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What makes patients engaged: a meta narrative review and multilevel perspective on patient engagement

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Abstract

Patient engagement is increasingly recognized as a crucial aspect for healthcare quality, safety, and outcomes. While literature highlights its multidimensional nature, encompassing individual behaviors, relational dynamics, organizational practices, and social influences, there remains limited integration of these perspectives. This complexity makes it difficult to understand how to define and promote patient engagement, as its antecedents and mechanisms are not fully understood.

The aim of the present study is to provide a comprehensive framework that clarifies the antecedents of patient engagement and guides its implementation across the healthcare system to benefit patients and providers alike. Drawing on the meta-narrative review approach, four databases (SCOPUS, Web of Science, PubMed, and PsycINFO) were used to collect and synthesize multiple systematic reviews and meta-analyses on the topic of patient engagement. Fifty-one items were included in the review. Data extracted were inductively categorized by levels, factors, and elements associated with patient engagement.

Findings highlight the multilevel nature of patient engagement, characterized by individual, task, relational, organizational, and social levels. The emerged integrative model maps interconnected factors and highlights patient engagement's complexity and dynamic nature. The model offers a theoretical framework to diagnose and promote engagement, empowering patients, and enhancing the quality of the healthcare service.

Keywords Patient engagement, Multilevel, Healthcare, Meta-narrative review

Introduction

In literature, scholars and practitioners have recently witnessed a growing attention to the study of patient engagement (PE) across various disciplines (e.g., medicine, psychology). This reflects a broad consensus that PE is a critical factor for improving healthcare quality and patient safety, contributing to better clinical outcomes, higher patient satisfaction, and more effective, responsive care delivery [1]. Several studies have demonstrated that patients who actively and effectively manage their healthcare achieve more favorable clinical outcomes than those who are disengaged or passive [2, 3]. This change

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stems from a shift in healthcare paradigms—from viewing patients as passive recipients of medical and nursing knowledge to recognizing them as active partners in their care [4]. In particular, nursing research has linked PE in mental health inpatient care to improved health outcomes [5], more positive care perceptions [6], and higher patient satisfaction [7]. The relevance of PE is now widely recognized across different healthcare domains, including disease-specific populations [8–10] and throughout different phases of treatment, such as rehabilitation [8], clinical pathway development [11], and maintenance therapies [12].

The literature describes PE as a multifaceted construct that closely relates to other concepts, such as *Patient-Centered Care*, *Patient Activation*, *Patient Involvement*, and *Patient Participation,*which not only coexist but also overlap, intersect, and influence one another. All these terms refer to supporting patients in taking a more active role in their healthcare journey. Research on this topic [13] suggests that each concept carries a specific meaning depending on the role that patients assume when interacting with healthcare services. Accordingly, the literature often uses PE interchangeably with these related terms. Although PE differs from them, reflecting subjective, contextual, relational, and organizational aspects, it may foster or hinder patients' ability to become central actors in their own care (e.g., in the case of *Patient-Centered Care*).

Indeed, there is a burgeoning interest in the scientific literature on PE, yet the factors underlying this concept remain insufficiently clarified. Different authors describe PE as a positive, multi-level construct with individual, relational, organizational, and social implications [14–16]. Graffigna et al. [17] conceptualized PE as a multidimensional psychosocial process emerging from individuals' cognitive, emotional, and behavioral responses to health conditions. Other scholars have defined it as the active involvement of patients and informal caregivers in the planning, execution, analysis, and dissemination of research—a practice commonly referred to as "co-production" [14, 18, 19]. According to Carman et al. [15], PE encompasses a set of behaviors and healthcare policies operating at multiple levels of the healthcare system to enable collaboration and improve health outcomes. Moreover, several studies have identified individual-level factors such as demographic characteristics [14, 20], personality traits [20], health self-efficacy [21], perceptions of healthcare professionals [12, 22], and satisfaction with care [20] as relevant factors for PE Relationally, shared decision-making and attention to patient needs enhance the likelihood of successful treatment outcomes [15]. Promoting a shared organizational vision for PE through coordinated actions in the design, planning, and evaluation of health services is essential to ensure its effective implementation [23]. Moreover, new perspectives have highlighted societal factors influencing PE, such as cultural and social norms that contribute to the systematic exclusion of certain segments of the patient population, often those who are marginalized [24, 25].

Despite the extensive literature on different aspects of PE, there remains a lack of a comprehensive framework that articulates how these aspects interrelate and coexist within the concept of PE. That is, the literature still lacks a broader approach that integrates these various factors and promotes a paradigm shift by incorporating social structures, systems, institutions, and policies into the understanding of PE. Such an approach can complement multi-level perspectives by addressing individual, relational, organizational, and social levels, offering a more holistic and coherent framework for understanding and intervention.

Following the idea of PE as a multilevel construct, the overarching aim of the present paper is to provide a greater understanding of PE by identifying its antecedents at different levels (i.e., individual, relational, organizational, and social levels). The paper reports a literature review examining the antecedents of PE as they have been defined at multiple levels of analysis within existing systematic and scoping reviews conducted across different healthcare settings and patient populations. Given the conceptual heterogeneity in the field, a meta-narrative approach was adopted, as it is particularly well suited to synthesizing research conducted by distinct scholarly communities, each with its own assumptions, theoretical frameworks, and methodological preferences. By interpreting the literature across levels of analysis and research traditions the review aims to realize a coherent and multi-layered synthesis of factors contributing and influencing PE, integrating the divergent perspectives that have shaped its evolution. This integrative effort is intended to advance a nuanced understanding of the factors contributing to PE and support its further development in research and practice.

Method

Given the conceptual heterogeneity and disciplinary diversity surrounding the construct of PE, we selected the meta-narrative review as the most appropriate methodology to synthesize and interpret the existing literature. This approach is particularly suited to topics that have developed across multiple epistemic traditions, each with distinct assumptions, theoretical frameworks, and methodological preferences. It allows for the mapping of how a construct has been defined, operationalized, and theorized over time and across domains, facilitating a more integrated and reflexive understanding [26].

We conducted the review in accordance with the RAMESES publication standards for meta-narrative

reviews, as outlined by Wong et al. [27], and followed the five phases proposed by Greenhalgh et al. [26]—planning, mapping, appraisal, synthesis, and recommendations—while adapting specific steps to the scope and feasibility of our project. Notably, the review was conducted without a multidisciplinary team or the involvement of patient partners, which is often encouraged in meta-narrative reviews but was not feasible in our context. During the process, minor modifications were made to the initial review protocol in response to emerging findings. These included iterative refinements to inclusion criteria and coding categories, as well as adjustments to the analytical framework to ensure better alignment with the evolving structure of the literature. To enhance transparency and alignment with the RAMESES standards, the following subsections are structured according to the key methodological principles and procedural steps that define the meta-narrative review process.

