Definitions, instruments and correlates of patient empowerment: A descriptive review

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\textbf{Abstract}

Objective: This review aimed to: (i) inventory the definitions and measurements of patient empowerment in healthcare literature; (ii) appraise the conceptual and methodological rigor of included studies; and (iii) identify correlates of patient empowerment in persons with chronic conditions.

Methods: Four databases were searched to identify articles measuring patient empowerment in persons with chronic conditions, used a quantitative design and provided evidence on correlates of patient empowerment. Seventy-six articles were included and analyzed by descriptive statistics and summative content analysis.

Results: The articles used a range of definitions (n = 35) and instruments (n = 38), evaluating a range of correlates in four categories: sociodemographic characteristics, clinical outcomes, patient-reported outcomes, and patient-reported experiences. The most frequent associations were between patient empowerment and age (n = 21), sex (n = 18), educational level (n = 15) and quality of life (n = 13). However, they were not always significant.

Conclusion: The broad variation of definitions and instruments highlights the lack of consensus on how to interpret and measure patient empowerment. Although several covariates have been evaluated, there are few studies assess the same relationships.

Practice implications: Consensus on a definition and measurement of patient empowerment is needed to improve the quality of future research and to provide a more cohesive body of knowledge.

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1. Introduction

The World Health Organization (WHO) strongly advocates involving patients in the care process [1] and different models of care have incorporated patient empowerment as a way to achieve this aim [2]. Patient empowerment was initially introduced in healthcare as a means for health promotion [1]. Nowadays, it is suggested as an important construct in working towards improving the health of those with chronic conditions (CC), because patients participate more in care, become more autonomous and assume an active role in the decision-making process [3,4]. Patient empowerment has a key role in global health [2] and the extent to which strategies are implemented internationally to empower individuals, can vary depending on the country's healthcare system and resources. Current evidence suggests that high-income countries and particularly, European countries are the ones leading this field [5].

In the literature, different definitions of patient empowerment available occur, as well as models that try to explain how this construct is associated with other variables [6–8]. Given the variety of definitions, it is unclear whether all the available articles understand the construct in a similar way. Moreover, there are currently several instruments used to measure patient empowerment [6,9]. The instrument used determines how the construct is operationalized and which dimensions are captured. The broad range of definitions and instruments makes it possible to consider that there will be variations in how the construct is interpreted and used.

Given the lack of clear conceptualization, patient empowerment is used interchangeably with other concepts, for example self-efficacy and patient activation. These concepts have well-established definitions with the majority of authors referring to Bandura [10] and Hibbard [11], respectively. Yet, there are consistently used as synonyms of patient empowerment. Self-efficacy refers to the person’s ability to achieve a particular task [10], while patient activation refers to the ability to manage one's illness, collaborate with the healthcare provider, maintain health functioning and access appropriate care [11]. In practice, the use of self-efficacy, patient activation and other concepts as means to measure patient empowerment can be the result of a lack of high-quality measurements of patient empowerment or a lack of understanding on how these neighboring concepts differ from patient empowerment. Previous articles [8,12] have discussed the differences between patient empowerment and the previously mentioned constructs, as well as others. These studies have concluded that patient empowerment has individual and collective components that can be approached from different perspectives (i.e. the patient, the healthcare provider or the healthcare system) [3,8,12]. Thus patient empowerment not only leads to improved health and quality of life [13], but also improved social and health services, better policy prioritization and decreases cost-effectiveness [14]. Patient empowerment is also a construct associated with a collaborative and equal relationship with the healthcare provider [7].

Theoretical models have proposed that patient empowerment is associated with clinical and patient-reported outcomes. While previous empirical studies have found significant associations, the scope of variables associated with patient empowerment is yet to be determined. Additionally, it is unclear how the available evidence base evaluates all the potential variables associated with patient empowerment.

A broad picture of the different definitions and instruments of patient empowerment used in chronic care research can help understand whether those researching patient empowerment comprehend the concept in a similar way and whether the available evidence is comparable. Additionally, knowing the variables that are associated with empowerment would allow researchers and clinicians to gain insights on the mechanism of impact when empowerment is a target for intervention. Moreover, it will help gain an understanding of the current state of the art and avenues for further research and development. The aims of this study therefore are to: (i) inventory the definitions and measurements of patient empowerment in healthcare literature; (ii) appraise the conceptual and methodological rigor of published studies; and (iii) identify correlates of patient empowerment in persons with CC.

