Contents lists available at ScienceDirect

Patient Education and Counseling

journal homepage: www.elsevier.com

"Patient participation" and related concepts: A scoping review on their dimensional composition

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ARTICLE INFO

Article history:
Received 13 December 2018
Received in revised form 29 July 2019
Accepted 1 August 2019
Available online xxx

Keywords:
Patient participation
Patient empowerment
Patient centered-care
Scoping review
Thematic analysis

ABSTRACT

Objectives
Several concepts on collaboration between patients and healthcare systems have emerged in the literature but there is little consensus on their meanings and differences. In this study, "patient participation" and related concepts were studied by focusing on the dimensions that compose them. This review follows two objectives: (1) to produce a detailed and comprehensive overview of the "patient participation" dimensions; (2) to identify differences and similarities between the related concepts.
Methods
A scoping review was performed to synthesize knowledge into a conceptual framework. An electronic protocol driven search was conducted in two bibliographic databases and a thematic analysis was used to analyse the data.
Results
The search process returned 39 articles after exclusion for full data extraction and analysis. Through the thematic analysis, the dimensions, influencing factors and expected outcomes of "patient participation" were determined. Finally, differences between the included concepts were identified.
Conclusion
This global vision of "patient participation" allows us to go beyond the distinctions between the existing concepts and reveals their common goal to include the patient in the healthcare system.
Practice implications
This scoping review provides useful information to propose a conceptual model of "patient participation", which could impact clinical practice and medical training programs.

1. Introduction

Healthcare systems have been going through a progressive change, in which the biomedical perspective has been yielding to the biopsychosocial perspective [1,2]. Throughout this change, patients are expected to be more and more involved, not only in their care, but in the whole healthcare system [3,4]. The World Health Organization (WHO) has supported this change since 1978 with the Alma-Ata declaration that communicated the importance of individual self-reliance and participation in the planning, organization, operation and control of primary healthcare [5]. More recently, the WHO has continued to support this change with the Shanghai 2016 declaration that promotes health literacy and aims to empower individuals to enable their participation in decision making regarding their health [6].

Various factors have prompted these changes. First, the global demographic structure has changed over the past century. People are living longer and healthcare systems have had to accommodate these developments to continue to provide appropriate care to maintain quality of life [7]. The proliferation of chronic diseases and multiple morbidities has impacted healthcare systems as people require continuous and varied types of support to maintain quality of life while living with their disease, moving beyond the traditional biomedical focus of treatment [8]. Societal factors have also influenced patient willingness to participate in the healthcare system. Social movements

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https://doi.org/10.1016/j.pec.2019.08.001
0738-3991/

such as feminism have influenced these developments, especially concerning issues of power and control in the relationship between the healthcare professionals (HPs) and patients [9]. These movements fostered feminine autonomy in their care and influenced patient participation in the healthcare system [10,11]. Furthermore, the evolution of technology has increased patients' access to information and knowledge, raising patients' interest in being more involved in their care plan [12]. Finally, several studies have demonstrated that patients tend to prefer to be more active participants in their treatment plan [13,14].

This perspective of the healthcare system no longer treats patients solely based on their disease but also takes into account the patient's uniqueness, values and experience [15–17], and others go as far as recognizing the patient as a full member of the healthcare team [18]. This perspective aims to rebalance the HP and patient relationship to knowledge, control and power by recognizing patients' experiential knowledge [19] and expertise [20]. Furthermore, involving patients in the healthcare system has demonstrated positive outcomes such as higher patient satisfaction [21], better quality of care [22] and improved treatment [23], better health and costs outcomes [24], which drives public health actors to encourage and support the development of a healthcare system where patients take an active role.

Over the past 50 years, an extensive body of literature has emerged describing several concepts of the relationship between patients and healthcare systems, such as patient-centred care (PCC) [25,26], patient education [27], patient empowerment [28], patient engagement [29], patient involvement [24], patient activation [30], patient participation [19] and patient partnership [31]. Diverse methodological approaches have attempted to provide clear definitions of these concepts. Some authors have perceived these concepts as complementary and applied comparison methods to study them[32,28], whereas others, consider them independently and used concept analysis methods [33–35]. However, despite the popularity of these concepts and the wide range of studies on this topic there is no consensus on their meanings and how they differ from one another [20]. The lack of a universally agreed definition of these concepts has hampered their empirical developments and implementation [32,28]. For the purpose of this paper we used the generic term "patient participation" to refer to all of the concepts noted above. Table 1 displays the terminology used throughout the paper and helps to differentiate them (concept, conceptual model and dimension).

In public health, the dimensions that characterize a concept and on which actions can be undertaken matter more than the name given to it. Accordingly, "patient participation" has been studied by focusing on the dimensions that compose it. The objectives of this scoping review were: (1) to produce a detailed overview of the dimensions which compose the generic concept of "patient participation" for physical health; (2) to identify differences and similarities between the concepts.