Adherence to meta-narrative principles

In this review, methodological decisions were shaped by pragmatic considerations aimed at ensuring the relevance and usability of findings. The inclusion of different conceptualizations and paradigms reflected an effort to incorporate pluralism into the analytical process. Contestation was captured through the identification and comparison of areas of tension and disagreement between conceptual approaches. Reflexivity was actively promoted through ongoing internal discussions on how our assumptions may have influenced interpretation. Finally, the analytical strategy benefited from informal peer feedback gathered during consultations with external scholars throughout the process.

Scoping and literature identification

An initial exploratory scoping phase was conducted to identify core traditions and relevant disciplinary perspectives on PE. This step aimed to define conceptual boundaries and refine the focus of the review by tracing key developments in the field. The goal was to capture both influential conceptual models and robust empirical contributions from across the health and social sciences. Particular attention was given to the multilevel nature of PE, including antecedents and influencing factors at the individual, task, relational, organizational, and social levels.

Search strategy

The structured search strategy built upon insights gained during the scoping phase. Search strings included the terms "patient engagement," "patient involvement," "patient activation," "patient empowerment," "patient participation," and "patient-centered care," combined using Boolean operators. Four electronic databases were searched—SCOPUS, Web of Science, PubMed, and PsycINFO—covering literature from the first known review on PE in 2002 to January 2024. The search was limited to peer-reviewed review articles published in English or Italian. After the removal of 256 duplicates from an initial pool of 3,693 articles, 3,383 titles and abstracts were screened according to predefined inclusion criteria. The initial search yielded $N = 3{,}693$ items, which were screened and filtered for duplicates, leading to the removal of $N = 256$ items. The remaining $N = 3{,}383$ were screened by title and abstract based on the inclusion criteria, excluding an additional $N = 3{,}263$ items. After screening, the remaining $N = 120$ articles were read in full.

During this phase, we excluded all studies that did not meaningfully engage with the central aims of our review—namely, those that failed to explore how PE has been conceptualized and operationalized across different perspectives, that did not report empirical findings or influencing factors, or that lacked a comparative or integrative perspective. Ultimately, $N = 51$ articles met all inclusion criteria and were retained for the final analysis.

Selection and appraisal of documents

Articles were included if they were peer-reviewed review studies, qualitative, quantitative or mixed-methods, focused on adult populations in healthcare-related settings, and conceptually or empirically addressed PE-related constructs. Articles were excluded if they lacked empirical findings, focused solely on pediatric populations, or did not engage with the conceptualization of PE. In line with the RAMESES guidance, no formal quality appraisal checklist was applied. Instead, each article was critically appraised based on its conceptual relevance, methodological rigor, and epistemic contribution to the broader field.

Data extraction

A preliminary coding framework was developed based on the existing literature and refined inductively through immersion in the retrieved reviews. For each article, we extracted bibliographic details, conceptual definitions of PE, empirical factors influencing PE, identified levels (individual, task, relational, organizational, social), and methodological notes. Each article was carefully reviewed independently by the first and second authors. Data were extracted separately and then compared to identify elements, factors, and the corresponding levels of PE. Discrepancies were discussed until consensus was reached. This two-reviewer procedure was adopted to enhance the transparency, robustness, and validity of data extraction and synthesis.

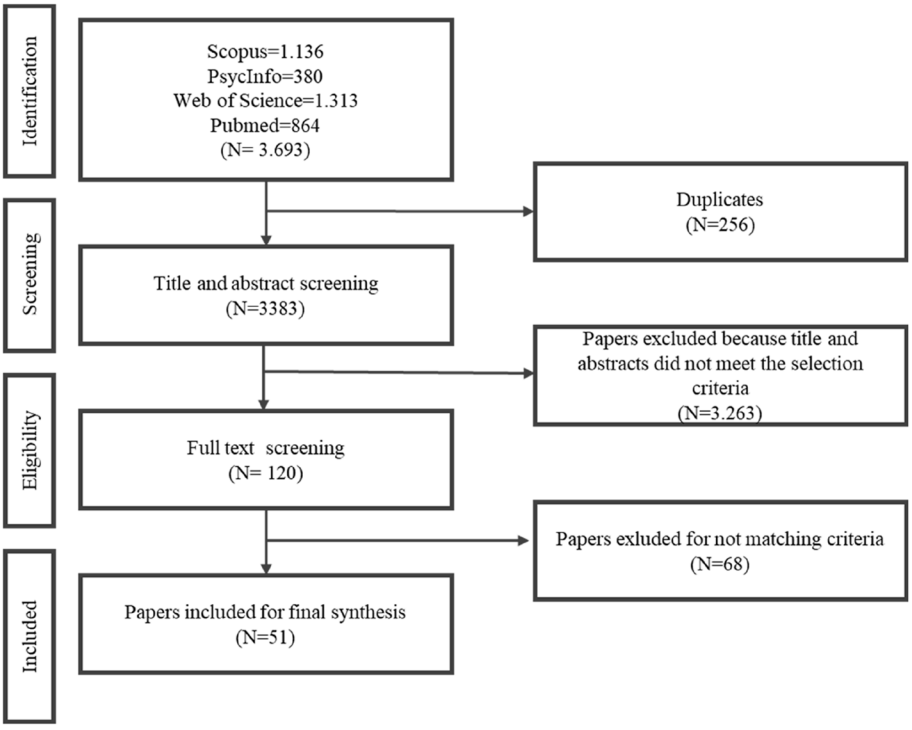

Fig. 1 Diagram of the process used to identify references for the review

Table 1 Multilevel factors influencing patient engagement

Setting	Number of studies	Sources
Cancer care	2	[32, 33]
Older adults with multimorbidity	3	[10, 34, 35]
Patient safety	3	[36–38]
Mental health services	2	[30, 39]
Planning of healthcare services	4	[23, 40–42]
Patient-centered care pathways	3	[43–45]
Drug management	1	[46]
Health research	9	[14, 19, 47–53]
Health community	4	[54–57]
COVID-19 pandemic	1	[18]
Inpatient settings	3	[31, 58, 59]
Health services and technology tools	12	[8, 28, 60–68]
General health setting	5	[29, 69–72]

Analysis and synthesis

The extracted data were first organized into a matrix to enable systematic comparison across articles. Elements were grouped inductively by levels and influencing factors. An inductiveanalysis was conducted to identify recurring patterns and divergent interpretations across research perspectives. Cross-tradition comparative synthesis (i.e., the integrative comparison of findings across different research perspectives to identify points of convergence, divergence, and complementarity in the conceptualization of the phenomenon) was used to explore how different disciplines conceptualize and operationalize PE. The synthesis aimed to generate integrative insights, highlight conceptual tensions, and contribute to the refinement of PE. Figure 1 shows the process and the results of search analysis.

Results

Overview of the collected items

Among the $N = 51$ collected items, there were one meta-analysis [28], one descriptive review [29], one integrative review [30], and a systematic rapid review [31], respectively. Most of the items collected were systematic reviews $n = 26$, $n = 14$ were scoping, $n = 5$ were narratives, and $n = 3$ were reviews. All these items referred to PE in different settings (see Table 1).