2. Methods

2.1. Study design

To achieve the aforementioned aims, a descriptive review was undertaken. This type of review aims to assess the extent to which empirical studies in a specific field of research reveal any trends [15]. By undertaking a descriptive review it is possible to identify patterns and draw conclusions about the existing findings, thus, providing a state of the art in a specific field [15].

2.2. Systematic search strategy

In order to identify relevant publications a systematic literature search was performed in PubMed, CINAHL, Scopus and PsycInfo.
inclusion in the database search, publications needed to have been written in English, Spanish or Swedish but there were no limits on publication dates to ensure all relevant articles were retrieved. The search strings included as key term “patient empowerment”, as well as different variations of search terms related to “chronic conditions” and “quantitative study designs”. The search strings used to retrieve the articles can be found in Supplementary File 1.

2.3. Eligibility criteria

2.3.1. Study population

The population of interest in this descriptive review were persons living with a CC. These are defined as “conditions that last or are expected to last twelve months or more and result in functional limitations and/or the need for functional limitations and/or the need for ongoing medical care” [16]. No age limit was established and studies were included independently of the country of origin.

2.3.2. Design and focus of included and excluded publications

Only quantitative studies were included, irrespective of whether they used an experimental, quasi-experimental or non-experimental design. The studies had to measure patient empowerment and provide information related to correlates of this construct. Studies that used instruments to measure patient empowerment that was actually associated with other constructs, such as self-efficacy or patient activation, were still included and this was because the authors of these articles intended to measure patient empowerment. Studies that assessed patient empowerment interventions but did not measure this construct were excluded. Additionally, articles that described the development and validation of patient empowerment measurements were excluded because they do not provide information on correlates of patient empowerment.

2.4. Review criteria

Seven criteria were developed to appraise the conceptual and methodological rigor of the included studies. These criteria were based on criteria previously developed by Gill and Feinstein to evaluate the quality of quality-of-life studies [17] and subsequently refined and used in reviews [18,19]. The criteria used in the present review assess whether the studies (1) provide a definition of empowerment; (2) propose dimensions/domains of empowerment; (3) give the reasoning for selecting a specific instrument; (4) use an instrument intended to measure empowerment; (5) measure empowerment with a subscale; (6) differentiate other concepts; and (7) allow the calculation of a total score. See Supplementary File 1 for a description of the review criteria.

2.5. Study selection process

Articles were selected in a two-stage process. The first stage involved reviewing titles and abstracts against the aforementioned inclusion and exclusion criteria. The second stage was the full-text revision of the articles included during stage one. The selection process was primarily carried out by the first author and any uncertainties were discussed with the two co-authors (CSL, ELB). In order to report the results from the study selection process, the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) flowchart was used (See Fig. 1).

2.6. Data extraction and management

For the management of the retrieved references, EndNote software was used to remove duplicates and to screen titles and abstracts. An Access Microsoft Office database was created to facilitate the data extraction. The authors pilot-tested the data fill of this form with two articles. Data retrieved from the articles included: year of publication, country where the study was performed, type of study design, definition of empowerment, dimensions/domains of empowerment, study aim, instrument used to measure empowerment, sample size, study duration, age group, type of CC and assessed covariates. Studies were classified according to their design, following the definitions of the Joanna Briggs Institute [20]. Data extraction was undertaken by all authors individually and then compared. If discrepancies arose, these were discussed among all authors.

2.7. Data synthesis and analysis

Descriptive statistics were used to summarize the characteristics of the included studies. To indicate how well the articles fulfilled the review criteria (in regards to their conceptual and methodological rigor) a summary score was calculated. If the articles fulfilled a criterion (i.e. yes), they received a score of 1. The exception to this was criterion 5, for which the authors were expected not to have used a subscale to measure patient empowerment, in which case a score of 1 was given if the criterion was not fulfilled. A total score was calculated by counting the number of criteria the article fulfilled and dividing this figure by the number of criteria that were eligible for the article. The resulting value was multiplied by 100, yielding a score range from 0 to 100. The higher the score, the better the conceptual and methodological rigor. Medical specialties were coded according to the chronic condition of the included participants in the articles. Identified correlates were categorized to facilitate understanding of the available evidence and identification of potential patterns. Categorization was by summative content analysis [21], conducted by three of the authors (MAM, CSL, ELB).