Table 1
Terminology used in this review.

Term	Definition
Concept	Mental construction or representation, by which we understand knowledge and experiences on a specific matter [36].
Conceptual model	Representation of a concept, in which the dimensions composing the concept and their connections are described, for the purpose of understanding and communication [37].
Dimension	One of the aspects, attributes, elements or factors that make up an entity, item, phenomenon or situation [38]. In this paper a dimension refers to a component that characterises the content of the conceptual model. Dimensions are usually used at a practical level since they are less abstract than concepts.

2. Methodology

2.1. Design

We performed a scoping review of the literature following the PRISMA checklist extension for scoping reviews [39]. This form of research synthesizes an exploratory research question with the aim of mapping key concepts, types of evidence, and gaps in research related to a defined area by systematically searching, selecting, and synthesizing existing knowledge [40].

2.2. Search strategy & eligibility criteria

An electronic protocol driven search was conducted, this was combined with snowball sampling and supplemented with articles that were recommended by experts [41].

The protocol driven search was developed with a health research librarian. Two bibliographic databases – MEDLINE (Ovid), PsycINFO (Ovid) – and the first five pages of Google Scholar were searched for English and French articles up to June 2018 with the following keywords: "patient-centred care", "patient participation", "patient engagement", "patient empowerment", "patient activation", "patient education", "patient partnership", "patient involvement", "conceptual model" and "conceptual framework". These terms are included in the search strategy because they are related to "patient participation". Even though patient education is often considered as being an intervention of "patient participation" it was included in the search strategy because it is considered as the main concept of patient inclusion in healthcare in the French speaking scientific literature [42,43]. The search strategy is displayed in Appendix A in supplementary material.

In the first phase of screening, titles and abstracts were screened to exclude irrelevant records. Records that were short commentaries, conference abstracts, book reviews and letters to editors were excluded, as well as articles that focused on the concept implementation or measurement. Articles that referred to mental healthcare were also excluded because patients suffering from mental illness could have their perception of reality impaired and be subject to specific needs. Therefore, the dimensions that compose "patient participation" could be different for mental healthcare. Finally, articles with a conceptual model of the concept, showing how they are understood and described were included. No publication year limit was applied.

The snowball sampling was conducted using reference tracking. The reference lists of all the articles selected through the protocol driven search were scanned. For articles recommended by experts' clinicians, and researchers working in public health, suggested relevant literature. We ensured that articles retrieved through the snowball sampling and articles recommended by experts were consistent with the eligibility criteria.

2.3. Data collection & content analysis

The process to extract and assemble the data consisted of collecting the emergent dimensions from the studied conceptual models and classifying them into three levels of analysis. These levels were chosen based on the retrieved conceptual models that already based their representation and analysis systemically [26,18,29,44,45]. These levels were: the micro level (day-to-day operational management of care), the meso level (hospital governance and institutional decisions that takes place within healthcare institutions) and the macro level (government decisions that determine the basic structure, organiza-

tion and funding of the overall healthcare system and healthcare sector) [46]. Based on this categorization, two researchers, working independently encoded the first three articles. A comparison of this sample was done in order to evaluate the congruence of the results and to test the reliability of the method. The research team came to an agreement on the classification and the lead researcher finished encoding the articles.

A thematic analysis methodology was used to analyse the data [47]. This method consists of transposing the collected data into three representative categories: (1) the rubric, which are the largest thematization; (2) the themes; and (3) the sub-themes. This thematic analysis aimed to extract the components of the conceptual models. It was done in the three levels of analysis used to collect the data and took place in four stages. First, the lead researcher did the analysis and proposed a first version of a thematic tree. Second, another researcher did the work independently. Third, both researchers, working together, built the final thematic tree, and lastly, a third researcher settled any disagreements that were encountered by the first two researchers. Finally, the thematic tree was validated by the multidisciplinary research team.

3. Results

3.1. Characteristics of included articles

The search strategy identified 5953 records. After removing duplicates, 5558 articles remained. With the title and abstract screening, 5404 were removed. A total of 154 full-texts were selected for further assessment. A total of 115 records did not include a conceptual model and were excluded, 39 articles remained for full data extraction and analysis. The selection process is summarized in Fig. 1.

The selected references showed geographical and cultural diversity since 21 studies came from North America, 13 from Europe, four from Australia and one from Asia. The included references were published between 1991 and 2018. The majority of articles concerned PCC (n=23), five were on patient participation, four on patient empowerment, four on patient partnership, and only one article was retrieved for each of the following concepts: patient engagement, patient involvement and patient education. No article on patient activation matching the eligibility criteria was found. Table 2 displays a list of the articles included in this study.