Factors related to patient engagement

Table 2 provides the differentiation of each level and the factors and elements associated with each level of PE.

Individual level

Multiple factors characterize individual-level experiences of PE. These factors span from (i) socio-demographic characteristics to (ii) psychological dimensions (i.e., cognitive, emotional, and behavioral but also include the level of (iii) health status and (iv) health literacy of patients. All these factors impact PE, yet they may act in tandem or parallel as they have interrelated relationships that determine variability between and within individuals.

Table 2 Multilevel factors influencing patient engagement

LEVELS	FACTORS	SPECIFIC ELEMENTS IDENTIFIED	REFERENCES (AUTHOR/S, YEAR)
INDIVIDUAL	Socio-demographic characteristics	Age	Cadel et al., 2021 [18]; Chegini et al., 2021 [36]; Irizarry et al., 2015 [62]; Kovacs Burns et al., 2014 70; Newman et al., 2021 [37]; Ocloo et al., 2021 [38]; Sarrami-Foroushani et al., 2014 55; Woodall et al., 2010 [53]
		Gender	Cadel et al., 2021 [18]; Filler et al., 2020 [43]; Gagliardi et al., 2019 [44]; Jørgensen et al., 2018 [33]
		Economic status	Cadel et al., 2021 [18]; Irizarry et al., 2015 [62]
		Ethnicity	Irizarry et al., 2015 [62]; Kovacs Burns et al., 2014 [70]; Sarrami-Foroushani et al., 2014 [55]; Woodall et al., 2010 [53]
		Language	Chegini et al., 2021 [36]; Filler et al., 2020 [43]; Irizarry et al., 2015 [62]; Kovacs Burns et al., 2014 [70]; Woodall et al., 2010 [53]
		Religion	Filler et al., 2020 [43], Jørgensen et al., 2018 [33], Pel-Littel et al., 2021[10]
		Culture	Chegini et al., 2021 [36]; Gartner et al., 2022 [45]; Irizarry et al., 2015 [62]; Newman et al., 2021 [37]; Ocloo et al., 2021 [38]
	Psychological characteristics (cognitive, emotional, and behavioral)	Awareness	Bonetti et al., 2022 [32]; Menichetti et al., 2018 [34]; O'connor et al., 2016 [65]
		Belief	Cozad et al., 2022 [8]; Pel-Littel et al., 2021 [10]; Sarrami-Foroushani et al., 2014 [55]; Woodall et al., 2010 [53]
		Trust	Almutairi et al., 2023 [28]; Dukhanin et al., 2018 [73]; Gartner et al., 2022 [19]; Harrison et al., 2019 [50]; Ocloo et al., 2021 [38]; Selvan et al., 2022 [56]
		Hope	Golubinski et al., 2020 [69], Woodall et al., 2010 [53]
		Mood status	Cadel et al., 2021 [18]; Chegini et al., 2021 [36]; Golubinski et al., 2020 [69]; O'connor et al., 2016 [65]; Woodall et al., 2010 [53]
		Self-efficacy	Barello et al., 2016 [60]; Bonetti et al., 2022 [32]; Cozad et al., 2022 [8]; Golubinski et al., 2020 [69]; Kovacs Burns et al., 2014 [70]; McCarron et al., 2019 [71]; Menear et al., 2020 [39]; Ocloo et al., 2021 [38]; Pel-Littel et al., 2021 [10]
		Coping skills	Barello et al., 2016 [60]; Bonetti et al., 2022 [32]; Dukhanin et al., 2018 [73]; Golubinski et al., 2020 [69]; O'connor et al., 2016 [65]
	Health status	Level of illness	Chegini et al., 2021 [36]; Golubinski et al., 2020 [69]; Kovacs Burns et al., 2014 70; Menichetti et al., 2018 [34]; Ocloo et al., 2021 [38]; Sarramii-Foroushani et al., 2014 [55]; Simblett et al., 2018 [68]; Woodall et al., 2010 [53]
	Health literacy	Medical knowledge/competencies	Barello et al., 2016 [60]; Bonetti et al., 2022 [32]; Cadel et al., 2021 [18]; Cozad et al., 2022 [8]; Kovacs Burns et al., 2014 [70]; Manafò et al., 2018 [31]; Menear et al., 2020 [39]; Menichetti et al., 2018 [34]; Mora et al., 2022 [29]; Newman et al., 2021 [37]; Snyder & Engström, 2016 [72]
		Technology literacy	Barello et al., 2016 [60], O'connor et al., 2016 [65]

Table 2 (continued)

LEVELS	FACTORS	SPECIFIC ELEMENTS IDENTIFIED	REFERENCES (AUTHOR/S, YEAR)
TASK	Online Medical Information	Accessibility	Newman et al., 2021 [37]; Ng et al., 2019 [64]; Oktay et al., 2021 [66]; Sawesi et al., 2016 [67]
		Credibility and Completeness	Dedding et al., 2011 [61]; Ng et al., 2019 [64]; Oktay et al., 2021 [66]; Prey et al., 2014 [59]
	Type of Treatment/Intervention	Educational (training and coaching)	Auwal et al., 2023 [46]; Gartner et al., 2022 [45]; Leung et al., 2019 [63]; McCarron et al., 2019 [71]; Menichetti et al., 2018 [34]; Ocloo et al., 2021 [38]; Sawesi et al., 2016 [67]; Søgaard et al., 2021 [35]; Woodall et al., 2010 [53]
		Workshop and focus group	Domecq et al., 2014 [49]; Leung et al., 2019 [63]; McCarron et al., 2019 [71]; Ocloo et al., 2021 [38]; Søgaard et al., 2021 [35]; Woodall et al., 2010 [53]
	e-Health tools (M-health, IT patient portal, Health Apps, etc.)	Perceived Value	Barello et al., 2016 [60], Irizarry, DeVito Dabbs, & Curran, 2015 [62]; Oktay et al., 2021 [66], Sawesi et al., 2016 [67]
		Type	Barello et al., 2016 [60], Leung et al., 2019 [63]; Ng et al., 2019 [64], Sawesi et al., 2016 [67]
		Usability	Irizarry, DeVito Dabbs, & Curran, 2015 [62]; Newman et al., 2021 [37, 64], O'connor et al., 2016 [65]; Sawesi et al., 2016 [67]; Simblett et al., 2018 [68]
		Health Information Exchange	Barello et al., 2016 [60]; Dedding et al., 2011 [61]; Gartner et al., 2022 [45]; Newman et al., 2021 [37]; Ocloo et al., 2021 [38]; Prey et al., 2014 [59]; Sawesi et al., 2016 [67]; Simblett et al., 2018 [68]
		Tailoring/personalization	Almutairi, Vlahu-Gjorgievska, & Win, 2023 [28], Dedding et al., 2011 [61]; Irizarry, DeVito Dabbs, & Curran, 2015 [62]; Prey et al., 2014 [59], Simblett al., 2018 [68]
		Self-Monitoring	Almutairi, Vlahu-Gjorgievska, & Win, 2023 [28]; Gartner et al., 2022 [45]; Irizarry, DeVito Dabbs, & Curran, 2015 [62]; Prey et al., 2014 [59]
		Trustworthiness	Almutairi, Vlahu-Gjorgievska, & Win, 2023 [28], Dedding et al., 2011 [61]; Irizarry, DeVito Dabbs, & Curran, 2015 [62]; Newman et al., 2021 [37], Prey et al., 2014 [59]
RELATIONAL	Inter-relational elements	Motivational Support for significant others (and family)	Bombard et al., 2018 [23]; Bonetti et al., 2022 [32]; Cené et al., 2016 [54]; Golubinski et al., 2020 [69]; Jørgensen et al., 2018 [33]; Manafo et al., 2018 [51]; 65 et al., 2016; Woodall et al., 2010 [53]
		Value	Chudyk et al., 2022 [48]; Fox et al., 2021 [19]; Kovacs Burns et al., 2014 [70]; Newman et al., 2021 [37]

