



Concepts and measures of patient empowerment: a comprehensive review

Del concepto de empoderamiento del paciente a los instrumentos de medida: una revisión integrativa

Do conceito de empoderamento do paciente aos instrumentos de medição: uma revisão integrativa

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ABSTRACT

Objective: Analyze the definitions and dimensions of empowerment. Identify the strengths and weaknesses of empowerment measures based on the conceptual model.

Method: This was a comprehensive literature review of publications on the MEDLINE and Cumulative Index to Nursing and Allied Health Literature (CINAHL) databases.

Results: Twenty-nine articles were selected. Seventeen definitions and seven dimensions of empowerment, and 10 empowerment measures were selected. Empowerment can be seen as an enabling process involving a shift in the balance of power, or as an outcome of this process. The dimensions reflect outcome indicators, such as participation in decision-making and control, and process indicators, such as knowledge acquisition and coping skills. Six of the tools analyzed by this study could be said to provide a robust measure of patient empowerment. **Conclusion:** we propose a definition of empowerment that helps to deepen understanding of the term and, therefore, its operationalization.

DESCRIPTORS

Patient Participation; Power; Self Efficacy; Decision Making; Personal Autonomy; Review.

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INTRODUCTION

In 2012, the World Health Organization's (WHO) Regional Office for Europe unveiled Health 2020⁽¹⁾, which sets out strategic directions and priority areas for European policy action for health and well-being up to 2020. One of the specific objectives of the framework is citizen and patient empowerment. The report regards empowerment and patient-centered care as key elements for improving health outcomes, user satisfaction with health care, communication between patients and health professionals, bringing about better adherence to treatment regimes, and ensuring the efficient use of primary health resources.

The concept of empowerment is employed in a wide range of contexts. In the sphere of health, the expression has been adopted primarily as a guiding basis for health promotion approaches and, in recent years, as a strategy for the management of chronic conditions. However, although there is broad consensus on its importance and its multidimensional nature, a universally accepted definition of the concept, its dimensions and its operationalization does not exist, thus giving rise to a variety of different measures of empowerment⁽²⁻⁵⁾.

The main purpose of this article is to analyze the different definitions and dimensions of the concept of empowerment that appear in the literature in order to identify differences and similarities and propose a single definition that embraces their essential characteristics. The secondary objective of this work is to identify the strengths and weaknesses of the tools designed to measure empowerment based on the conceptual model.

METHOD

A review of the literature on empowerment was undertaken in four stages (Figure 1). The first stage consisted of a search of the MEDLINE and CINAHL (Cumulative Index to Nursing and Allied Health Literature) databases. The Medical Subject Headings (MeSH) controlled vocabulary was initially adopted for the search of MEDLINE. However, the concept empowerment is a descriptor in the MeSH and refers to "Power (Psychology)" and "Patient Participation", and thus it was decided to use an ad hoc strategy using the keyword "Patient Empowerment" together with another descriptor "Chronic Disease" and the Boolean Operator AND. Language (English) was used as a limit. No time limit was added.

Controlled vocabulary was also used for the search of the CINAHL database, where empowerment is a Subject Heading. A first search was therefore carried out using the keyword "Patient Empowerment" and language (English), study population (adults) and peer-reviewed as limits, whereby 86 results were obtained. A second search was carried out combining "Patient Empowerment" AND "Chronic Disease", which gave rise to three results.

The searches resulted in a total of 137 articles, which was reduced to 126 after excluding repeated articles.

The second stage consisted of a title and abstract review using the following inclusion criteria: titles including at

least one of the terms *empowerment, self-efficacy, self-management, self-care, patient participation, patient engagement, patient involvement, expert patient, shared decision-making, and health literacy*; abstracts mentioning the term empowerment or referring to a review of the concept or the design of questionnaires or measures of patient empowerment. Articles that did not have an abstract were excluded. A total of 45 articles were selected for the next stage.

In stage three, the full text of each selected article was reviewed. Those articles that provided a definition of the concept, illustrated its relationships with other concepts or outlined the dimensions of the main concept and proposed empowerment measuring tools were selected, resulting in a final sample of 29 papers.