3. Results

3.1. Systematic literature search

An initial database search identified 11,142 publications, of which 9349 were kept after removing duplicates. The revision of titles and abstracts led to the inclusion of 327 articles for full-text eligibility. After reading the full-texts, 76 papers were included for analyses. The majority of studies excluded during full-text revision were not in line with the study’s aim. Additional reasons for exclusion are provided in the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) flowchart (Fig. 1).

3.2. Publication characteristics

The included studies were published between 1998 and 2018 and performed in 26 different countries. Five different types of designs were employed. The majority of studies had a cross-sectional design (n = 53, 69.7%), and the rest were longitudinal (n = 23, 30.3%). Of the longitudinal studies, 8 had an experimental design. The median sample size was 204.5 (35–11,500) and only seven studies included more than 1000 participants. The participants’ mean age was 46.6 (±14.8) and the studies were mostly focused on including adults, with only six studies recruiting participants under the age of 18 years (Table 1).

Psychiatry (n = 33) and endocrinology (n = 20) were the two medical specialties with the highest number of publications. Within these specialties, schizophrenia, schizotypal and delusional disorders (e.g. schizophrenia, psychosis), mood and affective disorders (e.g. depression, bipolar disorder, affective disorder) and diabetes mellitus were the most frequent chronic conditions (Table 1).
3.3. Inventory of definitions and measurements of patient empowerment

3.3.1. Definitions

A total of 49 (64.5%) studies had a definition for patient empowerment and 12 of these included more than one. There were 35 different definitions used in the included studies, corresponding to 29 different authors, with some authors having more than one definition. The most frequent definitions were the ones proposed by Funnell and Anderson (n = 7, 14.2%) [22,23], Rappaport (n = 7, 14.2%) [24,25], Zimmerman (n = 6, 12.2%) [26] and Corrigan (n = 6, 12.2%) [27]. A table with all the identified definitions can be found in Supplementary File 1.

3.3.2. Instruments

The included publications used 38 different instruments to attempt to measure patient empowerment. See Table 2 for a list of the identified instruments. Eight studies measured patient empowerment by using questionnaires which the authors considered to be associated with different components of patient empowerment (i.e. control, advocacy, coping). However, none of those measures were precisely designed to measure the overall construct of empowerment. Seven studies used a self-developed questionnaire to measure empowerment, with some of these questionnaires based on items retrieved from other empowerment scales.

Two scales were used by more than 50% of the publications the Making Decisions Empowerment Scale (n = 24) developed by Rogers and colleagues [28] and the Diabetes Empowerment Scale (DES) (n = 19) developed by Anderson and co-authors [29]. In the latter, variations of the scale (e.g. Diabetes Empowerment Scale Short Form [30], Chinese Diabetes Empowerment Scale [31]) are included.

3.4. Methodological and conceptual rigor

The mean summary score for the included publications was 63.38 ± 22.59. One publication had the lowest score of 14.29, whereas three publications had the highest score (i.e. 100). The least fulfilled criterion was related to authors explaining the reasoning behind choosing a particular instrument to measure patient empowerment (n = 61, 80.2%) (Table 3). Authors frequently described the number of items and scoring but did not provide information on the psychometric properties or theoretical support of the instrument. The second least fulfilled criterion was related to the domains of patient empowerment (n = 33, 43.4%). While some studies provided domains when describing their instrument, it was rare for the authors to mention domains of this construct in other circumstances. Lastly, around a third of the articles did not include definitions of patient empowerment (n = 27, 35.5%).