Table 2 (continued)

LEVELS	FACTORS	SPECIFIC ELEMENTS IDENTIFIED	REFERENCES (AUTHOR/S, YEAR)
		Effective Communication	Auwal et al., 2023 [46]; Bombard et al., 2018 [23]; Cené et al., 2016 [54]; Chegini et al., 2021 [36]; Chudyk et al., 2022 [48]; Filler, Jameel, & Gagliardi, 2020 [43]; Golubinski, Oppel, & Schreyögg, 2020 [69]; Harrison et al., 2019 [50]; Jørgensen & Rendtorff, 2018 [30]; Manafo et al., 2018 [51]; Ocloo et al., 2021 [38]; Pel-Littel et al., 2021 [10]; Sarrami-Foroushani et al., 2014 [55]; Shippee et al., 2015 [52]; Snyder & Engström, 2016 [72]
		Partnership with health professionals	Bombard et al., 2018 [23]; Cené et al., 2016 [54]; Chegini et al., 2021 [36]; Chudyk et al., 2022 [48]; Gartner et al., 2022 [45]; Manafo, Petermann, Mason-Lai, & Vandall-Walker, 2018 [51]; Newman et al., 2021 [37]; Shippee et al., 2015 [52]
		Relationship building	Bombard et al., 2018 [23]; Cené et al., 2016 [54]; Chegini et al., 2021 [36]; Chudyk et al., 2022 [48]; Gartner et al., 2022 [45]; Manafo, Petermann, Mason-Lai, & Vandall-Walker, 2018 [51]; Newman et al., 2021 [37]; Shippee et al., 2015 [52]
		Patients feedback	Angel & Frederiksen, 2015 [47]; Bombard et al., 2018 [23]; Cené et al., 2016 [54]; Chegini et al., 2021 [36]; Crawford et al., 2002 [42]; Liang et al., 2018 [58]
	Intra-relational elements	Healthcare team communication	Harrison et al., 2019 [50]; Pel-Littel et al., 2021 [10]; Snyder & Engström, 2016 [72]
		Guidance on role	Auwal et al., 2023 [46]; Bombard et al., 2018 [23]; Crawford et al., 2002 [42]; Fox et al., 2021 [19]; Gartner et al., 2022 [45]; Harrison et al., 2019 [50]; Liang et al., 2018 [58]; Ocloo et al., 2021 [38]
ORGANIZATIONAL	Environmental and Structural Design	Privacy and safety	Auwal et al., 2023 [46]; Bombard et al., 2018 [23]; Crawford et al., 2002 [42]; Menear et al., 2020 [39]
		Simplifying appointment procedures	Chudyk et al., 2022 [48]; Crawford et al., 2002 [42]; Filler et al., 2020 [43]; Fox et al., 2021 [19]; Kovacs Burns et al., 2014 [70]; Menear et al., 2020 [39]
		Participation of family members/caregivers	Ankomah et al., 2021 [40]; Bosch et al., 2019 [41]; Cadel et al., 2021 [18]; Chudyk et al., 2022 [48]; Filler et al., 2020 [43]; Gartner et al., 2022 [45]; Leung et al., 2019 [63]; Newman et al., 2021 [37]; Ocloo et al., 2021 [38]
	Patient-Centered Care	Sharing goals and values	Ankomah et al., 2021 [14]; Bethell et al., 2018 [14]; Bonetti et al., 2022 [32]; Filler et al., 2020 [43]; Gagliardi et al., 2019 [44]; Liang et al., 2018 [58]; Shippee et al., 2015 [52]
		Access to educational materials and peer support	Ankomah et al., 2021 [40]; Jørgensen et al., 2018 [33]; Usher & Denis, 2022 [57]
		Coordination of care and follow-ups	Bethell et al., 2018 [14]; Bombard et al., 2018 [23]; Filler et al., 2020 [43]; Fox et al., 2021 [19]; Gagliardi et al., 2019 [44]; 63et al., 2019; Søgaard et al., 2021 [35]
		Physical spaces	Chegini et al., 2021 [36]; Gartner et al., 2022 [45]; Usher & Denis et al., 2022 [57]

Table 2 (continued)

LEVELS	FACTORS	SPECIFIC ELEMENTS IDENTIFIED	REFERENCES (AUTHOR/S, YEAR)
	Health services accessibility and resources	Admissions, readmissions, and healthcare visit frequency	Bombard et al., 2018 [23]; Jørgensen et al., 2018 [33]; Kovacs Burns et al., 2014 [70]; Mora et al., 2022 [29]; Newman et al., 2021 [37]
		Extending opening times and improving transport to treatment units	Bethell et al., 2018 [14]; Crawford et al., 2002 [42]; Gartner et al., 2022 [45]; Kovacs Burns et al., 2014 [70]; Manafo et al., 2018 [51]; Pel-Littel et al., 2021 [10]; Shippee et al., 2015 [52]
		Support from existing resources and infrastructure	Bethell et al., 2018 [14]; Chudyk et al., 2022 [48]; Filler et al., 2020 [43]; Fox et al., 2021 [19]; Kovacs Burns et al., 2014 [70]; Manafo et al., 2018 [51]; Menear et al., 2020 [39]; Mora et al., 2022 [29]; Snyder & Engström, 2016 [72]
	Leadership and Healthcare Management	Institutional commitment and leadership involvement	Bombard et al., 2018 [23]; Chudyk et al., 2022 [48]; Gagliardi et al., 2019 [44]; Liang et al., 2018 [58]; Manafo et al., 2018 [51]; Menear et al., 2020 [39]
SOCIAL	Cultural and Social Norms	Gender inequality	Filler et al., 2020 [43]; Gagliardi et al., 2019 [44]; Jørgensen et al., 2018 [33]; Selvan et al., 2022 [56]
		Stigma	Filler et al., 2020 [43]; Selvan et al., 2022 [56]; Woodall et al., 2010 [53]
	Community Engagement and Support	Community health councils and patient groups/forums	Ankomah et al., 2021 [40]; Menear et al., 2020 [39]; Ocloo et al., 2021 [38]; Usher & Denis, 2022 [57]; Woodall et al., 2010 [53]
	Healthcare Policies and Systems	Healthcare policies	Ankomah et al., 2021 [40]; Cozad et al., 2022 [8]; Crawford et al., 2002 [42]; Menear et al., 2020 [39]; Sarrami-Foroushani et al., 2014 [55]; Usher & Denis, 2022 [57]
		Co-leadership in policymaking	Kovacs Burns et al., 2014 [70]; [39], Usher & Denis et al., 2022 [57]
		Systems of payment	Filler et al., 2020 [43]; Ocloo et al., 2021 [38]; Pel-Littel et al., 2021 [10]

