

Patient Empowerment and its neighbours: Clarifying the boundaries and their mutual relationships

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1. Introduction

In the last decades, Patient Empowerment has become a key priority for policy-makers under the premise that it would increase the sustainability of present paradigms of care delivery [46,63,11,13]. As a result, a variety of initiatives that aim at “empowering” patients in self-management [11] and shared decision-making [54] have been implemented in the most developed Countries.

Despite the wealth of studies, however, there is lack of consensus on the initiatives, inputs and conditions that patients and providers can adopt to obtain patient empowerment [5,14,35]. Two problems explain this struggle. First, the very concept of “patient empowerment” is ambiguous. Because of the vagueness and variability of its manifestations in different clinical and social contexts, the term has acquired multiple meanings and uses [4,35,54]. It is thus difficult to pool together evidence that patient empowerment improves the effectiveness and efficiency of care, since studies on this topic measure different phenomena. Second, it is unclear how patient empowerment is related to neighbouring concepts such as patient

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involvement, participation, enablement, engagement, and activation [40,11,21,31]. These concepts are sometimes treated as synonyms, other times in contraposition, yet others as unrelated concepts. As a result, we have a lot of valuable evidence that remains dispersed because different research streams struggle to communicate.

Our study seeks to address these problems by providing an in-depth analysis of the concepts that refer to patient empowerment, involvement, participation, enablement, engagement, and activation. The purpose of this study is to define neater boundaries between these concepts as well as to identify their mutual relationships in order to avoid further ambiguities and allow a reliable analysis of the evidence collected. Methodologically, we will present a review of contributions dealing with these terms in order to: (i) disentangle the multiple uses of each concept in the literature, and (ii) clarify overlaps between the concepts and identify mutual relationships, similarities and differences. Our study concludes with a state-of-art concept map of the extant terminology and with indications for future research.

2. Methods

We performed a review of studies dealing with patient empowerment and neighbouring concepts. Our review followed three steps.

In the first step, we performed a keyword-based search of studies in PubMed Database. We initially adopted MeSH controlled vocabulary to index articles. However, existing MeSH terms produced unstructured and out-of-focus results. Then, we adopted an ad-hoc keyword strategy to article titles/abstracts. The keywords were based on the terms “patient empowerment”, “patient activation”, “patient engagement”, “patient enablement”, “patient involvement”, and “patient participation”. We adopted three inclusion criteria. First, we included studies that investigated empowerment with the perspective of patients, possibly along with that provided by professionals. We excluded studies that investigated only the implications of patient empowerment on health professionals; and studies on professional empowerment as they were out of scope. Second, we included studies that embedded elements helpful to understand the meaning of constructs. Third, we considered articles, articles in press or reviews in English, published between 1990 and 2013.

In the second step, we included studies cited in the selected papers and that stood outside the PubMed Database.

Finally, in the third step, we checked studies that have cited the selected papers and were consistent with our inclusion criteria.

The review process identified 3088 eligible studies from all the keywords. We filtered the studies by scanning their titles and abstracts and selecting those consistent with the aforementioned inclusion criteria, resulting in 986 articles. Full-texts were assessed with the same criteria, to discard out-of-scope documents, resulting in 293 articles. Duplicates were then removed, so the final number was 286.

Fig. 1 outlines the number of papers considered at each of these stages.

We conducted the data analysis in four steps. First, we built clusters of studies according to the concepts used, thus separating from each other studies dealing only with patient empowerment, activation engagement, enablement, involvement, or participation. We then performed a within-cluster analysis, collecting and comparing the definitions and meanings of a given concept (e.g., patient engagement) across studies. At this stage, we could identify for each concept a number of diverse definitions/meanings, and then investigate common elements and differences across studies. Later, we performed a between-cluster analysis, i.e., we compared the diverse concept definitions and meanings with each other in order to sort out differences between concepts, and/or identify possible overlaps, and/or identify their relationships. Last, we developed a concept map that draws out boundaries between the different concepts and outlines mutual relationships.

3. Findings

A general overview of findings provides two preliminary insights: (i) the limited use of explicit definitions, and (ii) the presence of overlapping definitions and meanings that limit the possibility to demarcate the concepts.

Table 1 provides an overview of the first problem.

An explicit, or referenced, definition of the concept under investigation has been clearly stated in only 17% of studies about “patient involvement”, 29% about “patient engagement”, 30% about “patient enablement”, and 42% about “patient empowerment. The lack of definitions is not necessarily problematic, since it might indicate that the field already takes for granted a concept definition and no longer needs to reference it in its studies. This is however not the case with the definitions of patient empowerment, engagement, enablement and involvement since all concepts have no shared agreement, but rather overlap with others. Studies on “patient activation” showed a different pattern, with 72% of studies reporting an explicit definition, due to an increasing acceptance (and thus referencing) of Hibbard’s [26–28] theorization.