3.5. Correlates of patient empowerment

The included publications covered more than 50 different potential variables associated with patient empowerment. See Supplementary File 1 for a full list of the associations identified. These were classified under four categories: 1) sociodemographic characteristics; 2) clinical outcomes; 3) patient-reported outcomes; and 4) patient-reported experiences. Table 4 presents an overview of the major categories and subcategories that were identified. As the
The data are limited by the time span, as this provides information on a particular point in time, so it is not possible to establish which variable is the one that has a predicting effect. While this review did not aim to provide information on the predictive value of patient empowerment, it is plausible to conclude that evidence on this aspect is limited given the cross-sectional nature of the majority of the studies. It is therefore largely uncertain whether there is still sufficient evidence to help confirm theoretical models on patient empowerment and its possible effects on other outcomes.

Besides a limited number of study designs, the articles included mostly patients with diabetes mellitus and psychiatric disorders. Patient empowerment was suggested as a suitable approach and outcome for those with CC more than 15 years ago [22], yet, it appears that this has not been translated to research and clinical settings. This misfit between theory and practice can be the result of a combination of different factors. For instance, uncertainty on the effectiveness of different strategies to empower individuals can impact on how often they are used. Additionally, patient empowerment implies a change in the core on how healthcare providers care for their patients. It involves a structural change that might not be easy to implement. Moreover, available resources have also an impact on implementing patient empowerment. It is not only about educating the staff, developing educational material or learning platforms for the patient, but also having sufficient time to build a healthcare professional-patient relationship. These resources differ across healthcare contexts and it can be the case that certain countries have a structure that allows them to empower individuals more easily, while others do not have the capacity.

We did find other CC included in the studies, but the articles amounting to these CC are few and limit the generalizability of their results.

4.1. Limited to cross-sectional data and few chronic conditions
From the 76 included studies, 68.4% were cross-sectional studies. The data are limited by the time span, as this provides information on a particular point in time, so it is not possible to establish which variable is the one that has a predicting effect. While this review did not aim to provide information on the predictive value of patient empowerment, it is plausible to conclude that evidence on this aspect is limited given the cross-sectional nature of the majority of the studies. It is therefore largely uncertain whether there is still sufficient evidence to help confirm theoretical models on patient empowerment and its possible effects on other outcomes.

### Table 1

<table>
<thead>
<tr>
<th>Study designs</th>
<th>N = 76 (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cross-sectional</td>
<td>53 (69.7)</td>
</tr>
<tr>
<td>Observational studies without control group</td>
<td>12 (15.8)</td>
</tr>
<tr>
<td>Cohort study with control group</td>
<td>3 (3.9)</td>
</tr>
<tr>
<td>Pre-test/Post-test</td>
<td>2 (2.6)</td>
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<tr>
<td>Randomized controlled trials</td>
<td>6 (7.9)</td>
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<table>
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<tr>
<th>Sample size</th>
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<td>Median</td>
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<td>Intercquartile range</td>
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<th>Age range of the target populations</th>
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<td>Minimum</td>
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<tr>
<td>Maximum</td>
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<tr>
<td>Mean</td>
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<tr>
<th>Systems or conditions of the study</th>
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<tbody>
<tr>
<td>Psychiatry</td>
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<td>Endocrinology</td>
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<td>Rheumatology</td>
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<td>Immunology</td>
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<td>Cardiology</td>
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<td>Oncology</td>
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<tr>
<td>Developmental and physical disabilities</td>
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<tr>
<td>Unspecified</td>
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<td>Pneumology</td>
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<tr>
<th>Countries where studies were undertaken</th>
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<tbody>
<tr>
<td>United States</td>
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<td>Sweden</td>
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<td>The Netherlands</td>
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<table>
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<th>Others</th>
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<td>20 (21.3)</td>
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</table>

* Countries in this category only had one study each.

Table shows, the majority of potential correlates fell under the categories of patient-reported outcomes (n = 181) and sociodemographic characteristics (n = 122).

The most frequently studied associations with empowerment were participant age (n = 21), quality of life (n = 18), sex (n = 15), educational level (n = 15), employment (n = 15), and psychiatric symptoms (n = 12). Fig. 2 shows the most frequently studied correlates, i.e. those that had been investigated in five or more studies. These variables cover almost all the identified categories but the majority correspond to sociodemographic characteristics and patient-reported outcomes. The dots in the figure represent the number of studies that investigated those covariates, whereas the bars provide information on studies that yielded statistically significant relationships between patient empowerment and the respective correlates. Variables such as quality of life, health status, stigma, self-efficacy and self-esteem appeared to be always significant.

