The instrument focused on interventions which employed simple, pragmatic, enabling strategies to enhance patient's control over their health.
	Yeh et al. 2014 [47] Taiwan		n=554 inpatients in general hospitals	Information (3), Decision (2), Individual (3),		

				Self-management (3)		
2. Health education impact questionnaire (HeiQ)	Osborne et al. 2007 [30] Australia	Measure outcomes of patient education programs	n=598, 46 % from hospital outpatients, 54 % administered in community setting (arthritis, hypertension, anxiety or depression, asthma, injury, diabetes, heart diseases)	Positive and Active engagement life (5), Health Directed Behavior (4), Skill and Technique Acquisition (5), Constructive Attitudes and Approaches (5), Self-Monitoring and Insight (7), Health Services Navigation (5), Social Integration and Support (5), Emotional Wellbeing (6)	-	Health education programs lead to improve outcomes such as empowerment including increase in knowledge, change of perception on the impact of the illness, change in behavior and also benefit for the community and enhanced public health.
3. Health Care Empowerment (HCE)	Johnson et al. 2012 [31] USA	Measure of health care empowerment	HIV infected patients, Sample 1: n=275, Sample 2: n=370	HCE ICCE: Informed, Committed, Collaborative and Engaged (4) HCE TU: Tolerance of Uncertainty (4)	5-point Likert scale (strongly disagree - strongly agree)	Health care empowerment is the process and state of being engaged, informed, collaborative, committed to one's health care and tolerant or resilient to uncertainties in treatment outcomes.
4. Health Empowerment Scale (HES)	Park & Park 2013 [36] South Korea	Assess health empowerment of older adults	n=20 pilot study, n=175 older people in senior center in China	No subscales (8)	5-point Likert Scale (1 = strongly disagree, 5 = strongly agree)	Empowerment was not defined

	Serrani Azcurra 2014 [48] Argentina		Urban-dwelling seniors (n=648) in Spain			Empowerment refers to patient skills that allow them to become primary decision-makers in control of daily self-management of health problems
5. Instrument developed by Small et al.	Small et al. 2013. [37] UK	Measure empowerment in patients with long-term conditions	n=197, mainly older with different types of long-term conditions	Positive attitude and sense of control (21), knowledge and confidence in decision making (13) and enabling others (13)		An enabling process or outcome arising from communication with the health care professional and a mutual sharing of resources over information relating to illness, which enhances the patient's feelings of control, self-efficacy, coping abilities and ability to achieve change over their condition
6. China Client Empowerment Scale, CCES	Zhou et al. 2016 [38] China	Measure clients' empowerment, predict clients' self-management practices, and evaluate the effectiveness of empowering programs.	n=317 with chronic diseases	Informed Confidence, Client–Provider Relationship, Social Advocacy, Awareness, Control and Client–Client Support Number of items were not clear (44)	5-point Likert Scale (1 = strongly disagree, 5 = strongly agree)	Empowerment was not defined.
Patient enablement						
7. Patient Enablement Instrument – (PEI)	Howie et al. 1998 [39] UK	Measure patient enablement	n= 613 primary care patients	No subscales (6)	3-point Likert Scale (much	Enablement process confirmed importance of themes of patient

					better - better - same or less)	centeredness and empowerment, and patients' ability to understand and cope with their health and illness.
	Lam et al. 2010 [49] Hong Kong		n=152 Chinese patients in primary care clinic			
	Hudon et al. 2011 [50] Canada		n=110 French patients in family medicine clinic			
	Kurosawa et al. 2012 [51] Japan		n=256 patients in outpatient clinic in Japan			
	Rööst et al. 2015 [52] Sweden		n=153 primary care Swedish patients			
Patient activation						
8. Patient Activation Measurement (PAM)	Hibbard et al. 2005 [40, 41] USA	Assess patient knowledge, skill and confidence for self-management	n=1551, adults, aged 45 years and older	No subscales (13), Four stages of Activation: Believes active role important, Confidence and knowledge to take action, Taking action and Staying the course under stress	4-point Likert Scale, strongly disagree - strongly agree	Patient activation appears to involve four stages: (1) believing the patient active role is important, (2) having the confidence and knowledge necessary to take action, (3) actually taking action to maintain and improve one's health, and (4) staying the course even under stress.
	Maindal et al. 2009 [53] Denmark		n =358 Danish people with dysglycaemia			
	Skolasky et al. 2009 [54]		n=122 lumbar spinal surgery			