3.2. Overview of the results

Fig. 2 displays the flow chart detailing the steps of the thematic analysis. The data collected in the 39 articles resulted in a massive

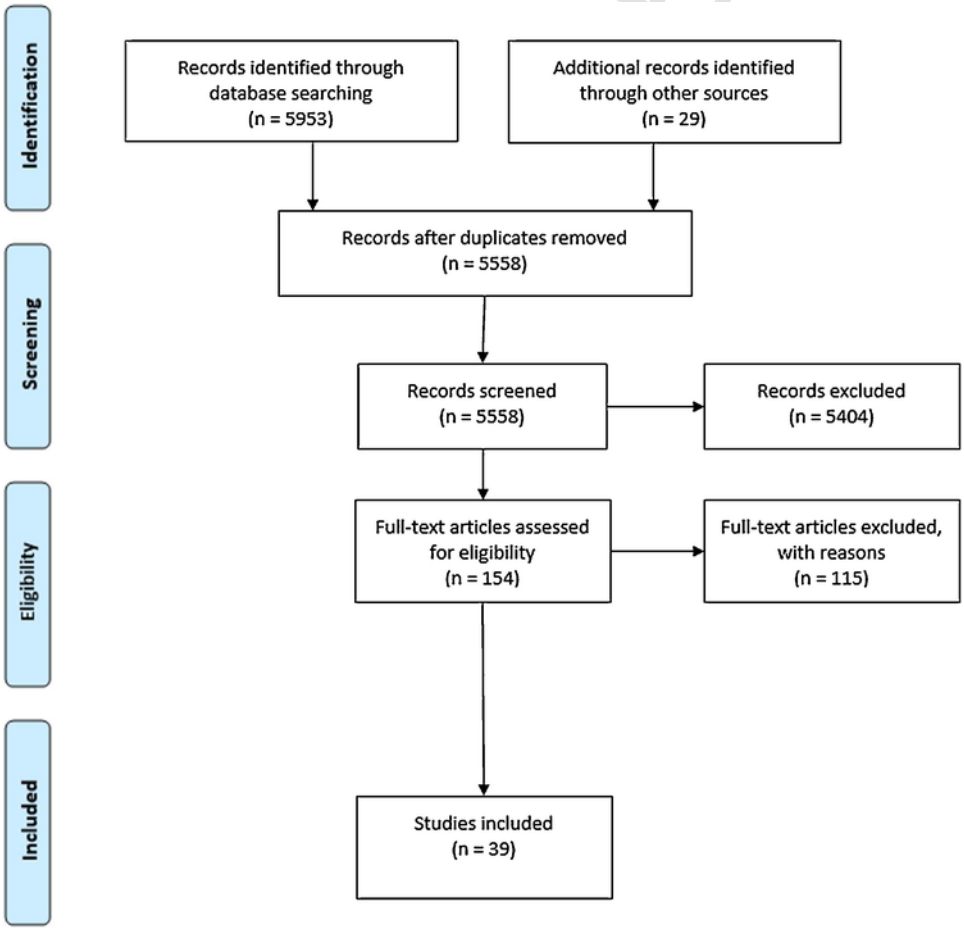

Fig. 1. Flow diagram summarizing the selection process.

Table 2
Included articles and conceptual models.

Concept	Author
Patient-centred care	Athwal et al. (2014) [48]
	Bilodeau et al. (2015) [49]
	Brewer et al. (2013) [50]
	Glass et al. (2012) [51]
	Greene et al. (2014) [52]
	Håkansson Eklund et al. (2019) [53]
	Hobbs (2009) [44]
	Lusk et al. (2013) [21]
	Mead et al. (2014) [54]
	Pelletier et al. (2014) [55]
	Scambler et al. (2014) [56]
	Scholl et al. (2014) [34]
	Morgan & Yoder (2012) [57]
	Davis et al. (2005) [58]
	Hoff et al. (2012) [22]
	Jayadevappa et al. (2011) [59]
	Ogden et al. (2017) [60]
	Robinson (1991) [61]
	Kamei et al. (2017) [62]
	Kremitske & West (1997) [63]
	Mead & Bower (2000) [26]
	McCormack et al. (2006) [64]
	Wagner et al. (2005) [65]
Patient empowerment	Bravo et al. (2015) [35]
	Umar et al. (2015) [66]
	Falk-Rafael (2001) [67]
	Spence Laschinge et al. (2010) [68]
Patient participation	Angel et al. (2015) [33]
	Thorarinsdottir et al. (2014) [69]
	Cahill et al. (1996) [70]
	Haidet et al. (2006) [71]
	Sahlsten et al. (2008) [19]
Patient partnership	Pomey et al. (2015) [18]
	Lecocq et al. (2017) [45]
	Dontje et al. (2004) [72]
	Courtney et al. (1996) [73]
Patient engagement	Carman et al. (2013) [29]
Patient involvement	Snyder et al. (2016) [24]
Patient education	Colson et al. (2014) [74]