Socio-demographics characteristics

Socio-demographic characteristics are elements of individuals' biographies. This is the case for age, which appears to be one of the mainstays in the empirical literature on PE. Evidence suggests that age differences reflect variations in PE experiences [18, 36, 53, 55, 62], as age is also closely related to patients' health status [38]. For example, younger patients appear less compliant with their care compared to older ones [37]. Similarly, gender seems to lie at the nexus between compliance with care and the availability of treatments, showing differences between male and female patients [18, 33, 43, 44, 53, 62].

Patients' proactive behaviors and decisions can also be affected by economic constraints, especially among marginalized groups [43]. Financial status, which is closely related to other individual elements such as language, ethnicity, and religion, can significantly affect decision-making and participatory behaviors—critical components of PE [18, 62].

Moreover, ethnicity [53, 55, 62], religion [10, 33, 43], and language [36, 43, 53, 62] are also interrelated elements influencing PE experiences. For example, due to ethnicity, gender, and age, there seem to be differences in care provision, with less involvement of minority ethnic groups [53]. Pel-Littel et al. [10] showed that religion-based values can affect how individuals view suffering, shaping PE experiences, while language differences may also influence how patients understand care and treatments [36, 43, 53, 62]. Overall, this group of factors highlights the role of culture and cultural beliefs [36–38, 45, 62], reminding us of the importance of addressing patients' cultural backgrounds to enhance their proactive approaches and awareness [37].

Psychological characteristics

Scholars discuss a series of psychological elements broadly grouped into cognitive, emotional, and behavioral domains that characterize the experience of PE. The primary evidence on cognitive aspects concerns the role

of patients' awareness of their health status and symptoms [34, 65], which affects their agency in treatment. Knowledge, skills, and confidence are crucial in determining patients' involvement [32]. Additionally, scholars have discussed how personal beliefs can hinder or facilitate PE [55], such as the belief that patients are "the ones with the most knowledge about their own body and conditions" [10] and the belief in disease control [8].

Regarding emotional elements, trust and hope are widely discussed as essential emotional components of patient engagement [28, 53, 69]. For example, trust mitigates power imbalances because it supports open dialogue with the care team [38, 50] and ensures effective interactions for monitoring patient progress [45]. This is particularly evident among minority groups, such as refugees, for whom trust and mistrust are crucial for engagement in care pathways. Refugees tend to trust community members who support healthcare practices more than clinicians themselves [56]. In contrast, negative psychological states such as depression and anxiety [39, 69] represent barriers to positive levels of PE due to the stigma associated with these conditions [33, 36, 53].

Lastly, we also identified behavioral elements characterizing the experience of PE. At the intersection between cognitive and behavioral components, self-efficacy improves the PE experience and expression [8, 10, 38, 39, 69–71]. For example, patients actively engaged in their healthcare demonstrate more adaptive behaviors, resulting in a significant and positive enhancement in self-efficacy for health self-management [60]. Moreover, for some scholars, self-efficacy reflects engagement through relatively stable patient behaviors [32]. This refers to patients' coping skills, which affect how they manage illness experiences, for example, in a proactive way [32, 60, 65]. Scholars have also highlighted that improving patient engagement may require training in motivational and coping skills to increase self-management [69].

Health status

Unsurprisingly, health status represents a key element of PE, with different experiences and treatments arising from variations in disease type and severity [34, 36, 38, 69]. Regardless of the specific disease, there is broad consensus on distinguishing between the effects of acute exacerbations of health problems and long-term illness, with the former representing a pressing barrier to PE [53, 55, 68, 70]. Conversely, chronic illness and the passage of time, rather than symptom flare-ups, can function as both enablers and barriers to engagement [38, 69].

Health literacy

Although connected to psychological characteristics, health literacy is a core element of PE that warrants specific attention. It is a multifaceted concept encompassing medical and health-related skills and competencies. Scholars have shown that transferring medical knowledge to non-medical audiences through educational programs can improve patients' attitudes toward treatment [29, 34, 39, 51, 60, 70, 72]. Patients' expertise in treatment and disease positively influences beliefs and self-efficacy, improving treatment adherence [32, 378], whereas over- or underestimation of self-perceived health literacy may negatively affect PE [67].

Studies have also highlighted that low levels of technological literacy (e.g., limited proficiency in information technologies, technical limitations such as unstable rural internet connections [60], or lack of familiarity with using technology such as websites, smartphone apps, and wearable devices) can pose challenges or create frustration for patients [65, 68].

Task level

Patient interaction with healthcare systems plays a pivotal role in their experience of PE. This interaction is shaped by multiple system components, ranging from access to reliable online medical information—used by patients to learn about symptoms or treatments—to providerled educational interventions that foster awareness and shared decisionmaking. We classified these system features as potential task influencers, representing the actions patients perform or receive while engaging with the healthcare system. In the literature, there are a series of actions that include (i) online medical information that patients can have access to, (ii) type of treatment/intervention offered by the healthcare organization to accompany patients, and (iii) e-Health tools (M-health, IT patient portal, Health Apps, etc.). As for the other levels, tasks also directly influence PE, yet they also interact with different factors at the various levels.

Online medical information

Online medical information is distributed across various websites, and patients may use this information to understand their symptoms or medical treatments. The accessibility and quality of health information sources are key enablers of PE that foster the development of well-informed consumer patients [37, 64, 67]. Characteristics related to these elements include the effectiveness of content, which must be readable to individuals with different health literacy levels [66]. In this regard, the credibility and completeness of online medical information serve as boosters for promoting PE [59, 61, 64]. The primary features influencing the credibility and completeness of information that affect PE include authorship, institutional affiliation, editorial team, creation date, update date, backing, accreditation, and funding [66]. Additionally, a lack of credibility and completeness in medical information can present a significant barrier to

leveraging the Internet effectively as a resource [59, 61, 64]. Accordingly, when healthcare organizations cannot provide training or access to medical information, they can recommend specific sources to inform patients and, in turn, promote their PE.

Type of treatment/intervention

Patients may receive specific training to increase their knowledge and awareness of medical treatment, diagnosis, and other health aspects. Whether offered by a healthcare provider or by external entities such as nonprofit and voluntary organizations, these training programs represent opportunities for increasing PE [38, 46, 53, 63, 67]. Menichetti et al. [34] indicated that adherence to and engagement in medication regimens were most effectively achieved through educational, behavioral, and affective training. Providing opportunities for patients to interact with other patients or practitioners gives them a sense of value and enhances their confidence and self-esteem [45, 71] and that continuous provider training is necessary [34].