4. Discussion and conclusions

4.1. Discussion

To our knowledge this is the first descriptive review that has aimed to inventory definitions and instruments of patient empowerment, assess methodological and conceptual rigor of included studies, and identify correlates of this construct in individuals with CC. From the results, there are three overall aspects that are important to highlight.

4.1.2. Conceptual and methodological limbo

As has been found in previous research [8], there is no consensus on a definition for patient empowerment and the available articles use a broad range of definitions, as well as instruments. The most common definitions in the literature were the ones written by Funnell and Anderson [22,23] and Rappaport [24]. Surprisingly, the definition from the WHO [32] was not used more frequently, since these definitions are usually well known, such as the definition for health. While the WHO's definition highlights the individual and community component of patient empowerment, it is rather vague to operationalize and therefore could explain why it is not used more often.

There were articles that included more than one definition of patient empowerment. This raises the question of how these authors understand the construct, as even when there are definitions that propose the construct similarly, not having a clear definition from the beginning, complicates its operationalization, and likewise the choice of instrument to assess it and how to use the concept throughout the paper. Additionally, there were studies that employed self-developed scales of patient empowerment using items from previous instruments. Questions about the validity and reliability of these scales is uncertain, as well as the interpretation of the authors regarding the construct.

Even when the included studies do not shed light on how they understand or operationalize patient empowerment, there are recently published studies that have aimed to develop high-quality measurements of patient empowerment with a clear theoretical background and that are meant to be used in those who have a CC [33,34]. Additionally, there are recently published studies that used these measures and provide evidence on correlates of patient empowerment [35].
There were also authors who used instruments that are not intended to measure patient empowerment, but rather self-determination or patient activation [11]. This variation in how the authors measure patient empowerment, highlights the problem of whether the studies are interpreting patient empowerment similarly and whether the evidence obtained is comparable. This lack of clarity on the conceptualization is further supported by existing instruments, such as the Diabetes Empowerment Scale (DES), which is one of the most commonly used scales in the included studies [29]. Although the scale has “empowerment” in its title, the authors who developed the scale state the scale measures psychosocial self-efficacy [29]. Unlike DES, the Making Decisions Empowerment Scale (MDES) intends to measure patient empowerment, but its development did not follow a clear theoretical framework and it is not of high quality [36]. It is plausible to say from the findings of this study and from previous studies [6], that one of the most important gaps when developing an instrument to measure patient empowerment, is the lack of a thorough assessment of the literature and following a clear theoretical framework during item development. Additionally, during evaluation of a new instrument, different aspects associated with validity and reliability should be considered, as suggested by the COSMIN checklist [37].

A common characteristic between the MDES and DES, is that they are both disease-specific. These scales are meant to be used with users of mental health services [28] or those with diabetes mellitus [29]. Some authors suggest empowerment is bound to its context and is thus disease-specific [26,38], but the majority of the literature leans towards a generic approach. Future research should determine...
whether the aforementioned other available scales have been developed to be used solely on a particular group or whether they are applicable on other CC and age groups.

Around a third of the studies did not use the concept of patient empowerment consistently, which meant they used it interchangeably with other concepts or even provided evidence related to other constructs as relevant for patient empowerment. These findings support a call to come to a consensus on what patient empowerment is and which dimensions comprise it. By clarifying its boundaries to other concepts, it will be easier to compare the evidence around this complex construct.

4.1.3. A variety of correlates to patient empowerment, but a lack of sufficient evidence available

The included articles have assessed a broad range of potential correlates to patient empowerment but the majority of the associations were investigated less than five times. Moreover, the small sample of studies assessing a particular correlation with patient empowerment, complicates their generalizability and potential to expand the theoretical foundations of patient empowerment.

From the associations that proved to be significant there is a clear significant effect between patient empowerment and quality of life, health status, self-efficacy, self-esteem, stigma, social support and psychiatric symptoms. These significant effects are in line with changes theoretically associated with patient empowerment [8,13]. Nevertheless, these findings have to be considered in light of the quality of the studies, which was not evaluated here as this was beyond the scope of the present review.