We observed concept overlaps by counting the times a concept was used as a synonym to others in the same study. This problem is most apparent with “Patient engagement” (48% papers), “activation” (39%), and “empowerment” (33%). The case of “patient activation” is notable because its definition has consolidated over the years, but there is still a recurrent overlap with “patient engagement” and “empowerment”. Building on these premises, we can outline the definitions collected on each concept.

3.1. Patient empowerment

Past research has developed three interpretations of patient empowerment as (i) *emergent states* that allow patients to have an active role in their own care; (ii) *processes* leading to patients’ acquisition of these emergent states; (iii) *behaviours* through which patients participate in self-management and shared decision-making (Fig. 2).

Table 1

Obtained results on the basis of key contents searched.

	No. studies	Definitions occurrence	Without definitions	With health outcomes reported	With unclear definition or relationship with other concepts
Empowerment	64	27 (42%)	37 (58%)	20 (31%)	21 (33%)
Involvement	96	16 (17%)	80 (83%)	34 (35%)	18 (19%)
Activation	46	33 (72%)	13 (28%)	25 (54%)	14 (39%)
Engagement	21	6 (29%)	15 (71%)	13 (62%)	10 (48%)
Enablement	40	12 (30%)	28 (70%)	8 (20%)	4 (10%)
Participation	19	14 (74%)	5 (26%)	13 (68%)	3 (16%)
Total	286				

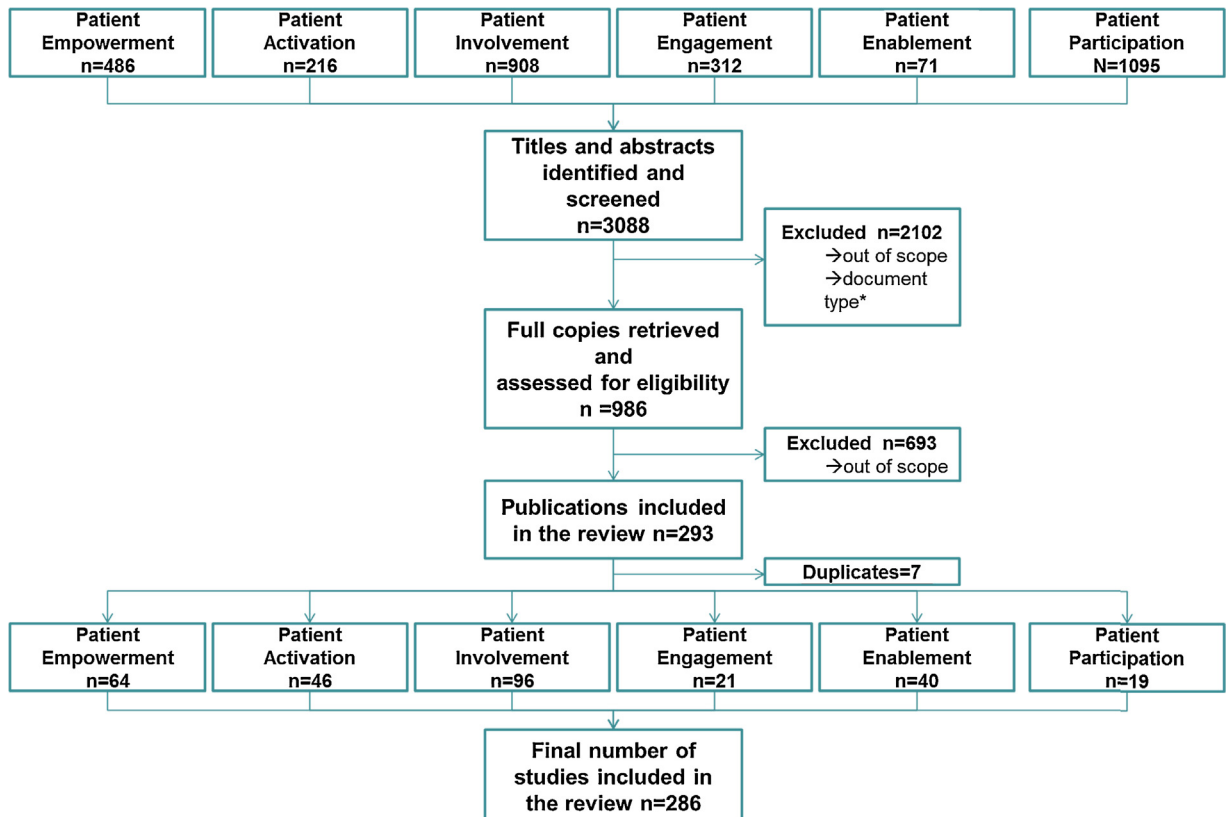
3.1.1. Patient empowerment as “emergent state”

Several studies draw upon psychological research to explain empowerment as the possession of cognitive, motivational and affective conditions [42,48] – i.e. *emergent states* [41] – that allow self-care and shared decision-making.