The reviews conducted in the second and third stages were carried out by independent reviewers, resulting in a high level of concordance (κ -index >0.8). Any discrepancies between reviewers were resolved by consensus.

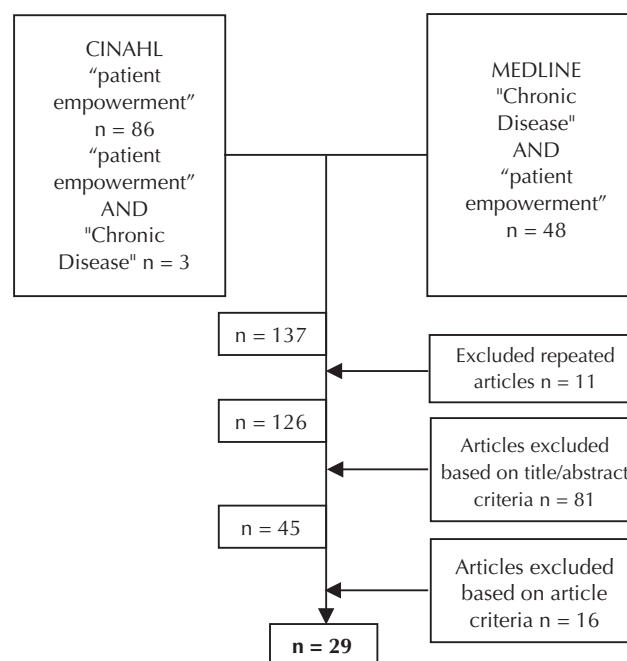


Figure 1 – Number of articles found on the databases, descriptors, criteria and sample selected for comprehensive review – Barcelona, Spain, 2015.

The Evaluating the Measurement of Patient-Reported Outcomes (EMPRO)⁽⁶⁾ tool was used to identify the strengths and weaknesses of empowerment measuring tools based on the recommendations of Medical Outcomes Trust. The EMPRO covers eight key attributes: conceptual model, reliability, validity, responsiveness, interpretability, burden, modes of administration, and cross-cultural adaptation. An approximate version of the tool was used to evaluate the conceptual model since the present review only considered whether each tool provided a definition of the concept of empowerment and outlined its dimensions, rather than other assessment criteria, such as the participation of the target population in defining instrument content, the variability

of the scale within the population, justifying the scale to measure empowerment, and the basis for calculating scores.

RESULTS

Seventeen definitions⁽⁷⁻²³⁾ (Chart 1) and seven dimensions^(9,14,24-28) of empowerment (Chart 2), and 10 empowerment measures^(9,13,24,29-35) (Chart 3) were selected.

The analysis showed that the concept of empowerment has been broadly used in the health sciences field, especially over the last 10 years. The majority of the publications studied trace the history of the concept back to pedagogy and community psychology⁽³⁶⁻³⁷⁾. This section is therefore structured into subsections: the first section outlines the history and evolution of the term, while the second contextualizes the concept within the health sciences field and outlines the different definitions of the term and empowerment measures.

EMPOWERMENT WITHIN OTHER DISCIPLINES: PEDAGOGY TO PSYCHOLOGY

One of the earliest references to the concept of empowerment was within the context of Paulo Freire's philosophy of emancipatory education^(8,20), in which empowerment is seen as a response to oppression and social inequality. Later, the concept was explored within community psychology, critical social theory, gender studies, rural economy and finally in health education and promotion^(1,35). Regardless of the disciplinary context in which it is used, the literature contains a wide range of meanings, definitions and interpretations of the term, thus transforming empowerment into a multidimensional concept.

One of the characteristics of the concept when viewed through the lens of psychology is that empowerment is an attribute of the community and not the individual. Authors differentiate between empowerment and concepts such as personal agency, self-efficacy, autonomy, self-determination,

personal control, self-regulation, all of which have a generally equivalent meaning. The latter characteristics are considered individual attributes, and one can only talk of empowerment when these processes have an impact on the community, that is, when individuals actively participate in the community or organization⁽³⁸⁻³⁹⁾.