	USA					
	Skolasky et al. 2011 [55] USA		n=855 older adults with chronic conditions			
	Brenk-Franz et al. 2013 [56] Germany		508 patients from primary care practices in German speaking			
	Rademakers et al. 2012 [57] Netherlands		n=1837 (study A), n=672 (study B) with chronic conditions			
	Magnezi & Glasser 2014 [58] Israel		n=203 Hebrew-speaking Israeli adults			
	Graffigna et al. 2015 [59] Italy		n=519 chronic patients in Italy			
	Packer et al. 2015 [60] Canada		n=724 adults with neurological conditions residing			
	Schmaderer et al. 2015 [61] USA		n=313 multimorbid inpatients			
	Prey et al. 2016 [62] USA		n=100 cardiology and oncology patients			
	Moreno-Chico et al. 2017 [63] Spain		n=208 patients in primary health care centre in Spain			

9. Consumer Health Activation Index (CHAI)	Wolf et al. 2018 [42] USA	Measure healthcare activation	n=301 English-speaking, community-dwelling adults	No subscales (10)	6-point Likert scale was used to ascertain item agreement (strongly disagree – disagree)	An individual's willingness to take on the role of managing their health and healthcare.
Patient engagement						
10. Altarum Consumer Engagement (ACE) Measure	Duke et al. 2015 [43] USA	Measure individual's engagement in health and healthcare decisions	n=2079 web portal to a general population panel of US adult respondents	Commitment (6) Informed choice (5) Navigation (5) Ownership (5)	-	Engaged patient is one who is competent in self-care. Engagement is as "actions individuals must take to obtain the greatest benefit from the health care services available to them''.
11. Patient Health Engagement Scale (PHE)	Graffigna et al. 2015 [44] Italy	Measure of patient engagement	n=382 patients with chronic disease	No subscales (5)	4-point Likert Scale	Patient engagement is a process-like and multidimensional experience, resulting from conjoint cognitive (think), emotional (feel), and conative (act) enactment of individuals toward their health management.
	Zhang et al. 2017 China [64]		n=377 patients with chronic disease in China			
12. Patient Engagemen Index (PEI)	Xu et al. 2018 [45] Hong Kong	Evaluate patient engagement in a general outpatient setting	n=324 general outpatient setting in Hong Kong	Self-information search (3), Communication with professionals (6), Partnership (6)	5-point Likert rating scale (from "never" to "always)	Patient engagement should be a relationship, which is reciprocal, dynamic, and pluralistic, rather than an invariable status among patients, professionals, and the

				and Health maintenance (5)		organizations. The framework presented five levels of patient engagement (self-information search, enquiry, bidirectional communication, discussion, and partnership)
Perceived control						
13. Multidimensional Health Locus of Control Scale, (C-MHLC), Spanish version	De las Cuevas et al. 2015 [46] Canada	Evaluate patients' perceived control	n=507 patients with psychiatric disorders (schizophrenia bipolar affective disorder, depressive disorder, neurotic, stress-related disorder, disorders or adult personality and behavior)	Internal health locus of control (6), chance health locus of control (6), Doctors health locus of control (4) and other people health locus of control (2)	6-point Likert Scale (totally disagree-totally agree)	Health locus control refers to the belief individuals who or what is the agent determines the state of their health.

Next, the main content of instruments was analysed based on the previous definitions of empowerment. The subscales of the instruments were classified in four elements of empowerment: 1) patient's capacities [5,7,13,14,20,21], 2) patient's knowledge [5,7,16,20], 3) patient's behaviour [4,5,7,13,16,20,21], and 4) support by others [7,22,23] (Table 2). After that, the items of each instrument were explored. If the instrument did not include any subscales, analysis was done based only on the items of the instrument. Analysis was done on subscale and item level by two researches (AP, SE).