A seminal definition indicated empowerment as “the ability of people to gain understanding and control over personal, social, economic and political forces in order to take action to improve their life situations”; p. 37. This definition was enlarged by [35] who defined patient empowerment as the possession of knowledge, skills, *attitudes and self-awareness*. This definition: (i) enlarges the notion of empowerment as the possession of both ability and motivation to improve their own life, and (ii) highlights in the nature of the ‘ability’ (a combination of knowledge

and skills) and ‘motivation’ (a combination of attitude and self-awareness). Empowerment thus represents the possession of conditions that make patients “willing and able” to play an active role in their care. Ability and motivation are necessary but not sufficient conditions for patients’ development of ‘power’. Patients are in fact ‘empowered’ when they are ‘willing and able’ to restore a balance of ‘power’ with providers, but also when providers delegate responsibilities to patients [20,24].

Several works replicated this definition or provided few changes that did not question the overall interpretation (e.g., [10,60]). Ref. [3] and [46] observed that patient empowerment could be defined also “by its absence, for example in terms of helplessness, paternalism and dependency, as well as more actively, as a feeling of having greater control over one’s life” (p. 1763).

**Fig. 1.** Extraction and selection process of relevant documents.

Process of “empowering” patients		State of “being empowered”		Empowered behaviors	
Reference	Definition	Reference	Definition	Reference	Definition
From Redman, 2007, p. 247	<i>Patient empowerment is [defined] as helping patients discover and use their own innate ability to gain mastery over their disease. [Empowerment] educates patients to make informed decisions and to set behavioral goals to make changes of their own choosing. The ethos of empowerment affirms patients as experts in their own learning needs and as able to solve their own problems.</i>	From Johnston Roberts et al., 1999, p. 85	<i>Patients are empowered when they have the knowledge, skills, attitudes, and self-awareness necessary to influence their own behavior and that of others... to improve the quality of their lives</i>	From Shearer et al., 2007, p. 160	<i>Empowerment is “a complex and participatory process of changing oneself and one’s environment, recognizing patterns, and engaging inner resources for well-being.</i>
From Aujoulat et al. 2008, p. 1229	Patient empowerment is [defined] as a process of behaviour change, with a focus on how to help patients become more knowledgeable and take control over their bodies, disease and treatment. [Empowerment] is viewed as a process of “activating” patients	From Anderson and Funnel, 2010, p. 278	<i>Empowerment-based interventions include both a process and an outcome component... The outcome component occurs when there is a measurable increase in the patient’s ability to make autonomous, informed decisions.</i>	From Protheroe et al., 2008, p. 44	<i>Empowerment is used in a general sense to focus on individual actions in engaging with health care and in health care settings, and is closely aligned to a social psychological perspective of individuals’ developing control over their own lives</i>
From Anderson and Funnel, 2010, p. 277	<i>[Empowerment] is process designed to facilitate self-directed behavior change...(empowerment) is a process when the purpose of an educational intervention is to increase one’s ability to think critically and act autonomously</i>	From Holmström and Röing 2010, p. 168	<i>[The concept of empowerment] has been used to describe a relationship between health and power, based on the assumption that individuals who are empowered are healthier than those who are not. Secondly[to describe patients] who may become empowered via health education programmes initiated by healthcare systems, or one who may become empowered via their interactions with healthcare providers.</i>		
From: Hudon et al., 2011, p. 144	<i>In the health care context, individual empowerment includes the enablement process (professional intervention aiming to recognize, support and emphasize the patients’ capacities to have control over their life) and the appropriation process (results of this intervention on the patients)</i>				

Fig. 2. Selected definitions for patient empowerment according to the three perspectives.

3.1.2. Patient empowerment as “process”

Patient empowerment has been defined also as the process leading to personal transformation [7,45]. Ref. [4], for instance, defined patient empowerment as “a process designed to facilitate self-directed behaviour change” (p. 277). The attention shifts on the activities and inputs that increase patients’ ability and motivation—e.g., “education, counselling, patient-centred care, and use of community coaches”, [53] p. 160.

The dual view of patient empowerment as both emergent state and process underlies the notions that “knowledge, skills, attitudes and self-awareness” do not emerge spontaneously, but from socially-constructed development processes where such knowledge, skills and attitudes are provided and evaluated differently by patients and providers, as well as valued differently by different kinds of patients. Furthermore, “empowerment-based interventions include both a process and an outcome component. [The] process component occurs when the true purpose of the intervention is to increase the patient’s capacity to think critically and make autonomous, informed decisions. [The] outcome component occurs when there is a measurable increase in the patient’s ability to make autonomous, informed decisions”; p. 278.