EMPOWERMENT WITHIN THE HEALTH SCIENCES: HEALTH PROMOTION AND MANAGEMENT

When applied to the field of health, the concept of empowerment is diversely used and remains contested. Initially, it was adopted as the backbone of health promotion and later used as a way of increasing patient autonomy and participation in making decisions related to their health. Finally, with the increase in chronic diseases, empowerment began to be used as a strategy to ensure that patients participate in and take responsibility for their health care in order to improve health outcomes and control health expenditure⁽⁷⁾.

The WHO⁽¹⁾ defines empowerment as “a process through which people gain greater control over decisions and actions affecting their health, and as such individuals and communities need to develop skills, have access to information and resources, and the opportunity to participate in and influence the factors that affect their health and well-being”.

DEFINITION AND DIMENSIONS

Certain characteristics that are inherent in the concept of empowerment are common to all the definitions found in the review (Chart 1): empowerment can be seen as an enabling process involving a shift in the balance of power, or as an outcome of this process.

Chart 2 illustrates topics found in the literature that we have classified as dimensions. It should be noted however that the other writers have employed different terms such as themes^(13,19,40), elements⁽²²⁾, characteristics⁽¹⁷⁾, domains⁽³³⁾, and principles⁽¹⁰⁾.

Chart 1 – Definitions of empowerment taken from the review – Barcelona, Spain, 2015.

Definitions	References
A process of communication and education between professionals and patients, in which knowledge, values and power are shared, which is seen as a process of personal transformation.	Aujoulat et al., 2007 ⁽⁷⁾
The empowerment viewpoint conceives patients as self-determining agents with some control over their own health.	McAllister et al., 2012 ⁽⁸⁾
A process and outcome arising from communication between health care professionals and patients involving the sharing of resources over information relating to illness, which enhances the patient's feelings of control, self-efficacy, coping abilities and ability to effect change over their condition.	Small et al., 2013 ⁽⁹⁾
Empowerment applied to health is the degree of choice, influence and control held by patients over treatment, the disease and their relationship with health professionals.	Anderson et al., 2010 ⁽¹⁰⁾
A process and outcome through which patients gain self-confidence and self-efficacy in order to actively participate in their own health care and, ultimately, exercise power over decision-making concerning their treatment.	Aslani, 2013 ⁽¹¹⁾
Empowerment reflects a type of support that enables and motivates people to take the necessary steps to manage and improve their health in a self-directed manner.	Bann et al., 2010 ⁽¹²⁾
It is the capacity shown by patients with chronic disease to accept their illness and to develop and use specific coping strategies in order to regain a sense of control.	Bulsara et al., 2006 ⁽¹³⁾
An empowered patient is able to report changes, develop self-care activities, has the necessary skills and capacity to develop coping strategies and promote self-management independently and feels in control of his/her own life.	Fotoukian et al., 2014 ⁽¹⁴⁾

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Definitions	References
It is gaining the motivation and capacity (skills and knowledge) that patients can use to participate in decision-making, thus creating the opportunity to shift the balance of power in their relationship with health professionals.	Fumagalli et al., 2015 ⁽¹⁵⁾
Empowerment is the process of recognizing, promoting, and enhancing people's abilities to meet their own needs, solve their own problems, and mobilize the necessary resources in order to feel in control of their own lives.	Gibson, 1991 ⁽¹⁶⁾
It is power that is actualized through a beneficial relationship of mutual trust and respect for autonomy that develops within a dynamic and patient-centered process.	Jerofke, 2013 ⁽¹⁷⁾
Patient empowerment is achieved when there is an equitable or fair distribution of knowledge, and the patient is involved in a shared decision-making process.	McWilliam et al., 2009 ⁽¹⁸⁾
Empowerment enables patients to gain control over their health.	O'Cathain et al., 2005 ⁽¹⁹⁾
A process involving a helping relationship that enables people to take control and make decisions about their lives.	Rodwell, 1996 ⁽²⁰⁾
A process in which nurses collaborate with patients towards achieving the goal of disease self-management; this implies that patients actively participate in their care.	Shearer et al., 2007 ⁽²¹⁾
A collaborative approach in which health professionals help patients acquire the knowledge necessary to make informed decisions and whose outcome is a patient who is responsible for the management of his/her illness.	Wentzer et al., 2013 ⁽²²⁾
Empowerment is the process of people obtaining the knowledge and skills that enables them to become active partners with professionals in making informed decisions and choices about their own treatment and care and of enabling communities to exert informed influence on the health system.	Farrel & Gilbert, 1996 (cited by Boudioni et al., 2012) ⁽²³⁾

Source: authors' own elaboration, Barcelona, Spain, 2015.