Table 2. Elements of empowerment in different instruments

Name of the instrument	Element 1: Patient's capacities	Element 2: Patient's knowledge	Element 3: Patient's behaviors	Element 4: Support by others
Patient Perceptions of Empowerment Scale (PPES)*	+	+	+	+
Health Education Impact Questionnaire (HeiQ)	++	+	++	++
Health Care Empowerment Inventory (HCEI)	++	+	+	-
Health Empowerment Scale (HES)*	+	+	+	+
Instrument developed Small et al.	++	++	++	-
Chinese version of the Client Empowerment Scale (CCES)	++	++	++	++
Patient Enablement Instrument (PEI)*	+	-	+	-
Patient Activation Measurement (PAM)*	+	+	+	+
Consumer Health Activation Index (CHAI)*	+	+	+	-
Patient Health Engagement Scale (PHE)*	+	-	-	-
Altarum Consumer Engagement (ACE) Measure	++	-	++	-
Patient Engagement Index (PEI)	++	+	+	-
Health Locus of Control Scale (C-MHLC)	++	-	++	++
Subscales of the instruments connecting to elements of empowerment:				

Element 1: Tolerance of uncertainty, Skill and technique acquisition, Constructive attitudes and approaches, Self-monitoring and insight, Emotional well-being, Positive attitude and sense of control, Awareness, Internal health locus of control, Ownership, Self-information search
Element 2: Knowledge and confidence in decision making, Informed confidence
Element 3: Positive and active engagement in life, Health directed behavior, Health services navigation, Enabling others, Social Advocacy, Control, Chance health locus of control, Commitment, Informed Choice, Navigation, Partnership, Health maintenance
Element 4: Social integration and support, Integration, Client-Provider Relationship, Client-Client support, Control, Doctors health locus of control, Other people health locus of control
* not subscales in instrument
+ = item, ++ = subscales, - = no items or subscales in this element.

To assess the quality of the psychometric properties of the instruments, the criteria developed by Terwee et al. [34] were used. The criteria are suggested as a guideline for evaluating the psychometric properties and quality of instruments. The criteria have been used in earlier studies focusing on measurement of patient empowerment [e.g. 12,29]. The following criteria were used: content validity, internal consistency, construct validity, reproducibility (including agreement and reliability), responsiveness, floor and ceiling effects, and interpretability. Each criterion was rated as positive (+), intermediate (?), negative (–), or no information available on criterion (0) [34]. To get a positive rating, the criterion had to be found and needed to be assessed as good, while to get a negative rating the criteria was found but was assessed as poor. We did not assess criterion validity by the Terwee's criteria because there is no gold standard comparison to measure empowerment [12,29]. Both the content analysis and the quality of the psychometric properties of the instrument were assessed separately by three researches (AP, SE, MS). Discrepancies were solved by discussion and consensus was achieved.

3. Results

A total of 13 instruments, developed 1998–2018, were identified (Table 1). **Based on the aims of the instruments, as described by original authors, and the earlier review [12], six instruments were developed to measure patient empowerment**: Patient perceptions of Empowerment Scale (PPES) [35], Health Education Impact Questionnaire (HeiQ) [30], Health Care Empowerment (HCE) [31], Health Empowerment Scale (HES) [36], Instrument developed by Small et al. [37], and China Client Empowerment Scale (CCES) [38].

Seven instruments measured concepts related to empowerment (patient enablement, patient activation, patient engagement and perceived control): Patient Enablement Instrument (PEI) [39], Patient Activation Measurement (PAM) [40,41], Consumer Health Activation Index (CHAI) [42], Altarum Consumer Engagement Measure (ACE) [43], Patient Health Engagement Scale (PHE) [44], Patient Engagement Index (PEI) [45], and Multidimensional Health Locus of Control Scale (C-MHLC) [46].

Out of the 13 instruments, nine instruments were developed for different long-term conditions [30,31,35,37,38,39,44–46], and four for adults or older people [36,41–43]. Some of the instruments have later been validated in different patient groups and in different languages (Table 1) [47–64].