Falk-Rafael [39] suggests empowerment is associated with changes in self, an aspect primarily related to the individuals’ level of self-esteem and self-efficacy, so these significant associations are not unexpected. Moreover, considering empowerment is a multilevel construct (i.e. affects and it is influenced by individual, community and societal aspects) [26], aspects related to stigma and social network can have an important effect on the level of empowerment and vice versa.

Patient empowerment is also associated with changes in behaviors, which are eventually expected to lead to healthier choices [39]. These changes in behaviors are also associated with increased knowledge, skills development and increased awareness [3,8,13] and could potentially lead to changes in health status, quality of life and experiencing psychiatric symptoms. However, without knowing the directionality of the associations, it is also possible to hypothesize that people who report higher in variables such as the ones mentioned above, also feel more in control and therefore report higher levels of empowerment [13].

There was little research available evaluating the association between patient empowerment and clinical outcomes. Moreover, for
the largest category, patient-reported outcomes, most of them studied associations less than 3 times. If patient empowerment is meant to be understood as an intermediate outcome [13], then research has to start evaluating these type of associations more often. Of course, this will also require using longitudinal study designs that allow researchers to establish the predictive value of patient empowerment.

It is worth noting that the significant associations found could be influenced by the instruments used to measure patient empowerment. Around 15% of the articles did not use patient empowerment questionnaires. It is possible that if the authors had used another instrument to measure patient empowerment, the associations might have been significant.

4.1.4. Methodological considerations

The present systematic review has several methodological strengths. First, the search strings were developed following a systematic process and a librarian was consulted regarding their quality. Second, the data collection form was pilot-tested by all the authors and revised, in order to enhance the quality and consistency of the data extraction process. Third, discussions about the differences in the extracted data involved all authors. Nevertheless, there are certain limitations that should be considered. First, the search process involved only four databases and gray literature was excluded. This could mean that relevant literature was missed. Second, during the selection process only one person was involved, even when uncertainties were discussed with the other co-authors, it does not minimize the risk of selection error. Third, in this paper we did not make an evaluation of the appropriateness of conceptual models, current definitions or available instruments. Fourth, we do not provide information on the statistical method or the effect size of any of the associations. Fifth, we do not assess the quality of the included studies. While this is of relevance, it was out of the scope of the review. Sixth, it is possible that not all measurements of patient

![Fig. 2. The bars and the upper axis (0–100) are the proportion of associations that were significant. The dots and the lower axis (0–25) in the graph correspond to the number of studies that included the identified associations.](image-url)
empowerment were identified, since we excluded articles aimed to
develop and evaluate patient empowerment instruments.

4.2. Conclusions

This review highlights that there is still a need to undertake
thorough conceptual work. The heterogeneity across articles entails
that it is not possible to conclude whether all the available evidence
on patient empowerment is actually related to the construct itself.
Even when a wide range of potential correlates have been in-
vestigated, the majority focus on sociodemographic and patient-
reported outcomes. Additionally, limited evidence for the majority of
identified associations exists, as only a limited number of articles
have investigated them. This lack of evidence also limits whether we
can confirm or falsify available conceptual models that attempt to
explain the association between patient empowerment and other
constructs.

4.3. Practice implications

Future research should focus on streamlining available defini-
tions and determining which instruments are best at capturing this
construct. Moreover, in order to facilitate the understanding and
improving the quality of available evidence, researchers should
clarify certain aspects, such as providing a description, rationale be-
hind selecting a particular instrument and use the construct con-
sistently. Future studies should consider using recently-developed
measurements, which have followed a more thorough development
and validation process.

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CRediT authorship contribution statement

Mariela Acuña Mora: Conceptualization, Methodology, Investigation, Formal analysis, Writing - original draft. Carina Sparud-Lundin: Conceptualization, Methodology, Investigation, Supervision, Formal analysis, Writing - review & editing. Philip Moons: Conceptualization, Methodology, Investigation, Supervision, Writing - review & editing, Funding acquisition. Ewa-Lena Bratt: Conceptualization, Methodology, Investigation, Supervision, Formal analysis, Writing - review & editing, Funding acquisition.

Declaration of Competing Interest

The authors declare that they have no known competing fi-
nancial interests or personal relationships that could have appeared
to influence the work reported in this paper.

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Appendix A. Supplementary material

Supplementary data associated with this article can be found in
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