Scholars have also reported the role of coaching by specialists in supporting patients before, during, and after treatment, which can alleviate pain and accelerate the recovery process [49, 53, 67]. Additionally, conducting focus groups with patients to solicit feedback on specific treatments (e.g., the use of particular technological tools or the need for changes in tacit knowledge) can be helpful for a comprehensive evaluation of the treatments themselves [38, 63]. Workshops also play a crucial role in helping patients develop the skills necessary to participate in specific tasks and improve self-efficacy [35], as evidenced by studies highlighting their role in creating a shared definition of patient-centeredness [71].

e-Health tools

The term *e-health tools* refers to a broad range of technological instruments developed and used for medical purposes. These tools vary in scope and functionality, some directly contributing to improved PE [60, 61, 66]. The perceived value and usability of such technologies influence how patients and healthcare providers engage in care [62, 67]. User-centered interfaces enhance the experience and encourage sustained use, while the type and accessibility of technologies adopted for medical purposes shape how PE is promoted and experienced [60, 63, 64, 67].

However, the absence of adaptive or responsive interfaces that adjust to users' behavior, progress, or literacy levels can hinder sustained engagement. When systems fail to adapt to patients' needs or preferences, users may perceive the interaction as static and disengage over time [60, 66].

Internet-based and mobile technologies have been widely applied to engage patients and support behavior change [62, 64, 65, 67, 68], which are often linked to better health outcomes [37, 67]. Nevertheless, technical issues such as system errors, unstable connections, or slow data synchronization can interrupt these processes and create frustration, reducing patients' trust in the system and ultimately hindering engagement [66, 68].

Moreover, e-health tools can facilitate the exchange of medical information and communication between patients and providers [37, 60, 67], as well as among professionals themselves. For instance, national electronic health record systems enable information sharing and coordination across providers [38]. These technologies also offer interactive mechanisms, supporting patient decision-making and fostering self-disclosure [59, 61]. Providing tailored information helps patients perceive these systems as reliable and authoritative, enhancing their involvement [59, 68].

Given their scalability, e-health tools can be tailored to patients' needs, preferences, and contexts, thus strengthening engagement in health interventions [61, 68]. Self-monitoring functions allow individuals to track various health aspects and feel more involved in their care pathways [28, 45, 59, 62]. Likewise, providing interactive reports about progress, care plans, or team information can reduce anxiety and reinforce engagement [59]. Integrating care flow management systems aligned with clinical workflows enables visualization of real-world data through performance dashboards, which facilitate timely adjustments and support patient participation [45].

Finally, trustworthiness and transparency are essential for maintaining patients' confidence in these technologies [37]. The continued use of e-health systems depends largely on how transparent and fair they are perceived to be [61, 62]. When systems ensure privacy and provide accurate, unbiased information, patients show a greater willingness to use them and engage in their care [28, 59].

Relational level

As a relational experience, patient engagement is influenced by multiple factors. On the one hand, intergroup dynamics, particularly the relationships between healthcare providers, patients, and their families or significant others, play a crucial role. On the other hand, intragroup interactions among all actors within healthcare services, including team dynamics, also significantly shape the engagement process. We have grouped these relational factors into two main categories (i.e., inter and intra-relational elements), encompassing all the characteristics that can shape care relationships between patients and healthcare providers.

Inter- relational elements

The literature indicates that among the interrelated characteristics of relational dynamics, motivational support

from significant others—including family members—plays an increasingly important role in shaping patients' experiences [19, 32]. For example, social support from family members affects patients' activation in their care [51, 53, 69], as well as their involvement and collaboration in medical rounds, which are associated with positive outcomes and increased satisfaction from both patients' and healthcare providers' perspectives [23, 54]. These effects are generally attributed to the opportunities patients have to share information or experiences within a group or to receive support from others, facilitating empowerment [33] and leading to positive care outcomes [65, 71].

Moreover, respecting and valuing all actors in the healthcare system—including patients and relatives—as equal partners, by understanding their values and needs and emphasizing informed and shared medical decisions (37, 48, 70]. These dynamics are made possible through practical and open communication with healthcare providers [23, 46, 50–52, 55, 69], who can influence positive patient behaviors by encouraging proactivity and involvement [30, 54, 72], and assist in selecting appropriate treatment options [48, 72]. This approach can deepen the understanding of patients' subjective experiences [52], for example, by taking extra time to check patients' comprehension, becoming familiar with their cultural backgrounds, and accommodating cultural differences [43]. These practices contribute to building a trusting environment that encourages patient involvement and engagement in their care [36, 38]. Conversely, poor communication techniques—including inadequate language choices and a lack of empathy—are significant barriers to shared decision-making [10].

Closely intertwined, establishing quality and reciprocal relationships with healthcare providers is a critical component of the patient experience [23, 37, 48, 51, 52, 54]. Developing trust-based relationships is viewed by patients as an important factor in sharing concerns freely [36]. On the other hand, studies suggest that poor relationships can negatively impact processes and tasks associated with care, highlighting this factor as a fundamental requirement [45].

Some authors emphasize the importance of physicians' ability to engage in dialogic communication, actively listen [36], utilize various communication methods [38], allocate adequate interaction time [30], and encourage or instruct patients to ask questions or participate in specific actions [14, 23, 43, 51, 52, 54, 55, 69]. From the healthcare provider's perspective, the collection of patient feedback contributes to the enhancement of healthcare services, emphasizing the importance of cooperation in fostering patient involvement [23, 36, 47, 58]. Patient feedback has also proven valuable in helping clinicians better understand the patient experience [42, 54].

Intra- relational elements

Regarding intra-related characteristics, effective communication within the healthcare provider team [50], reasonable cooperation, and consistent vocabulary among interdisciplinary team members [10] facilitate shared decision-making. Interestingly, research highlights the need for specific training to improve healthcare providers' communication skills within work teams [72].

Moreover, a clear definition of guidance and roles [46], such as specifying the tasks and responsibilities of each team member [19], can act as a catalyst for promoting PE [23, 38, 42, 45, 50, 58].

Organizational level

The healthcare organization's environment and design can influence variations in the expression and experience of PE. Tailoring healthcare pathways to align with individual needs and external and internal resources, along with the support of other institutions, provides the strength and resources necessary to foster and promote PE. Specifically, these factors include (i) environmental and structural design, (ii) person-centered care, (iii) health services accessibility and resources, and (iv) leadership and healthcare management.

Environmental and structural design

Regarding the general healthcare environment and organizational design, a crucial element pertains to safety and privacy concerns [23, 39, 42]. For example, there is a need for prior documentation, such as consent agreements, to provide all parties with the necessary protection concerning independence, privacy, confidentiality, and expectations [46]. Systematically, simplifying and making appointments more flexible could also benefit patients with multiple jobs or shift work, thereby ensuring greater engagement and involvement [43]. As frequently reported, there is a need to improve service accessibility by simplifying appointment procedures through various methods (e.g., digital tools, extended hours) [19, 39, 42, 48, 70].