3.1. Structure and main content of instruments

The structure of the instruments was heterogeneous (Table 1). The number of subscales ranged from two [31] to eight [30]; six instruments did not have any subscales (PEI, PAM, PPES, HES, PHE, CHAI). The number of items ranged from five [44] to 47 [37] and the response scale ranged from 3 to 6-point Likert Scale, the most frequently used scale being a 5-point Likert scale (Strongly disagree - Strongly agree). In two instruments, the response scale was not described [30,37].

The content of the instruments was variable (Table 2). All instruments included the element patient's capacity and most of the instruments included the element patient's behaviour. Instead, the element support by others was rarely included. The element patient's knowledge was

included in all empowerment instruments [30,31, 35–38] whereas only three instruments measuring related concepts of empowerment included this element [41,42,44]. **Five instruments covered all the four elements used to define of empowerment** (HeiQ, PPES, HES, CCES, PAM).

3.2. Psychometric properties of the instruments

The psychometric properties of the instruments varied (Table 3), and none of them was tested with all the criteria of Terwee et al. [34]. Content validity was assessed as positive or intermediate ratings in all other instruments except PEI [39] and C-MHLC [46] where information on target population involvement was not found. Construct validity was assessed by positive or intermediate ratings in all other instruments except PPES [35] where the information was not found.

Table 3. Quality of psychometric properties of the instruments (Terwee ratings 2007)

Instrument	Author, year	Content validity	Internal consistency	Construct validity	Reprodubility		Respon-siveness	Floor and ceiling effects	Inter-pretability
					Agreement	Reliability			
Patient perceptions of Empowerment Scale (PPES)	Lewin & Piper 2007 [35]	+	?	0	0	0	0	?	?
	Yeh et al. 2014 [47]	?	?	?	0	0	0	0	0
Health education impact questionnaire (HeiQ)	Osborne et al. 2007 [30]	+	+	?	0	0	0	0	0

Health Care Empowerment Inventory (HCEI)	Johnson et al. 2012 [31]	+	?	+	0	0	0	0	?
Health Empowerment Scale (HES)	Park & Park 2013 [36]	+	?	?	0	0	0	?	?
	Serrani Azcurra 2014 [48]	+	+	?	0	+	0	?	?
Instrument developed Small et al.	Small et al. 2013 [37]	+	?	+	0	0	0	0	0
Chinese version of the Client Empowerment Scale (CCES)	Zhou et al. 2016 [38]	+	+	?	0	+	0	0	0
Patient Enablement Instrument (PEI)	Howie et al. 1998 [39]	0	?	?	0	0	0	0	?
	Lam et al. 2010 [49]	0	?	0	0	+	0	?	?
	Hudon et al. 2011 [50]	0	?	0	0	-	0	0	0
	Kurosawa et al. 2012 [51]	0	+	?	0	0	0	+	?

In all instruments, internal consistency was assessed at least by intermediate ratings, and in five instruments (HeiQ, CCES, CHAI, PEI, HES), by positive ratings [30,38,42,45,48]. Also Japanese versions of PEI [51], Chinese version of PHE [64], German versions of PAM [56] and studies of PAM in different patient groups received positive ratings [60,61]. Cronbach's alpha was not reported for two instruments (HCEI, original PHE), which instead used Raykov's ρ [31] and Ordinal alpha [44]. Reproducibility was evaluated by two different properties, agreement and reliability. It was not stated that the instruments found information on agreement. Four instruments (CCES, PAM, original PHE, HES) assessed reliability by positive ratings reporting Intraclass correlation or weighted Kappa 0.75–0.95 [38,41,44,48]. The original PEI did not report reliability [39], whereas the Chinese [49] and Swedish [52] versions of PEI received positive ratings.

It was not stated that the instruments reported information on responsiveness and therefore none of them got positive ratings on interpretability. The main reason for this was the lack of definitions of minimal important change. Floor and ceiling effects were given positive ratings in three instruments: PEI in Japanese [51], PAM in Hebrew [58] and PHE in Chinese [64] while five instruments were given intermediate ratings: PPES [35], PHE [44], PEI [45], HES [48]. In most cases, the instruments had no floor effects whereas ceiling effects were evident as more than 15% of respondents achieved the highest possible score of the instrument.