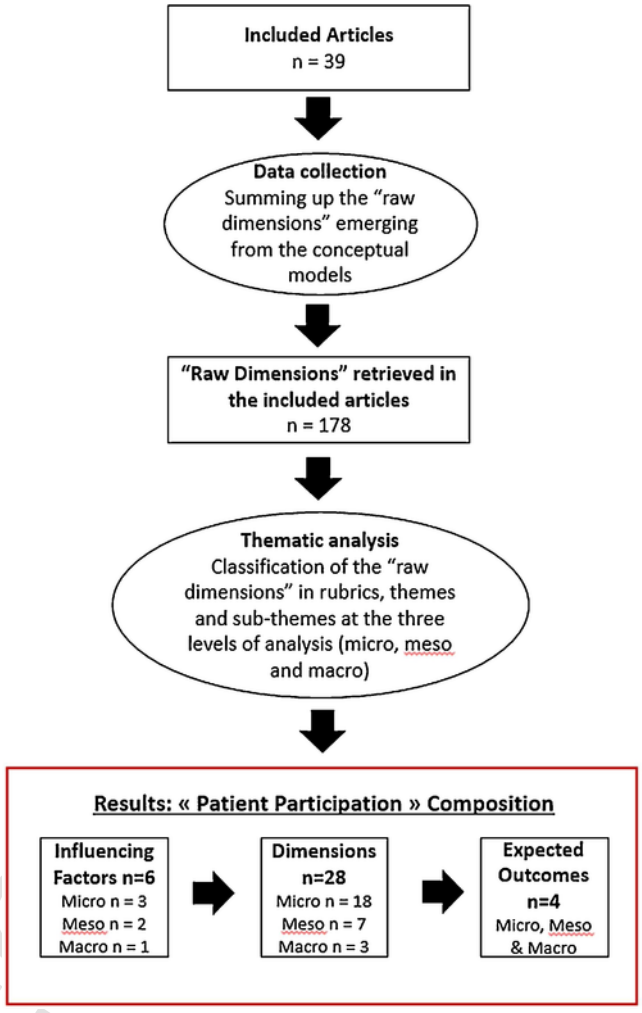

Fig. 2. Flow chart of the conceptual models' thematic analysis.

corpus composed of 178 "raw dimensions". The content analysis gathered these "raw dimensions" to produce a thematic tree (Fig. 3), which resulted in a detailed description of "patient participation" at the three levels of analysis. For all three levels we identified: 28 dimensions composing "patient participation", six influencing factors, and four expected outcomes. This stratification in dimensions, influencing factors and expected outcomes was adopted based on the articles included in this review that already stratified their conceptual model in this manner and that appeared to be the most suitable way to present the results. Appendix B in supplementary material shows the integrality of the corpus.

3.2.1. Thematic tree

3.2.1.1. Micro level

At the direct care level three rubrics were identified: (1) collaboration, (2) patient and (3) HP.

Three themes were identified under **collaboration**. First, the *healthcare professional and patient relationship* included seven dimensions. The first dimension that is required for a participative care relationship is **time**. Indeed, taking the time to get to know each other, to construct a relationship, to

exchange information, to enter into dialogue and to reach an agreement is essential for "patient participation"[26,33,68]. The second dimension is **teaching and learning**. This dimension refers to the education of patients by the HP in order for patients to acquire and maintain the necessary knowledge and skills to help them become active partners of care [24,66,54,55,56]. The next dimension is **sharing information and knowledge**. This phase goes one step further since the exchange is bi-directional [29]. This entails obtaining the patient's opinions and experiences, and requires an open dialogue between the HP and the patient [19,34,51,66]. The goal is to narrow the knowledge gap between the HP and the patient [70]. Sharing information and knowledge has been demonstrated to have a close connection with sharing time [33] and appears to be a prerequisite for shared-decision making (SDM) [69]. **Sharing leadership, power and responsibilities** is also perceived as a prerequisite for SDM [69]. "Patient participation" requires that the HP shift to working "with" not "doing to" the patient [73]. Therefore, the HP needs to surrender some power and control [19,68]. This shift of power is relative to the level of patient autonomy, given that as power is shared the patient's ability to control their care increases and patient autonomy is enhanced [21]. All of the previous dimensions will allow **SDM**. In this dimension, patients are introduced to the idea of having a choice over how they manage their condition [35,69,56,48]. SDM must involve a process of negotiation that takes into account patients' values and preferences [64]. By sharing the knowledge and the power in the relationship the patient is empowered to make the final decision treatment [21,34]. Finally, **partnership care** is the final step of this collaboration and is a reciprocal relationship that is characterized by