Structurally, including families in organizational design can help engage diverse patients from different ethnic and cultural backgrounds [40]. Studies have shown that relatives play a significant role in safety by helping to prevent medication errors, providing home supervision, and offering support [38, 43, 45, 48, 63]. Research has demonstrated that better healthcare services are often evaluated not only through patient satisfaction but also through the preferences of families and caregivers [41]. Based on these findings, an organizational cultural shift toward valuing patients, families, and caregivers as partners is essential [37]. This means that caregivers should be included as team members or co-designers of

interventions [18] and as facilitators from a cultural perspective [40].

Patient-centered care

According to the patient-centered care approach, it is essential at every organizational level to establish clear and shared goals, values, and practices that ensure meaningful participation and prevent patients and service users from being treated as passive recipients of care (for example, when clinical decisions are made without considering patients' preferences or experiences). [43, 58]. The patient-centered approach prioritizes respect for individual needs and preferences, fosters empathy and trust, and seeks to deliver personalized, responsive, and dignified care tailored to diverse patient contexts and needs to improve healthcare quality and reduce gender and social disparities [44].

Regarding this approach, some practices, such as providing information, including service user networks, healthcare forums, and interventions by trained peers at the organizational level, can enhance service accessibility and improve PE [33, 57]. Organizations must consider care coordination and follow-ups [44, 63] in terms of different solutions and terms of different patient needs [35]. For example, Bombard et al. [23] developed a model for shared care in secondary cancer follow-up involving general practitioners supported by specialists,setting expectations for follow-up care can help patients prepare for self-management of their health and well-being [43]. Moreover, how physical spaces are designed, such as open spaces, where patients may exchange knowledge, thereby developing and spreading capacities among each other independently from healthcare providers, may increase PE [45, 57]. Conversely, inadequate infrastructure, including communication failures and lack of patient-centered support, was identified as a barrier to PE [36].

Health services accessibility and resources

Due to a lack of resources and the complexity of care systems, innovative solutions are needed to ensure that service users can influence the delivery of their care, particularly at critical points of admission and discharge, to improve PE [29, 33, 37, 70]. Furthermore, research has shown that involving patients in the delivery or redesign of healthcare at the organizational level can reduce hospital admissions and readmissions [23].

Utilizing systems that reduce the distance between patients' homes and healthcare services (e.g., telemedicine) and extending opening hours can enhance the ability to reach more patients, including those in rural areas, international locations, or with low socioeconomic status, thereby improving access and PE [14, 42, 45, 51, 70]. One of the organizational constraints is the lack of resources, particularly in terms of time [10, 52].

Kovacs Burns and colleagues (2014) [70] emphasized a key aspect: the added value of patient involvement has often not been measured economically and therefore needs to be appropriately compensated. Consequently, research indicates that external organizations actively endorsing PE serve as catalysts for its success [14, 19, 29, 39, 43, 48, 51, 72].

Leadership and healthcare management

Actions and involvement by organizational leaders are critical facilitators of successful engagement [23, 44, 48, 51]. Having managers recognize and advocate for the importance of patient involvement may increase patients' sense of empowerment and commitment, ensuring the organizational sustainability of engagement [23]. Furthermore, members of citizen advisory panels assist leaders in various processes [58], and strong co-leadership shared with patients and families is a crucial element in fostering PE [39].

Social level

Due to its complex and multifaceted nature, PE can be described as a social phenomenon in which various social structures and institutional systems shape patients' engagement experiences. This perspective, emerging from recent studies on PE, highlights how certain groups may be systematically excluded from engagement processes due to cultural and social inequities [24, 25]. It reinforces the idea of a multilayered structure of PE, in which social components play a crucial role in facilitating—or hindering—patients' involvement. Specifically, these factors include (i) cultural and social norms, (ii) community engagement and support, and (iii) healthcare policies and systems.

Cultural and social norms

From a societal perspective, the variance in the experience of PE may be influenced by disparities between women and men, commonly referred to as gender inequality. In situations where women had limited mobility and interactions outside their families, they were not expected to seek community-based or PE-related practices [56], furthermore, in these scenarios, both patients and clinicians viewed the same culture or gender as facilitators [43]. Gagliardi and colleagues' (2019) [44] review of patient-centered care for women aimed to address socio-economic factors contributing to gender disparities in healthcare quality, such as emphasizing the need for integrated programs that meet women's needs across their lifespan, enhanced provider training on women's specific health issues, and strong public health leadership

to advocate for women's health by considering their social and economic contexts [33].

Lastly, cultural perspectives, together with norms and rules, can raise issues of stigma (e.g., related to mental illness, racism, or gender bias). Moreover, reluctance to seek help for certain health conditions (e.g., HIV/AIDS) may be exacerbated by a tendency to rely on traditional medicine or religious beliefs [56]. Stigma and general distrust can also stem from a lack of understanding about an illness [53], particularly for health issues such as mental disorders [43]. In addition, another form of stigma that is not disease-related concerns systemic racism and discrimination, particularly among refugee populations [56]. This review highlights two types of systemic discrimination: direct discrimination, through the denial of services, and indirect discrimination, through substantial waiting times despite having scheduled appointments for health services..

Community engagement and support

A key role in promoting a positive PE experience can be played by communities willing to engage with and support healthcare services [39, 40]. Support mechanisms that assist patients in accessing healthcare include consultations, patient representation on advisory boards, surveys, community health councils, patient groups or forums, and various projects within hospitals or the community [57]. Ocloo and colleagues (2021) [38] found that incorporating community engagement—by allocating sufficient time for community members and other stakeholders to build relationships, ensuring agreement on a "level playing field" regarding language, negotiation, and collaboration skills, and increasing awareness of funding opportunities—may enhance the PE experience.

In some contexts, ongoing consultation with community leaders (e.g., spiritual leaders or elected representatives) is essential to ensure that feedback from the community is received and that programs address their specific needs [53]. Public meetings, such as town halls, represent another, more politically oriented method to encourage community involvement in healthcare services.

Healthcare policies and systems

Social and cultural norms shape and influence the development of healthcare policies [8, 39, 42]. These may include, for example, the design and implementation of new healthcare technologies in which patients and the public can participate [55]. At the macro policy and strategic level, such as national government policies, strategies aimed at improving the overall health system also play a critical role in enhancing PE [40]. However, achieving this requires a shared language and a deeper understanding of what PE entails—both essential for developing knowledge that drives innovation in clinical practice and health policy [57].

Since the early twenty-first century, the lack of sufficient political commitment to patient involvement has been identified as one of the most persistent barriers to PE [39, 70]. Usher and colleagues (2022) [57] demonstrated that the theory of change in co-leadership governance emphasizes the development of new capacities and conditions for joint action in public and PE initiatives.