Four instruments had the best overall psychometric properties by three positive ratings: PAM [41], HES [48] and CCES [38] and PHE in Chinese [64]. Evidence for one positive rating was found on PPES [35] while no positive evidence was found on the MHLC [46] and the original PEI [39]. However, the PEI has been developed and tested further, confirming the two acceptable positive psychometric properties [47].

4. Discussion and conclusion

4.1 Discussion

The purpose of this systematic review was to identify generic instruments for adults measuring patient empowerment including its related concepts and to analyse the main content and psychometric properties of these instruments. Previous studies [4,5,12,29] have referred to instruments that include related concepts of empowerment as having a similar construct as empowerment instruments, but we did not find any studies describing how these instruments include elements of empowerment. In contrast to earlier studies, this review complements the missing knowledge in this field. As a result of this review, we found four empowerment instruments which have not included in earlier reviews [12,27–29].

The included instruments were developed mostly for patients with chronic conditions. This finding is in line with many health policy programmes which highlight patient empowerment particularly in long-term conditions [2,12]. However, empowerment is also important in other patient groups, such as surgical patients. Hospital care periods have become shorter [65] and patients have to manage their own care independently at home earlier than before. This management could be supported by empowerment approaches [11] and use of the concept should be extended to diverse patient groups.

Most of the instruments have been developed during the last ten years. This might be a consequence of health care becoming more patient-centred, emphasizing patients' participation in and responsibility for their own care. The oldest instrument was PEI [39], which was published in 1998. The engagement instruments [44,45] were published in 2015 which shows that the concept is a rather new, use of this concept has increased in recent years [25]. Studies of empowerment instruments have done around the world but the studies which focusing concept of activation and engagement have done mostly in North America and in Europe. This may be due to different cultures. The concept of empowerment has used around the world and it also has included in WHO statements [1,32]. In America and Europe, individual value is highlighted, and patients are expected to be more active and engagement in their own care.

The structure of the instruments was heterogeneous. From the perspective of applicability, instruments including more than 40–50 items could be too long to use in clinical context due to time limitations and burden to respondents [66]. Mostly, the instruments were rather short (≤ 18 items), indicating good applicability in terms of time resources in the clinical context. Three instruments included items between 40 and 50. The empowerment instruments were longer than the other instruments possibly due to the multidimensional of the concept.

In the content of the instruments, both similarities and differences were found. All the instruments included the element of patient's capacity, emphasizing patients' role in their own care. Instead, the element support by others was rarely included in the instruments. In earlier, support by health care professionals has been highlighted in patient empowerment [7,23] but over the last years supporting has taken on different forms, such as Internet discussion groups, social media or searching independently for information on the Internet [23].

Differences between the content of instruments are reflected differences between the concepts of the instruments. Both enablement and engagement are more restricted concept than empowerment and content of these instruments were focused patient's capacity and patient's behaviour. Patient enablement focused as the extent to which a patient is capable of understanding and coping with his or her health issues [39, 50]. Engagement is as "actions individuals must take to obtain the greatest benefit from the health care services available to them'' [43]. Patient activation requires patients to have the knowledge, skills and confidence to manage one's health [26]. The most explicit difference between empowerment and other instruments connected in the element patient's knowledge: All empowerment instruments included this element, but in other instruments only PAM included this element. Patient's knowledge is an essential element for patient empowerment and patient education is a key intervention by health care professionals to support patient empowerment [67–69]. Patients who are empowered can make justifiable decisions about their own health and their own life, which can lead to better well-being and improved health outcomes [7–11]. Therefore, it is important that health care professionals ensure that patients have sufficient knowledge about their own health situation.