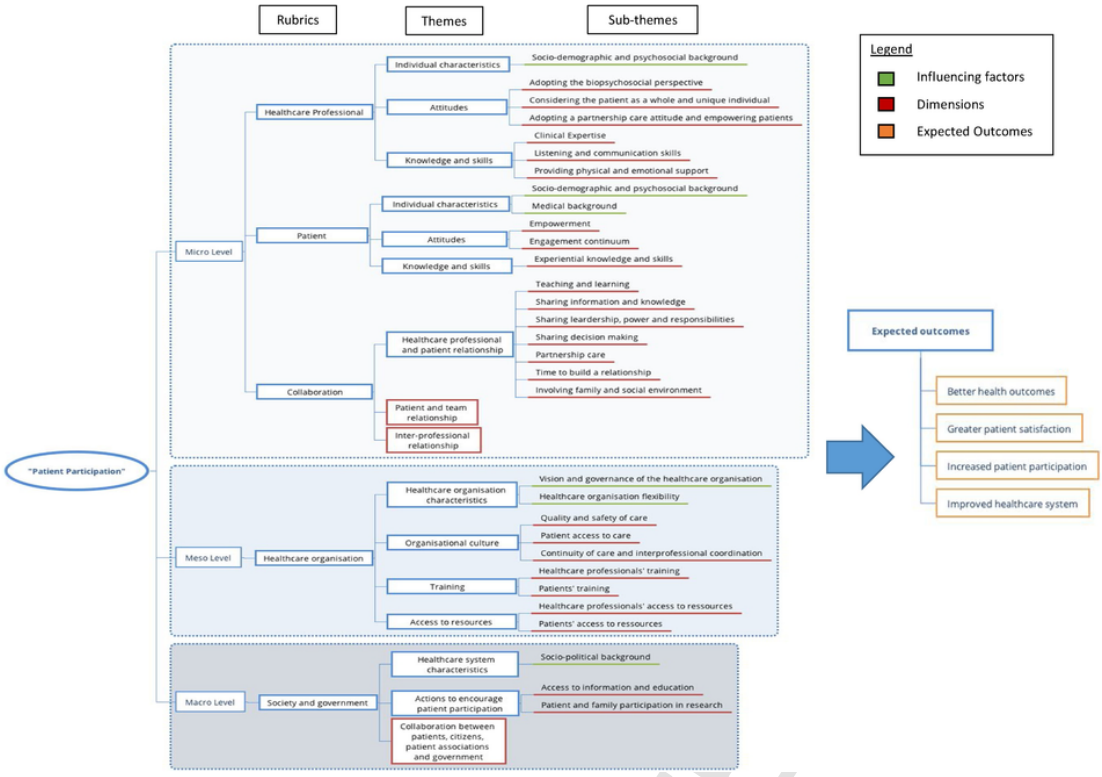

Fig. 3. Thematic Tree.

trust, open dialogue, mutual caring, agreement over the treatment goals, co-learning, active mutual engagement, mutual understanding of roles and responsibilities [19,73,34,48]. In partnership care the HP does not impose treatment, rather they propose expertise [48]. Finally, the **involvement of family and social environment** can be implemented throughout this whole process of collaboration in the HP and patient relationship since they provide informal support and resources for day-to-day management of health issues [68]. Establishing partnerships with families and the social environment is an important empowerment strategy [74]. The second and third themes that were identified were the *relationship between the patient and the whole healthcare team,* which refers to a two-way consultation between the HP, the patient and the team [45,48,50], and the *inter-professional relationship* that is essential and required role definition, coordination, communication, trust and respect among team members [34,72,50].

Three themes were classified for the **HP.** First, the *individual characteristics of the HP* are the socio-demographic and psychosocial background (goals, beliefs, values and interpersonal qualities are components that influence HPs' capacity to be involved in a partnership relationship [26,64,67]). According to the articles included in this review, HP's values and beliefs need to be in line with those rooted in "patient participation" [26,34,64]. Second, the HP needs to adopt *attitudes* to allow "patient participation" such as adopting the biopsychosocial perspective (involvement in all the difficulties the patient brings, and not just the biomedical problems [26,34,72]); considering the patient as a whole and unique individual (capacity to understand the patient's personal experience and meaning of illness [26,55,60]); and adopting a partnership care attitude and empowering patients (commitment to a partnership process that requires acknowledging a patient's ability to self-manage his or her illness [34,57,72]). Finally, the HP needs to develop the necessary *knowledge and skills* such as clinical expertise (commitment to evidence based practice, capacity to take decisions and competence in physical and technical aspects of care [26,34,63]); listening and communication skills (set of verbal and non-verbal behaviours that facilitate communication [34,59,69]); and the capacity to provide physical and emotional support (caring for the patient by providing medical and non-medical care [34,54,51]).