This dual view has generated a few concerns due to unwarranted confusion between different meanings. Ref. [31], for instance, observed it could be “confusing because it can represent patient’s outcome after the *enablement process*”, i.e. “professional intervention aiming to recognize, support and emphasize patients’ capacities to have control over their life” (p. 1301). Ref. [11] also

suggested important overlaps between ‘empowerment’ and ‘enablement’ as they both indicate processes that get patients to “know,” “be able,” and “want”. Few studies have thus proposed to distinguish the ‘patient empowerment’ process into an “enablement process [and] an appropriation process” [32]; p. 144.

3.1.3. Patient empowerment as an “active behaviour”

A third interpretation conceives patient empowerment as the actual *behavioural change* that follows the acquisition of “knowledge, skills, attitudes and self-awareness”. Patient empowerment does not reflect a state of “being empowered” or a process of “getting empowered”, but the “exploitation” of power in real-life contexts, where the patients assume the responsibility of self-care and decision-making [7,29]. Ref. [57], for instance, defined empowerment as “a complex and participatory process of changing oneself and one’s environment, recognizing patterns, and engaging inner resources for well-being” (p. 160).

These definitions consider a strong continuity between patients’ acquisition of relevant ability and motivation and their participation, possibly suggesting that, on one hand, participatory behaviours signal that patients have acquired sufficient “knowledge, skills, attitudes and self-awareness”; and, on the other hand, patients who have sufficient “knowledge, skills, attitudes and self-awareness” would eventually participate in self-care and shared decision-making. Both interpretations have met a few reservations, and two arguments suggest caution in equating empowerment with participation.

First, empowered patients do not necessarily undertake the responsibility of self-care. Ref. [46] suggested to appreciate non-participation as appropriate in specific cases and context; “individuals can be assertive in some interactions with health professionals and on other occasions give responsibility over to health professionals when they are in pain, or highly anxious about the safety of a loved one. At these times they may value ‘being cared for’ more highly than being ‘empowered’. Rather than viewing the need to be cared for as a weakness, or associating it with childhood, it could be viewed as a human state which different people occupy at different times” (p. 1770).

Second, undertaking the responsibility of self-care or shared decision-making is not by itself a proof of being empowered. Ref. [55] observed that “allowing patients to participate in health-related decisions [without] taking care they have the necessary abilities [puts] them in jeopardy. And giving them these abilities without granting them responsibility frustrates them and costs money” (p. 9). Similarly, problems in patient-professionals entailed by bad literacy explains why “members of the medical profession have seen the move towards the expert patient as a threat, representing a loss of power within the consultation, in which a patient grasping print-outs from the Internet entails a time-consuming negotiation of illness management” ([18], p. 1307).

A few experiences are providing fuel to the criticism that patients/citizens might grow extensive self-awareness and attitude (i.e., feel empowered) and thus challenge providers’ decisions, participate in self-care and exert power in policy-making—without however having appropriate knowledge and skills that would lead to appropriate involvement (e.g. [1,37]).

These commentaries suggest the opportunity to demarcate more strongly between “being empowered” (emergent state and process) and “exerting power” (active behaviour). The latter definition appears in fact disconnected from the other two. The former two interpretations emphasize the all-inclusive acquisition of self-awareness, attitude, power and knowledge and skills, while the latter interpretation does not. In doing so, “being empowered” embeds an intrinsically positive view of patient empowerment (i.e., quality and efficiency of care would improve because patients know more and are more aware); “exploiting power” appears more problematic (i.e., patients exploit power more, and this might improve or deteriorate the quality and efficiency, depending on if and how patients possess adequate knowledge).

Drawing upon this, we decided to privilege the former two interpretations as more consistent with (and more relevant for) policy-makers who pursue care improvements through better-informed decisions and self-care from patients; and to adopt other, neighbouring concepts, such as patient involvement and participation, to evaluate if and how patients use their power in practice.

3.2. Patient activation

Patient activation has a quite clear and universally recognized definition (e.g., [26–28,34]): “an activated patient is someone who knows how to manage their condition

and maintain functioning and prevent health declines; and they have the skills and behavioural repertoire to manage their condition, collaborate with their health providers, maintain their health functioning, and access appropriate and high-quality care”; p. 1010. In a subsequent study,[27] defined activation as a process through which patients become aware of their role. Ref. [58] synthesized four steps: “(1) patients believe they have important roles to play in managing their conditions, (2) they possess the knowledge needed to manage their health, (3) they take action, using their skills and behavioural repertoire to maintain their well-being, and (4) they stay the course under stress” (p. 458).