In conclusion, according to Ocloo and colleagues (2021) [38], adequate funding and resources—including transparency regarding the availability of funds and significant investment from higher education institutions to integrate engagement practices [43]—are crucial for effective PE. Moreover, payment systems are usually based on productivity, meaning that compensation is provided only when a medical treatment or intervention is performed. This can hinder the shared decision-making process, as it incentivizes selecting an intervention over watchful waiting [10].

Discussion and theoretical integration

The review mapped existing theoretical and empirical perspectives on PE focusing on the antecedents of PE. The review presented a specific structure composed of five levels (individual, task, relational, organizational, and social) within which related factors and elements appear to be crucial for PE. That is, findings indicate that PE operates across multiple levels, where various factors and elements exert influence, and these factors are interdependent, creating a dynamic and interconnected system. Considering PE via a multi-level perspective can help address both theoretical gaps and practical challenges. These findings may have implications for different healthcare sectors [8–10], types of interventions [8, 11, 12], and fields of research [49]. Ultimately, understanding how and which factors and elements could impact PE at different levels is essential to the effectiveness and quality of healthcare services.

Based on the review's findings, we can suggest an integrative multilevel model of factors and elements fostering PE, as illustrated in Fig. 2. This model illustrates the relationships among the individual, task, relational, organizational, and social levels identified in the literature review. All the factors at the different levels presented in the model appear to be separeted but cross-influenced. For example, factors at the individual level may be influenced by task level factors and vice-versa. Likewise, societal factors can influence individual aspects which in turn may result in patient engagement. Nested circles visually represent these structures and their relational architecture. Starting from the micro level and progressing to the macro, with the task level intersecting throughout,

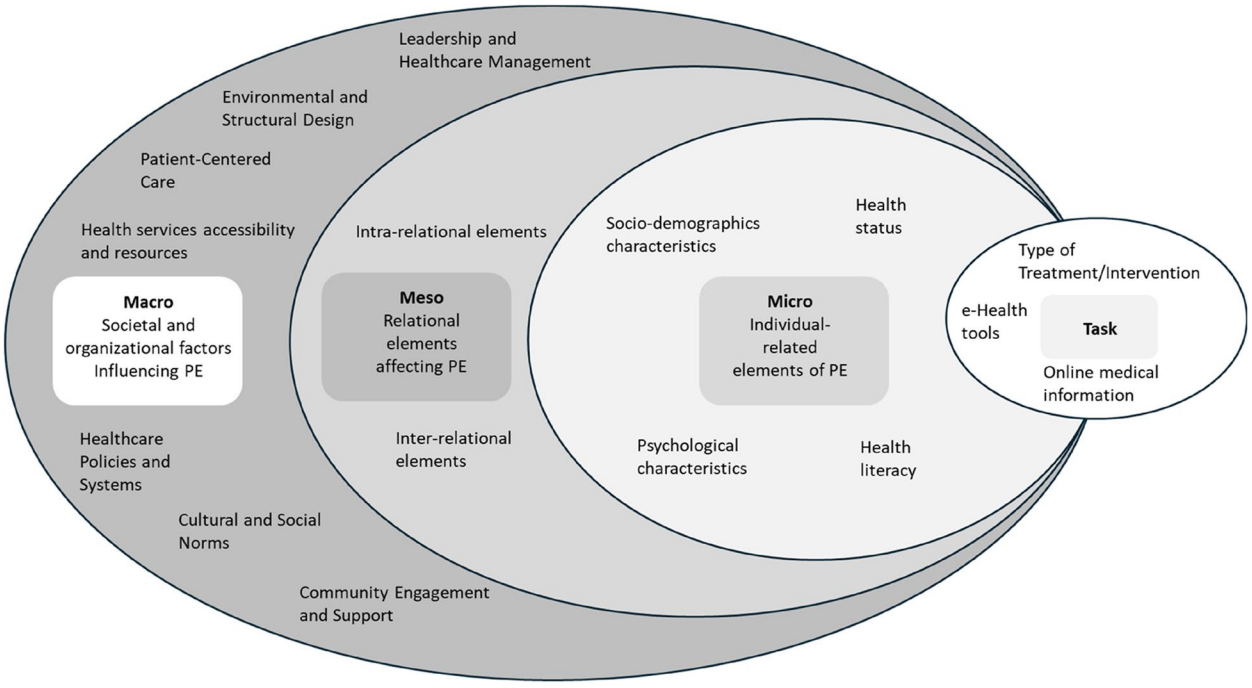

Fig. 2 Representation of a multi-level integrative model of patient engagement

it is crucial to understand how the surrounding context shapes individuals' behavior.

According to the macropsychology approach of MacLachlan and McVeigh [74], the multilevel PE model can be understood as an open system embedded within its environment. For instance, the causes and effects at different levels, along with the associated factors and elements, are bidirectionally related in a continuous feedback loop. Changes at one level can have identifiable effects on other levels. For example, patients who fail to communicate effectively with healthcare providers may experience a decrease in trust [36, 38, 50]. Thus, the relational level can influence the individual level within this model, highlighting the need for a multilevel understanding of these dynamics.

This holistic approach to PE, integrating micro-, meso-, and macro-levels with the task level, facilitates targeted interventions across these interconnected networks. This framework pinpoints the elements and their relationships both within and across different levels. Furthermore, identifying which factors are distinct and which overlap across levels is essential for better understanding and mobilizing PE. These efforts clarify what constitutes PE and create opportunities for actionable strategies. However, future research is needed to test the integrative model. Testing the model in its entirety is highly challenging, given its complexity. Therefore, several methodological possibilities could help examine the multilevel nature of PE and develop an inventory applicable to specific healthcare contexts or disease-related studies. Diary studies conducted with specific patient populations could be particularly effective in assessing the fluctuations of elements and factors that are strongly dependent on context. Furthermore, qualitative studies could also be conducted to explore the reciprocal influences among different dimensions.

Lastly, this contribution is not exhaustive. The review is limited to pre-existing studies that may not cover all possible management options. Moreover, we have analyzed PE as a theoretical phenomenon without situating it within a specific context. Our model does not reflect a particular group of people with a specific pathology; therefore, it could be tested with specific populations and illnesses. Nevertheless, the present paper represents the first attempt to offer a holistic and integrative approach to PE that can inform future studies and practices.

Abbreviations

PE	Patient Engagement
RAMESES	Realist And Meta-narrative Evidence Syntheses: Evolving Standards
SCOPUS	Elsevier's Scopus database
WOS	Web of Science
PubMed	U.S. National Library of Medicine biomedical literature database
PsycINFO	Psychological Information Database (American Psychological Association)
e-health	Electronic health (use of digital technologies in healthcare)
m-health	Mobile health (use of mobile devices in healthcare delivery)
IT	Information Technology
HIV/AIDS	Human Immunodeficiency Virus / Acquired Immunodeficiency Syndrome

Supplementary Information

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Supplementary Material 1.

Supplementary Material 2.

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