Finally, three themes were also identified for the **patient**. First, the patient's *individual characteristics* are the socio-demographic and psychosocial background (age, gender, ethnicity, level of education, socioeconomic status that might influence patient's participation in care [18,24,26]), and the patient's medical background (severity of illness and the space it takes in the patient's life [33,35,44]). The second theme is the patient's *attitudes* such as empowerment (patient's acquisition of motivation, abilities and power in the healthcare relationship [24,35,66]), and patient engagement continuum (stages a patient can go through in the process of participation (from passive to active) [29,71,62]). Finally, the patient's *knowledge and skills* are the patient's experiential knowledge (patient's experience of management of chronicity and associated lifestyle [18,29,74]). In order for patients to be empowered and to be able to manage their level of participation in their care (engagement continuum), they need to have received appropriate training, which appears to depend predominantly on the responsibility of the HP [24,66,74].

3.2.1.2. Meso level

At the healthcare organisational level four themes were identified. First the *healthcare organisation characteristics* includes the vision and governance of the healthcare system (structures, mission, values, policies, procedures and guidelines that support patient participation [18,55,57]), and the *healthcare organization flexibility* (capacity to facilitate reflection, change and actions for improve-

ments [57,60,75]). The second theme is the *organisational culture*, which includes quality and safety of care (patients co-lead hospital safety and quality improvements committees [18,29,50]), patient access to care (care should be universally accessible and responsive to the patient's values, priorities, perspectives and concerns [54,48,65]), and the continuity of care and inter-professional coordination (preparing transitions from inpatient to outpatient, providing follow-up services after discharge, assigning patients to the same primary care practitioner [34,72,60]). The third theme is *training*, which includes HPs' training and patients' training [18,24,35]. Training HPs is an efficient way to improve patients' skills and help them overcome obstacles to self-management. HPs can improve their communication skills and, in turn, encourage patients to participate more actively in consultations [18,50,59]. Patients can participate in HP training by helping identify and develop required skills. The healthcare institution can put in place several actions to foster "patient participation", such as chronic disease self-management programmes, personalised care planning, and patient education programmes [24,35]. Finally the third theme is *access to resources*, which included HPs and patients access to resources provided by the healthcare institution to foster "patient participation [18,68,58].

3.2.1.3. Macro level

At the society and government level, three themes were identified. First, the *healthcare system characteristics* refers to the socio-political background that influences the healthcare system and thus "patient participation" (patients, HPs, and institutions are influenced by social norms, societal values, social cultures, health priorities, legislations and policies [29,18,45,29,72]. Social and community norms can be more or less favourable to "patient participation" and thus have an impact on its perception [35,65]). The other themes are *actions that are put in place to encourage "patient participation"* (actions that foster access to information and education, and patient participation in research [18,24,66]) and *the collaboration between patients, citizens, patient association and the government* (solving community and social problems, shaping healthcare policies and set priorities for the use of resources [18,29]). Patients can collaborate with community leaders and policymakers to solve community and social problems, shape health care policy, and set priorities for the use of resources. Ideally, patients' representatives and governments' representatives set priorities and make decisions together.

3.2.1.4. Expected outcomes

Four expected outcomes were retrieved: *better health outcomes* (better control of chronic condition, decreased hospitalisation and readmission, improved emotional and physical health status, and the ability to carry out activities of daily life [22,55,57]); *greater patient satisfaction* (with the overall quality of care, with healthcare professionals and with the healthcare relationship [22,57,64]); *increased patient participation* (enhanced care experience that will ensure empowerment, activated personal responsibility to act on owns behalf, increased shared decision making, and greater use of chronic disease services [22,64,65]); and *improved healthcare system* (an environment where decision-making is shared, staff relationships are collaborative, leadership is transformational and innovative practices are supported [64]).

3.2.2. Differences between the concepts

The studied articles were all centred on the micro level, 22 mentioned the meso level, 10 mentioned the macro level and 16 talked about expected results. They also all mentioned the three analysis levels except for patient education that did not mention the meso nor the macro levels; and patient participation that did not mention the macro level. At the **direct care level,** "empowerment" and "patient socio-demographic and psychosocial background" were mentioned by all articles. "SDM" and "adopting a partnership care attitude and empowering patient" were retrieved in all concepts except in patient education. Likewise, "involving family and social environment" and "considering patient as a whole and unique individual" were retrieved in all concepts except for patient involvement; and "teaching and learning" was also mentioned by all concepts except for patient participation. Furthermore, patient engagement, patient education and patient involvement did not mention "sharing leadership, power and responsibilities", "partnership care", and "patient's medical background" whereas they are cited in all the others concepts. Patient education did not mention **the organisational level** and none of the dimensions were common to all concepts. "Healthcare professionals' training" was mentioned by all concepts except by patient education and patient participation and "quality and safety of care" was the most cited but only by three concepts (PCC, patient partnership, and patient engagement). At **the governmental level** "socio-political background' is the most mentioned. Patient education and patient participation did not mention the macro level. Finally, "collaboration between patients / citizens / patient associations and government" was only mentioned by patient partnership and patient engagement. Better health outcomes" was the most cited **expected outcome,** and mentioned in most articles, except in the patient engagement and patient education articles.