The relationship between activation and empowerment is straightforward. Both concepts relate to an increased ability and motivation [2, 23] and growing patient awareness of having an important role in the management of own healthcare [16]. Ref. [7] observed that the definition of patient empowerment as a process emphasizes “how to help patients become more knowledgeable and take control over their bodies, disease and treatment. In this definition, empowerment is viewed as a process of ‘activating’ patients, who as a result of rejecting the passivity of sick role behaviour and assuming responsibility for their care [are] more knowledgeable about, satisfied with, and committed to their treatment regimens” (p. 1229).

The definitions of patient activation and empowerment thus manifest important overlapping areas to such an extent that it is unclear whether some conceptual differences do exist or they are synonyms. To clarify this situation, we move to compare their measurement scales. Patient empowerment measures typically refer to a broad lifestyle domain, collecting information on patients’ “self-efficacy, perceived power, optimism about and control over the future, and community activism”, p. 933, with items like “I feel powerless most of the time”, “I am often able to overcome barriers”, “I am generally optimistic about the future” [50]. Patient activation measures refer instead to a tighter domain, collecting information on patients’ knowledge, skills, and motivation on specific healthcare-related behaviours, rather than on life-style. Ref. [23], for instance, employed items such as “How confident are you that you can follow through on medical treatments you need to do at home?” and “How much do you know about why you are supposed to take each of your prescribed medicines?” Comparing the two concepts, thus, it can be argued that patient empowerment has a larger connotation than activation. The acquisition of ‘ability and motivation’ does not involve exclusively a capacity to make decision on the specific diseases but in life as a whole. Activation instead is more focused on precise and specific improvement goals.

3.3. Patient enablement

The most recurrent use of ‘patient enablement’ is linked with the process of “enabling” patients, by (i) providing appropriate knowledge, skill and abilities to understand their condition and make decisions; and (ii) developing appropriate contexts that allow patients to learn such knowledge, skill and abilities [30, 64, 65, 47]. Ref. [31] defined enablement as an intervention by which the

healthcare provider recognizes, promotes and enhances people's ability to control their health and life. Accordingly, studies have focused on what would make patients "able" to play an active role in their care. Enabling interventions have been understood as a "contribution to the therapeutic relationship, consideration of the person as a whole, valorization of the person's strengths, broadening of the possibilities, facilitation of learning, implication and support to decision making" [32,33].

The concept of enablement has also been used in the context of clinical consultations [44] to reflect a patient's emergent state and, in particular, "the gained measure in which patients understand their health conditions and feel able to cope with them"; p. 396.

While past research on enablement does not provide a clear-cut distinction with empowerment, this can be inferred from its definition. Patients are "enabled" when they are able to participate in self-care or shared decision-making, but not necessarily the motivation and power. As such the concept of "enabled patient" can be considered as a subset of the more comprehensive concept of "empowered patient".

3.4. Patient engagement

Patient engagement has rarely received an explicit and precise definition. Amidst the paucity of definitions, however, two distinct interpretations can be recognized [12,39,62]: (i) patient engagement as the participation of patients in self or shared management, i.e. engagement as the consequence of empowerment; (ii) the behaviours that patients perform to improve their role in healthcare, i.e. engagement as a cause of empowerment.

These interpretations typically coexist in the same study. Patient engagement has in fact a recursive relationship with empowerment, i.e. patients need to be engaged to increase their power in the relationship with the professionals, but also need to have enough power to engage in self-management. The achievement of a high level of empowerment (or activation) thus depends on health interventions that stimulate engagement in the healthcare system [16], while patients are asked to maintain a steady engagement to preserve their empowered relationship.

Research has dedicated a specific attention to identify the "actions individuals must take to obtain the greatest benefit from the healthcare services available to them", p. 351. The authors developed an 'engagement behaviour framework' that describes what patients might do to gain most benefits from their care. The list includes behaviours for an 'active engagement in managing health' – e.g., healthy behaviours and chronic disease self-management behaviours – and for 'managing healthcare' – e.g., making appointments, fortifying relationship with healthcare professionals, searching for the appropriate healthcare setting, staying informed about potential follow-up treatment option. As a whole, the 'engaged patient' appears at its best when s/he deploys a strong *motivation* to become more knowledgeable (e.g., by preparing in advance questions, gathering additional expert opinions) and more 'powerful' (e.g., by fortifying the relationship with the professionals, by seeking more appropriate settings and providers).

3.5. Patient participation/involvement

The terms involvement and participation have been often used interchangeably to describe patients "taking an active part in their consultations with professionals [with-out] a clear understanding of their difference" (p. 1299. In this regard, [61] provided a notable contribution in three aspects.