Chart 2 – Dimensions of empowerment found by the review – Barcelona, Spain, 2015.

Dimensions	References
Participation in decision-making	Small et al., 2013 ⁽⁹⁾ Fotoukian et al., 2014 ⁽¹⁴⁾ Ouschan et al., 2000 ⁽²⁵⁾ Salmon et al., 2004 ⁽²⁸⁾
Gaining control	Small et al., 2013 ⁽⁹⁾ Fotoukian et al., 2014 ⁽¹⁴⁾ Ouschan et al., 2000 ⁽²⁵⁾ Aujoulat et al., 2008 ⁽²⁶⁾ Oh et al., 2012 ⁽²⁷⁾ Salmon et al., 2004 ⁽²⁸⁾
Knowledge acquisition	Aghili et al., 2013 ⁽²⁴⁾ Ouschan et al., 2000 ⁽²⁵⁾ Aujoulat et al., 2008 ⁽²⁶⁾
Coping skills	Fotoukian et al., 2014 ⁽¹⁴⁾ Aghili et al., 2013 ⁽²⁴⁾ Salmon et al., 2004 ⁽²⁸⁾
A positive attitude	Salmon et al., 2004 ⁽²⁸⁾
Sense of meaning to patients' experience with disease	Aujoulat et al., 2008 ⁽²⁶⁾
Motivation	Oh et al., 2012 ⁽²⁷⁾
Trust	Oh et al., 2012 ⁽²⁷⁾
Self-care	Fotoukian et al., 2014 ⁽¹⁴⁾ Aghili et al., 2013 ⁽²⁴⁾
Sharing and capacity building	Small et al., 2013 ⁽⁹⁾

Source: authors' own elaboration, Barcelona, Spain, 2015

EMPOWERMENT MEASURES

Ten empowerment measures were selected from the literature. The context in which these tools were applied and the operationalized constructs are described in Chart 3. Four tools were developed in the United States^(29,31,33-34), four in Great Britain^(9,30,32,35), one in Australia⁽¹³⁾, and one in Iran⁽²⁴⁾.

All but one of the tools⁽³¹⁾ are setting (primary health care^(9,32) and hospital care⁽³⁰⁾) or condition-specific. With respect to the condition-specific tools, one addressed mental health⁽³³⁾, two diabetes^(24,29), two cancer^(13,34), and one clinical genetics⁽³⁵⁾. One of the tools⁽³⁴⁾ addressed two levels of specificity since it assessed cancer patients in virtual spaces.

Chart 3 – Measures of empowerment found in the reviewed articles – Barcelona, Spain, 2015.

Measure	Context	Dimensions measured	Reference
Patient empowerment in long-term conditions	Specific: primary care and patients with chronic diseases	Positive attitude and sense of control, knowledge and confidence with respect to decision-making, sharing and enabling others.	Small et al., 2013 ⁽⁹⁾
Patient Empowerment Scale (PES)	Specific: cancer	Coping strategies and self-efficacy.	Bulsara et al. 2006 ⁽¹³⁾
Diabetes empowerment questionnaire	Specific: diabetes	Knowledge, self-care, coping.	Aghili et al., 2013 ⁽²⁴⁾
Diabetes Empowerment Scale (DES)	Specific: diabetes	Managing the psychosocial aspects of disease (self-management and coping), openness to change, ability to define and set objectives.	Anderson et al. 2000 ⁽²⁹⁾
Patient Empowerment Scale (PES)	Specific: hospital care	Identification of activities that illustrate empowerment and disempowerment in relation to the nurse/patient relationship.	Faulkner, 2001 ⁽³⁰⁾
Patient Activation Measure (PAM)	Generic	Skills, knowledge, and beliefs needed by patients to self-manage, collaborate with healthcare providers and maintain their health.	Hibbard et al. 2004 ⁽³¹⁾
Patient Enablement Instrument (PEI)	Specific: primary care	Aspects of perceived control over illness.	Howie et al. 1998 ⁽³²⁾
The Empowerment Scale (ES)	Specific: mental health	Self-efficacy, perceived power, optimism-control over the future, and community activism.	Rogers et al. 1997 ⁽³³⁾
CIDES: Cyber Info-Decisional Empowerment Scale	Specific: cancer patients who manage the disease through a network	Knowledge, participation, decision-making.	Seçkin, 2011 ⁽³⁴⁾
Genetic Counselling Outcome Scale	Specific: clinical genetics	Perceived personal control (decisional and behavioral control), hope and emotional regulation.	McAllister et al. 2011 ⁽³⁵⁾