4. Discussion and conclusion

4.1. Discussion

4.1.1. Focus of the review

The objectives of this review were to produce a detailed overview of the dimensions that compose the generic concept of "patient participation" and to identify differences and similarities between the related concepts. Given the lack of consensus regarding definitions and composition of these concepts, our study attempted to treat "patient participation" through a different methodology. By studying these transversally, the composition of "patient participation" was extracted independently from the different names given in the scientific literature. Moreover, a classification was proposed at each level of analysis with the aim to provide any actor of the healthcare system with a clear vision of what is required to operationalize "patient participation". Therefore, the 28 dimensions, six influencing factors and four expected outcomes proposed could provide clarity concerning its implementation and scientific interpretation since it shows, to our knowledge, the most complete representation of "patient participation".

4.1.2. Differences between the concepts

By studying the concepts related to « patient participation » transversally, our results are often in contradiction with studies that compare them. For instance, several authors, whom studied the concepts comparatively, place PCC, patient involvement and patient participation only at the micro level [20,28]. However, this study found that PCC is largely represented at the meso level [50,57,59,55], and that patient participation and patient involvement include dimensions of this level [24,33]. Based on the articles analysed, PCC came up as being the most complete concept since it included the wide majority of the retrieved dimensions. Evidently, this could be due to the fact that most of the articles that emerged from the search strategy were on PCC whereas very few articles emerged for the other concepts, espe-

cially for patient engagement (n=1), patient involvement (n=1), patient education (n=1) and patient activation (n=0). This predominance of PCC could be explained by the fact that this concept appeared in the scientific literature earlier than the others. Indeed, PCC was described by the psychologist C. Rogers in the early 1940s [25] and was later brought to medical therapy in 1969 by E. Balint [76]. To this day PCC is still at the core of health research with more than 20 literature reviews on its definition and composition [53]. However, the lack of representation of other concepts such as patient participation (n=5) and patient empowerment (n=4) is quite surprising since these concepts emerged in the 1980s [77–79], are widely used in the scientific literature, and are likely to be crucial for the evolution of healthcare systems [3,70].

In this study, patient empowerment, patient education and patient partnership resulted in being included as dimensions of "patient participation". Patient empowerment and patient education are dimensions of the HP and patient relationship since they are considered, in the vast majority of articles, as prerequisites of partnership care. For instance, patient empowerment is mostly perceived as the patients' acquisition of motivation, abilities and power in the healthcare relationship, in order to self-manage personal care by choosing realistic health related goals and taking steps to achieve those goals [35,68]. Therefore, patient empowerment can only be considered as a lever of "patient participation". This result is in opposition with the study of Castro et al. (2016) that concludes that patient empowerment is a broader concept than PCC and patient participation. They see PCC as a requirement for patient empowerment and patient participation as a condition for PCC and patient empowerment [28]. Another study, that also compared these concepts, perceived patient empowerment as a consequence of processes of engagement and enablement, and as an antecedent to patient participation and involvement [32]. However, other authors such as Graffigna and Vegni (2017) support the position of patient empowerment as a dimension of "patient participation" by seeing patient empowerment as the level of patients' power and as a potential prerequisite for the process of engagement [20]. For patient education, the results show that this concept does not focus on the further steps of the HP and patient relationship. For instance, sharing leadership, SDM and reaching partnership care were not present in the article retrieved for patient education [74]. Finally, for patient partnership, several conceptual models of PCC integrated partnership care as a component. This dimension refers to the notion that the patient and the HP reach a relationship where they are on an equal level [34,48] and is, in our interpretation, the final aim of "patient participation".

Patient engagement, PCC, patient involvement and patient participation appeared to be the concepts with the most overlap since none of them resulted in being a dimension of "patient participation". The differences between those concepts are thus not clear which is also reflected in the scientific literature. For instance, Castro et al. (2016) and Fumagalli et al. (2015) both state that patient participation and patient involvement are often used interchangeably to describe patients taking an active part in their consultations with HPs without a clear understanding of their difference [28,32]. However, Fumagalli et al. (2015) still found a difference between them by stating that patient involvement is determined by the patient and the HP independently from one another, whereas patient participation is perceived as being co-determined [32]. Furthermore, some research on PCC and patient engagement state that these concepts seem to occupy common ground and similar aims, but the degree of overlap is not clear and not frequently explored in the literature [20]. Finally, other research even mentions differences within one concept, for example Håkansson et al. (2019) state that PCC and person-centred care share numerous similarities but that their goal still differs by concluding that the goal of PCC is a functional life for the patient while the goal of person-centred care is a meaningful life for the patient [53].