First, the study provides a conceptualization of patient participation and involvement, distinguishing "patient participation from the precursor concepts of involvement (basic, often delegated tasks) and collaboration (intellectual co-operation) and the ultimate concept of partnership (joint venture)"; p. 1299. Collecting patients' views on involvement through interviews and focus groups, [61] regarded involvement as the "degree to which patients take part in the decision-making process connoting a degree of transfer of power from the professional to the patient in the form of increased knowledge, control and responsibility" (p. 1308). The taxonomy emphasizes how patient involvement differs if determined by patients rather than professionals. Specifically, the author distinguished four levels of involvement determined by patients (i.e., non-involvement, information-seeking, information-giving and autonomous decision-making) from five diverse levels determined by professionals (i.e., exclusion, information-giving, consultation, professional-as-agent and informed decision-making). Participation represents a different sub-set of involvement—one that is co-determined by both patients and professionals and materializes in the forms of dialogue or shared decision-making. It follows that making autonomous decisions is *not* participation if patients and professionals do not engage in two-way communication.

Second, the study emphasizes that there is no intrinsically "superior" or "preferred" form of involvement, but this depends on what a specific patient desires in a specific situation. It follows that patients might reasonably express their empowerment in a conscious decision to remain detached from involvement. As the author highlights, even "apparently passive positions adopted by patients can belie a potential for more assertive articulation of involvement should it be deemed appropriate and worthwhile" (p. 1306).

Third, the study implies connections between the concepts of patient involvement/participation and empowerment. It is argued that each degree of involvement is connected with different patients' level of power either granted by the professional or acquired by the patient. At the lowest level, patients are *excluded* from the decision-making process when exposed to professionals' paternalism. At the highest, patients have the technical expertise as well as the responsibility to make the final decision. It follows that, from one perspective, patient involvement is an antecedent of patient empowerment and, from another, one of its consequences. On one hand, professionals' involvement of patients involves the transfer of competence, responsibilities and awareness to patients to support autonomous, shared or informed decision making. In this perspective, patient participation is linked with "a narrowing of the information/competence gap between professional and patient, with some surrendering of power by

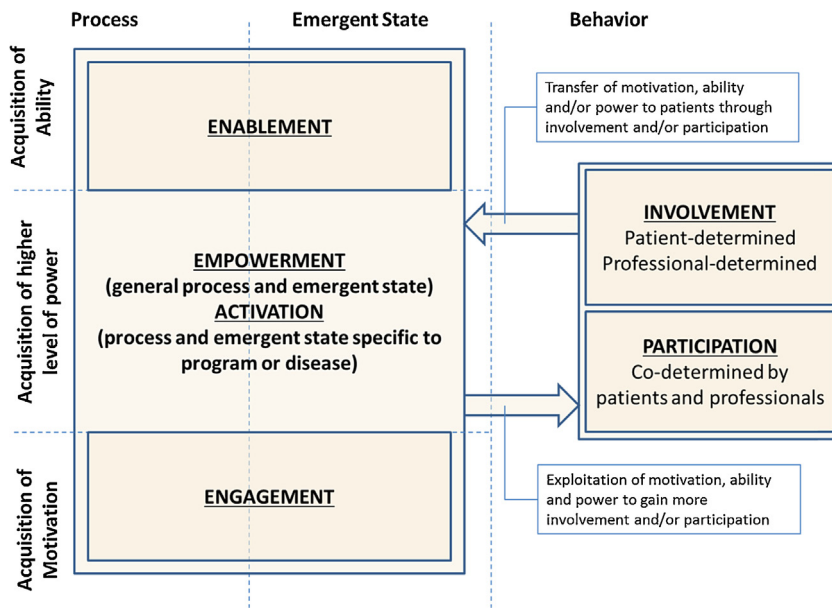


Fig. 3. Representation of a tentative concept mapping.

the professional which conveys benefit to the patient, even if there is no consensus" (p. 1299). Likewise, [59], observed that: "greater involvement in decision making, however, places increased demands on a patient's literacy skills, in order to understand complex health information and articulate their preferences" (p. 1806). These quotes reflect the notion that patient participation follows a process of *enablement*, i.e. narrowing the information/competence gap. On the other hand, professionals' empowerment might become the premise for stronger involvement. Once patients have acquired more knowledge, skills and awareness, in fact, they are more likely to challenge paternalistic approaches and demand a bigger role in decision-making. Further interpretations of involvement coexist in the field. Some studies reconsider the link between involvement and participation. Ref. [36] regarded involvement as a combination of public participation (i.e., involvement in decision-making processes) and private participation (i.e., involvement in self-care and treatment). Other studies pointed out more relevant shifts in meaning, especially when associated with "patient involvement". In these studies, involvement relates to those activities that could help patients to reach a more active role in choices about own healthcare (e.g., [8,19]). Here, patient involvement is interpreted as "getting patients involved", by providing information on national standards and possible treatment, quality of service delivery, patient satisfaction and consultations with healthcare professionals [15]. Likewise, participation is "where professionals and patient values are integrated to arrive a final decision", p. 19 and where professionals can inform patients about health conditions, treatments, risks, etc. and take into account their preferences and opinions [59,49]. Patient involvement and participation are thus regarded as antecedents, and not consequences, to patient empowerment. The coexistence of these meanings suggest a recursive role