Source: Authors' own elaboration, Barcelona, Spain, 2015.

DISCUSSION

DEFINITION AND DIMENSIONS

With respect to the first definition in terms of chronological order⁽¹²⁾, which regards empowerment as a social process of recognizing, promoting, and enhancing people's abilities to meet their own needs, solve their own problems, and mobilize the necessary resources in order to feel in control of their own lives, it can be observed that it contains three characteristics that are present in other definitions: for empowerment to occur, patients must have prior abilities^(9,12), and empowerment is both a process^(3,5,7-9,11,13,16-19) and outcome^(3-11,13-19). With respect to prior abilities, only one author⁽⁹⁾ highlights which abilities help patients to accept the disease.

With regard to process, the majority of authors regard empowerment as a communicative process that is developed between health professionals and patients^(7,9), involving helping partnerships^(20,23), a collaborative⁽²¹⁻²²⁾ patient-centered approach⁽¹⁷⁾, and fair and equal relationships⁽¹⁸⁾. The process should be guided by exchange of information involving knowledge and skill sharing^(9,14-15,22,26), coping strategies^(9,13), and should include motivational elements^(12,15).

For the majority of authors, self-efficacy is considered an outcome of empowerment, while some^(11,14) suggest that it is acquired during the process and that it is a necessary element for patient participation in decision-making, which is seen as the final outcome of empowerment.

Certain authors suggest that the outcome of empowerment are changes in the patient's condition^(7,9,21), while others propose that the ultimate goal of empowerment is patient self-management^(8,12,14,21-22), self-efficacy⁽⁸⁻⁹⁾, self-care⁽¹⁴⁾,

control over the situation^(8-9,13,16,19,20), participation in decision-making^(10-11,18,20,22), and shifting the balance of power in health professional-patient relationships⁽¹⁵⁾.

Only one author⁽²³⁾ considers empowerment at both the individual and community level, suggesting that an empowered patient can exert influence on the health system.

The dimensions reflect outcome indicators taken from the definitions, such as participation in decision-making and control, and process indicators expressed in terms of results, such as knowledge acquisition and coping skills.

Only one author⁽⁹⁾ incorporates sharing and enabling others, which is used along the same lines as community psychology. Other authors^(13,22) highlighted the importance of sharing the experience of the illness with peers in relation to feeling "more powerful", though did not refer to this as a dimension.

Self-efficacy as an outcome of the process of empowerment is one of the most frequently used concepts in the definitions; however, contrary to the concept of control and participation in decision-making, the term is not referred to as a dimension. This could be due to the fact that, despite being contextualized at different levels, efficacy and empowerment are overlapping concepts that have very similar attributes. Self-efficacy is seen as a concept employed at individual level, linked to personal levels of performance, and which has a clearly psychological component⁽⁴¹⁾, while empowerment has psychological, social and political elements and is used to describe personal variables, care practices and the characteristics of the system^(4,33,36).

MEASURING TOOLS

Given that the key concept was patient empowerment, only nine out of the 10 abovementioned measures were examined

in order to evaluate the conceptual model. Seven tools provide a definition of the concept being evaluated, five define the concept of empowerment^(9,13,24,29,35), one the concept of enablement⁽³²⁾, and one activation⁽³¹⁾. Based on the definitions and dimensions suggested by the authors, the latter two concepts may be considered synonyms of empowerment.