4.1.3. Implementation and operationalisation of the generic concept "patient participation"

Implementing and evaluating "patient participation" is a complex process. The large number of dimensions and their diversity is challenging and, though "patient participation" has been regarded as essential to healthcare, it remains poorly implemented [53]. The operationalisation and implementation will need to take into consideration four main points. First, "patient participation" is a process, which requires evolution and pre-requisites such as the phase of teaching and learning [24,55], sharing information and knowledge [34,69], and sharing leadership, power and responsibilities [69,58]. Another example is the HP's attitude that will have to evolve from biopsychosocial care to partnership and empowering care. This is in line with the literature on PCC that states that a biopsychosocial perspective alone is not sufficient to understand the patient's problem and experience of illness [53]. Therefore, the second point to take into consideration is the HP's and patient's training that will have to be in agreement with this change of paradigm. Indeed, the training of HPs appears to be crucial to support the realisation of "patient participation" in healthcare [35,60,18,20], as well as patients' training that is sometimes seen as a potentially effective tool for promoting "patient participation" and helping patients to maximize their healthcare interactions [23,18]. Therefore, such training will not only foster "patient participation" in their own care but also in the healthcare organisation. Patients might be able to partner with the healthcare institution representatives to shape and improve the organisational culture, vision and governance and thus participate in the organisational decision-making process [29], such as through patient committees or advisory councils [80,81]. A recent article on patient engagement highlight the importance of having patients as peer leaders and to recognise them as professionals who can managed administrative and organizational activities and that can be compensated for their work [82]. The third point to take into consideration is the factors that will influence the implementation of "patient participation", such as HPs and patient's socio-demographic and psychosocial background [26,29], the vision and the flexibility of the healthcare organisation [57,65] and the social and political background [26,18]. These influencing factors are not modifiable by the actors of the healthcare system and could be challenging. Finally, the last point is that implementation is a systemic process that should take place at all the levels of the healthcare system (micro, meso, and macro) and thus involves several actors including patients, HPs, patient representatives, policy makers and leaders of healthcare organisations [29,18]. This systemic aspect of "patient participation" appears to be the most challenging since the levels of the healthcare system are interdependent and do not all evolve at the same rate. For instance, while some authors state that including patients in the decision-making process at the governmental level (macro level) is crucial for implementation of "patient participation", little actions are put in place at this level to favour "patient participation" [29,18].

4.2. Limitations of this study

Only conceptual models were included in this study. This methodological choice of eligibility criteria limited results since not all of the concepts have been represented through a conceptual model. Therefore, some of the studied concepts might encompass more of the retrieved dimensions in other types of conceptualisation present in the

scientific literature. Also, more dimensions at the meso and macro levels may exist in more informal papers in grey literature, from which this study did not draw upon. Finally, only one researcher performed the selection of articles and this may have unintended consequences on the objectivity in the selection.

4.3. Conclusion

The literature shows that "patient participation" is documented as a lever for improving the healthcare system but with heterogeneous and more or less superimposable concepts. To facilitate the appropriation of "patient participation" by the stakeholders of the healthcare system, we aimed to go beyond the discussions of the epistemology of these concepts to focus on their content through an analysis of their dimensions. Therefore, we decided to use the generic term of "patient participation" to prevent the formation of new concepts that deal with the same problem: How can patients participate in the healthcare system and under what circumstances? Through a rigorous methodology, this paper resulted in a proposal that covers the three levels of the healthcare system, and the reconciliation of the different concepts makes possible to state a list of dimensions. These dimensions explain how to involve patients and under what conditions. This proposal is a necessary step towards the operationalization and the implementation of "patient participation" in practice.

4.4. Practice implication

The results of this study address the confusion existing in the scientific literature on "patient participation". First, to our knowledge, the studied concepts have never been studied transversally and this allowed us to go beyond the distinctions between them and revealed their common goal of including the patient in the healthcare system. Second, this review allows the proposal of a conceptual model of "patient participation" with practical descriptions of the 28 dimensions; the six influencing factors, and the four expected outcomes. Finally, this exhaustive representation of "patient participation" will not only impact clinical practice but it could also be a basis for creating training programs for HPs and patients.

Funding

This work was supported by the European Regional Developmental Fund (FEDER) under the INTERREG VA Greater Region Programme (grant numbers 032-3-06-013); and the Public Authorities of the Wallonie Region (grant numbers 032-3-06-013).

Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:https://doi.org/10.1016/j.pec.2019.08.001.

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