between involvement and empowerment, whereas (i) patient involvement is an effect of empowerment, because the latter develops the possibility for patients to participate in decision-making [43] and, in turn, (ii) patient involvement in self-care and decision making reinforces patients' power by consolidating their ability and motivation [56].

4. Concept mapping

Despite the fact that each concept has acquired multiple interpretations in past research, the results allow delineating a tentative concept mapping for patient empowerment, activation, enablement, engagement, involvement, and participation. We propose a concept map that marks neater distinctions and connections between the concepts (Fig. 3). We embed the concepts across two dimensions: (i) the nature of the construct (i.e., it represents a process, an emergent state or behaviour); and (ii) the focus of the definition (i.e., the acquisition of ability, motivation or power).

The review highlights how the concept of patient empowerment entirely embraces these dimensions, but also that the concept is best captured by process-related and state-related interpretations. The behavioural interpretation generates instead a few important ambiguities that can be avoided by considering patient participation (and involvement) as the measure for the actual behavioural change.

As a result, we made sense of the varied interpretations of patient empowerment, by combining key definitions into the following: "*Patient empowerment is the acquisition of motivation (self-awareness and attitude through engagement) and ability (skills and knowledge through enablement) that patients might use to be involved or participate in decision-making, thus creating an opportunity for higher levels of power in their relationship with professionals*".

Patient activation can be conceived as a subset of the larger concept of patient empowerment. Both concepts imply the need to develop ability, motivation and power; and both aim at changing patients' role from passive care recipients to active agents with power and control. The main difference lies in the application: while patient empowerment refers to a general emergent state, activation refers to specific diseases or programs.

The notion of patient empowerment and activation is where the concepts of enablement and engagement should converge. Patient enablement regards the acquisition of sufficient knowledge and skills for meaningful self-management, but not necessarily sufficient motivation. Engaged patients are instead those who express a strong motivation, but do not necessarily have already sufficient ability and power for self-care. We can thus conceive "empowered patients" to result from enablement and engagement processes.

Last, we observed two reasons not to associate patient empowerment and activation to active behavioural change. First, a few contributions suggest the conceptual difference between having power and translating it into an actual behaviour ([6,42]). Second, we have at our disposal the consolidated notions of patient participation and involvement which represent unambiguously their role in shared decision-making and self-care. We thus propose to consider patient participation and involvement as the unambiguous concepts for the actual behaviours (ranging from information seeking to shared decision making and self-care). We consider a bi-directional link between patient empowerment/activation and involvement/participation as: patients' acquisition of power, ability and motivation elicits demands for more involvement or participation; while patient involvement or participation supports the continuous improvement of patients' ability, motivation and power.

5. Implications for future research

The concept mapping suggests three directions for future research that might improve our understanding of patient empowerment. We specifically suggest four directions for future research.

5.1. *Research direction 1: Explore the link between engagement/enablement and empowerment*

Several studies have addressed the development of patient empowerment. Yet, there are few clear indications on good practices that policy-makers, patients and providers might endorse to achieve this purpose. Notably, the role of patients is most elusive since most studies emphasize providers' and policy-makers' initiatives.

We believe that future research should clarify more how programmes and practices of patient engagement and enablement contribute to increase patients' level of power, and then, empowerment. Despite a seeming consensus that motivation, ability and power are distinct features, there have been few attempts to unpack patient empowerment as a combination of these processes that lead to higher motivation, higher ability and higher power. Past

research already developed findings on patient enablement (which focuses on the acquisition of abilities), engagement (which highlights patients' motivation) and empowerment (which includes evidence on patients' acquisition of power along with providers' entrustment efforts). These research streams remain however separated, and bridging them together might improve our understanding of what is already known on the antecedents of patient empowerment.

On a related note, it appears particularly interesting to further our knowledge on the participation and involvement of patients who did not experience the acquisition of motivation, ability and power altogether. Patients might be enabled but not engaged – or vice-versa – as well as have motivation and ability, but are not granted sufficient power. By unpacking the differences between 'empowered', 'engaged', and 'enabled' patients, future research might shed new light on how different combinations of these properties engender different degrees, forms and consequences of involvement/participation. In doing so, such studies would expand earlier work, such as [61] which already connected diverse levels of power (but not ability and motivation) with diverse forms (but not degrees or consequences) of involvement or participation.

