



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



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ABSTRACT

Patients are increasingly encouraged to become active players in self-care and shared decision-making. Such attention has led to an explosion of terms – empowerment, engagement, enablement, participation, involvement, activation – each having multiple and overlapping meanings. The resulting ambiguity inhibits an effective use of existing evidence. This study addresses this problem by delivering an evidence-based concept mapping of these terms that delineates their boundaries and mutual relationships. We implemented a literature review of contributions associated to patient empowerment, activation, engagement, enablement, involvement, and participation. We implemented a keyword-based strategy collecting contributions published in PubMed database in the 1990–2013 timespan. A total of 286 articles were selected. The results identified three distinct interpretation of patient empowerment, either conceived as a process, an emergent state or as a participative behaviour. Most definitions recognize empowerment as the combination of ability, motivation and power opportunities. A concept mapping for patient empowerment, activation, enablement, engagement, involvement, and participation was then delineated. The concept map consists of two dimensions (nature and focus of concept) and marks distinctions and relationships between the concepts. 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.

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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).

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