Two tools^(9,24) outline the dimensions of the concept and its corresponding indicators. Others describe what could be considered dimensions, but which the authors term as domains⁽³³⁾, principles⁽²⁹⁾, themes^(13,31), or concepts⁽³⁵⁾.

For the purpose of the analysis, all were considered dimensions regardless of the terminology used for the operationalization, since the review showed that these terms were repeated in various measures, as shown in Chart 4.

Based on this criterion, the following tools could be said to provide a robust measure of patient empowerment: DES-28, PAM, PES2, GCOS-24, Patient Empowerment in long-term conditions, and the Diabetes empowerment questionnaire.

CONCLUSION

The findings of this literature review suggests that empowerment is a widely-used concept that has a major influence on health care, and highlights the multiple attempts to design empowerment strategies within education programs, operationalize the concept and develop tools and enable the measurement of empowerment in all its dimensions.

Based on the different definitions and dimensions analyzed by this review, it can be concluded that empowerment in the context of patients with chronic disease is a concept employed at individual level, which is regarded as both a process and an outcome. Empowerment may be seen as an enabling process whereby health care professionals collaborate with patients to help them acquire knowledge and resources and whose outcome is a patient with greater ability to exercise control, manage his/her condition and to make informed decisions.

Empowerment demands a paradigm shift in health care: the challenge lies in how to incorporate the concept into health care practice. Understanding strategies for increasing patient health literacy is not enough to foster empowerment. If the end goal is behavioral change, it is necessary to incorporate motivational strategies.

It is important to highlight the importance of developing patient empowerment measures that capture the above dimensions while encompassing the three levels of the concept: at a basic level, during the process, and at the outcome level. However, this analysis illustrates once again the complexities involved in developing an overarching generic measure translated into different languages that enables comparison between empowerment strategies at international level.

RESUMO

Objetivo: Analisar as definições e as dimensões do conceito de empoderamento. Identificar os pontos fortes e fracos dos instrumentos de medição de empoderamento a partir do seu modelo conceitual. **Método:** Revisão integrativa da literatura nas bases de dados MEDLINE e Cumulative Index to Nursing and Allied Health Literature (CINAHL). **Resultados:** Foram selecionados 29 artigos, 17 definições de empoderamento, sete propostas de dimensões e 10 instrumentos de medição. Empoderamento pode ser concebido como um processo de formação e habilitação em que se transfere o poder de um indivíduo a outro, ou como resultado/produto desse processo; as dimensões refletem indicadores de resultados, tais como a participação na tomada de decisões e assumir o controle; e os indicadores relativos ao processo referem-se à aquisição de conhecimentos e às habilidades de enfrentamento. Dos instrumentos analisados, seis têm maior robustez. **Conclusão:** Propor uma definição de empoderamento que possa ajudar a melhorar a compreensão do termo e, assim, operacionalizá-lo.

DESCRIPTORIOS

Participação do Paciente; Poder; Autoeficácia; Tomada de Decisões; Autonomia Pessoal; Revisão.

RESUMEN

Objetivo: Analizar definiciones y dimensiones de empoderamiento. Identificar fortalezas y debilidades de los instrumentos de medida de empoderamiento respecto al modelo conceptual. **Método:** Revisión integrativa de la literatura en las bases de datos MEDLINE y Cumulative Index to Nursing and Allied Health Literature (CINAHL). **Resultados:** Fueron seleccionados 29 artículos. Se identificaron 17 definiciones, 7 propuestas de dimensiones y 10 instrumentos de medida. Empoderamiento puede ser un proceso de capacitación o habilitación en el que se transfiere el poder de un individuo a otro, o bien un resultado producto de ese proceso. Las dimensiones reflejan indicadores de resultados como son la participación en la toma de decisiones y tomar el control, e indicadores relativos al proceso como son la adquisición de conocimientos y las habilidades de afrontamiento. De los instrumentos analizados seis son los instrumentos que presentan mayor robustez. **Conclusión:** Se propone una definición de empoderamiento que puede ayudar a mejorar la comprensión del término y por lo tanto a operacionalizarlo.

DESCRIPTORES

Participación del Paciente; Poder; Autoeficacia; Toma de Decisiones; Autonomía Personal; Revisión.

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