5.2. *Research direction 2: Explore how empowerment moves into involvement and participation*

Most research assumes that patient empowerment is closely linked with patient involvement and participation, meaning that empowered patients would participate in decision-making and, conversely, participation in decision-making comes from empowered patients. This translation is however elusive, since empowered patients might still translate in inappropriate behaviours, while non-empowered patients might decide to participate in self-care with negative results. As such, it is crucial to understand more clearly (i) under which conditions patient empowerment translates in the expected patient participation, and why, instead, this might translate in a refusal to participate or in deranged forms of participation; (ii) under which conditions patients that lack sufficient empowerment (especially in terms of literacy) decide to participate, and which barriers might correct this problem if empowerment interventions fall short.

Furthermore, patient participation might have important negative consequences that outweigh its benefits. Ref. [6] have, for instance, talked about a possible 'cacophony' between patients and providers' opinions—with the result of reducing the quality of outcomes. It is worth noticing that several studies in manufacturing companies have expressed strong concerns on the 'hidden agenda' of employees' empowerment, suggesting that delegating responsibilities to others (employees or, in our case, patients) creates only an 'illusion' of power and is instead a reinforcement of top-down control mechanisms (cf. [9]). Future research needs to pay an explicit attention to the 'quality' of the link between empowerment and participation, i.e. whether patient participation is a form of emancipation, or instead a way to strengthen providers' power.

5.3. Research direction 3: Explore the connection between empowerment and activation

The distinction between empowerment and activation is relevant to appreciate the contexts and situations in which patients are willing to participate in decision-making. There are cases in which empowered patients might not be 'activated', refusing to have a broader role in self-management and participation in decision-making. This divergence is not per se problematic, since patients face situations in which they are 'confident enough' to participate, and others in which they prefer not to take responsibility for negative outcomes and rather prefer to rely on providers. We believe that the debate on empowerment and activation should still clarify between if, how and when this difference should be corrected, i.e. in which case there is (perhaps) "too much" empowerment".

5.4. Research direction 4: Explore the translation of 'patient empowerment' programmes and ideas

The consequences of patient empowerment are to a large extent still unclear. This engenders the concern that the idea itself of patient empowerment "sits uncomfortably with other current medical ideologies, in particular Evidence-Based Medicine. Moreover it is, in reality, constrained by organizational, clinical or economic factors. The scientific basis for the importance of choice and control is also weaker than it first appears" [52], p. 53. It follows a need to further our knowledge on how and under which conditions empowerment actually improves the quality of care and makes patient's interest. Research connecting patient empowerment, involvement and participation with specific outcomes (e.g., costs, quality of care, satisfaction) remains highly warranted.

At the same time, the generalizability, or at least transferability, of programmes and ideas of patient empowerment also needs to be taken into account. The sociology of translation suggests that patient empowerment might struggle to be disseminated because its ideas and programmes change, i.e. "are translated", when carried from one setting to another, as a result of the actions perpetuated by relevant stakeholders (e.g. policy-makers, patients, professionals) [53]. As such, we argue that we need a more nuanced understanding of how processes and programmes of empowerment and activation have 'worked' and 'made to work'—revealing the context where they are embedded, and the actions carried out by stakeholders to interpret and adapt "patient empowerment" locally.

6. Conclusions

Within a rapidly growing body of research in the field of patient empowerment, its conceptualization and its connection with other neighbouring concepts present still many ambiguities. The present study sought to address this limitation by providing policy-makers and researchers with a review of the definitions of patient empowerment, engagement, enablement, activation, involvement, and participation. Despite many overlaps, the review

highlighted boundaries between the concepts. This study described the complex nature of each term and developed tentative relationships between the concepts. This gave the opportunity to distinguish patient empowerment as a consequence of processes of engagement and enablement, and as an antecedent for patient participation and involvement. The resulting concept map paves the way for a number of future research directions that can help improve our understanding of the antecedents and consequences of patient empowerment policies. We are aware that clarifying the boundaries between the wealth of terms in the literature is not by itself sufficient to allow the development of patient empowerment. At the same time, it is crucial to improve how we develop, understand and use the abundant evidence base that is steadily growing in recent years. We believe that our concept map might provide policy-makers and researchers with the opportunity to make a broader and more systematic use of past research as well as to channel future policy-enabled initiatives or academic researches within clearer directions. In the long term, we hope all these efforts could translated into a more profound support to enable policy-makers' and providers' evidence-based decision-making.

Conflict of interest statement

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