As in earlier reviews [12,29], the psychometric properties of the included instruments were described only partially, or the description was entirely lacking. The best psychometric properties were reported in CCES [38], HES [48], PAM [41] and PHE in China [64] with positive ratings on the three criteria. It has to be noticed the variation in quality of the psychometric properties of the instruments (i.e. PEI, PAM) in cross-cultural validation in different studies. Internal consistency, content validity and construct validity were mostly tested in the instruments. Content validity is the most important property [34], and all the instruments which content validity was reported got positive ratings. It was not stated that the instruments defined the minimal important change (MIC); consequently, some properties could not be assessed [34]. Additionally, floor and ceiling effects appeared in some instruments. This might be problematic as the response scales of instruments are very often of Likert scale type, with only a few response options.

However, there is no consensus which psychometric properties should be recommended to use in developing instruments. According to Terwee et al. [34], all measurement properties are not equally important: which properties are the most important depends on the situation where the instrument is going to be used. For example, responsiveness is important when using the instrument for evaluation of effectiveness of patient care. Without such information, it is impossible to know how the instrument is able to detect clinically important changes. Health care actions have to be based on evidence and we have to be able to demonstrate the effectiveness of patient care. Patients' important role in their own care has increased interest about patient report outcome measurements (PROMs). This requires high psychometric evidence of the instruments. Empowerment is a result in itself and it can be used as a PROM. In the future, development and testing of the instruments needs to be systematic and comprehensive when evaluating psychometric properties and consensus should be achieved as to what criteria should be used to evaluate the quality of the psychometric properties of the instruments. By using generic instruments, the outcomes of patient care may be evaluated in diverse patient groups and it enable comparability of results in health care [4,12].

In our evaluation, the best instruments were HES, CCES and PAM which included all four elements of empowerment. These instruments got the best overall psychometric properties by three positive ratings. HES (8 items) and PAM (13 items) are shorter than CCES (44 items). Hence, they would be easy to use in daily work, CCES would be use better in studies etc. giving a more comprehensive knowledge of patients' views.

Strengths and limitations

The strength of this review was the inclusion of instruments of related concepts of empowerment which have not included in earlier reviews [12,27–29]. The literature search was conducted in five databases, all covering areas of health care, and the search terms were formulated within the research team. Hence, the search sentence was sufficiently comprehensive. The selection process and evaluation of the articles was performed by two or three researches to ensure reliability.

However, this review has some limitations. Firstly, there are many different related concepts of empowerment some central terms might be lacking, but it was impossible to include all possible related concepts in order to the number of studies would have not increased so much that analysis would have been impossible. Patient empowerment mostly refer to a broad lifestyle domain, focusing for example to ability, perceived power, optimism about and control over the future [6]. Therefore, we excluded some concepts e.g. self-management although it has used as related concept of empowerment. In our opinion self-management is consequence of empowerment [7–9]. We chose the concepts which have in recent years been used as related concepts of empowerment [4,6,25], assuming they had an up-to-date view of related concepts. Secondly, analysing the content of the instruments could be carried out in more detail but as the instruments have been developed based on different theoretical frameworks, the comparison of the content of the instruments has to be made with great caution. Thirdly, some instruments were rather new, and their development may be still ongoing.

4.2. Conclusion

There are both empowerment instruments and instruments measuring related concepts of empowerment including elements of empowerment which can used in diverse patient groups. The instruments were heterogeneous in terms of structure and psychometric properties. **Based on our analysis, HES, CCES and PAM measured empowerment most comprehensively and they also demonstrated acceptable evidence of their validity and reliability.**

There is some overlap between the contents captured in the instruments identified in this review. However, Empowerment is more wide-ranging and multidimensional than its related concepts. In the future, to avoid confusion, a clear distinction should be made between empowerment and its related concepts.

4.3 Practice implications

This review reports useful information for clinicians and researchers about the content and the psychometric properties of different instruments measuring patient empowerment or its related concepts. To strengthen international research and to provide comparable results in different contexts or diverse patient groups, it would be beneficial to use generic instruments with high psychometric evidence. Additionally, to achieve accurate results, systematic and comprehensive testing of the psychometric properties is recommended. This may also facilitate the selection and use of empowerment instruments in clinical practice and research. Further testing of psychometric properties of each instrument is recommended.

Funding

This study has been funded by State Research Funding for university-level health research.

Declaration of interest

None

Acknowledgments

The authors would like to thank Anna Vuolteenaho for her expertise in the English language.

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