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# Unraveling the meaning of patient engagement: A concept analysis



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# ABSTRACT

*Objective:* Patient engagement has been credited with contributing to improved outcomes and experiences of care. Patient engagement has become a widely used term, but remains a poorly understood concept in healthcare. Citations for the term have increased throughout the healthcare-related disciplines without a common definition. This study seeks to define the concept by identifying its attributes in the context of its use.

*Methods*: A concept analysis of the scientific literature in the health disciplines was performed using the Rogers method.

Results: The analysis revealed four defining attributes of patient engagement: personalization, access, commitment and therapeutic alliance. Patient engagement is defined as the desire and capability to actively choose to participate in care in a way uniquely appropriate to the individual, in cooperation with a healthcare provider or institution, for the purposes of maximizing outcomes or improving experiences of care.

*Conclusion:* Patient engagement is both process and behavior and is shaped by the relationship between the patient and provider and the environment in which healthcare delivery takes place.

*Practice implications*: The definition and the identified attributes serve as a heuristic in designing patient engagement strategies and as a basis for future development of the patient engagement concept in healthcare.

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# 1. Introduction

As contemporary healthcare evolves from a disease-centered to a patient-centered model [1], the concept of patient engagement assumes a pivotal role. The use of the term patient engagement has rapidly expanded in the health sciences. The concept has been referenced in literature published on patient-centered medical homes [2], comparative effectiveness research [3], use of technology for inpatient settings [4], ambulatory chronic care management [5], patient safety for prevention of adverse events [6] and controlling healthcare costs [7]. Definitions of patient engagement have varied over time and across contexts, however, rendering the essential nature of the concept elusive. Nevertheless, the US National Coordinator (ONC) of Health Information Technology has described patient engagement as one of the most underutilized resources in healthcare and a potential "blockbuster drug" [8], but has not referenced a definition of the concept.

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The frequency of citations of the term "patient engagement" in the scientific literature has increased markedly since the introduction of the term in the 1990s, tripling between 2010 and 2013 in Web of Science. One reason for this increase is that the federal government now offers reimbursement for the use of health information technology to enhance patient engagement [9]. Conversations in social media and coverage by industry analysts reveal concerns about what patient engagement is and how to achieve it [10]. These concerns have arisen in part due to recent policy guidelines by the Centers for Medicare and Medicaid Services (CMS) that tie provider reimbursement to levels of patient engagement [11].

Accompanying this emphasis on patient engagement is emerging evidence of an association between patient engagement and quality in healthcare [12]. The meaning of the concept of patient engagement deserves close scrutiny to inform future practice, policy and research for improving quality of care. Outcomes research requires specific constructs and variables to measure the impact of patient engagement strategies, while efforts to improve the experiences of care may benefit from new insight into the definition of the concept of patient engagement. The varied and numerous references to patient engagement in the

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literature, combined with the emerging evidence of its potential to influence quality of care, constitute a relevant case for an in-depth analysis to construct a definition by determining the core attributes of the concept. Hence, the aim of this paper is to present a concept analysis of patient engagement to assemble that definition.

#### 2. Methods

Roger's Evolutionary Method [13] was used as the basis for this concept analysis. The method is comprised of six components described below where appropriate.

# 2.1. Identify the concept of interest and its associated expressions

# 2.1.1. Identify and select an appropriate realm (setting and sample) for data collection

The first author conducted a literature review using SCOPUS, CINAHL, Web of Science and Psychinfo using the term "patient engagement" in the title, keyword, or abstract. The review was limited to articles published between January 1, 1990 and June 1, 2014 in English. Final inclusion criteria were articles that used patient engagement as a measure within a study, defined the term within the article, or featured patient engagement as a topic in the article. The context for the use of the concept was noted in terms of the associated policy, clinical discipline or research activities. Individual attributes became evident in each article by consideration of explicit use, placement in the context of the article or the intent of the phrase being used [13].

# 2.1.2. Collect data relevant to identify

a) the attributes of the concept and b) the contextual basis of the concept including disciplinary, sociocultural and temporal (antecedent and consequential occurrences) variations: Words or phrases that represent attributes of patient engagement as they presented in each article as well as the antecedents and consequences were recorded on a spreadsheet. To ensure an unbiased interpretation of the data, a sample of ten articles was coded by two additional graduate students in the health sciences to compare the process of selection of attributes, antecedents and consequences. Any discrepancies were resolved by consensus. Frequency of use of the term patient engagement over time and within each discipline was calculated. The development of the concept over time was considered through a thematic assessment of the evolution of the concept in the literature. The complete list of attributes was reduced by combining synonyms and like phrases.

# 2.1.3. Analyze the data regarding the above characteristics of the concept

Using content analysis, the reduced list of attributes was reviewed, organized, clustered, and reorganized thematically. Through the hermeneutic process of thematic reflection at the micro level (by organizing the attributes) and the macro level (by rereading of the articles), a coherent, comprehensive yet parsimonious set of descriptors that served as the defining attributes of the concept was generated. The graduate students again reviewed the coding sheets, the researcher's journal, and 10% of the literature included in the analysis to verify the validity of the thematic coding and the presence of the attributes within the articles, and added insights into attributes of the concept. Further credibility for the analysis was maintained through an audit trail of the work processes, decisions, and interpretations in the researcher's journal as well as maintenance of the database in which the notes on each article was recorded. The reduction of attributes to those defining elements combined with consideration of the antecedents and consequences formed the creation of the definition of the concept of patient engagement.

# 2.1.4. Identify an exemplar of the concept

Potential exemplars (model cases) were noted during the article review and one was selected that illustrated the four defining attributes in a clinical setting.

# 2.1.5. Identify implications, hypotheses, and implications for further development of the concept

Once the inductive analysis was complete, a conceptual definition of patient engagement was created and the appearance of the attributes in various contexts was established.

#### 3. Results

# 3.1. Identification of the concept of interest and associated expressions

The concept of patient engagement was identified due to its frequent, wide ranging references in recent literature.

No appropriate surrogate terms for patient engagement were identified as no other term proposes the same breadth of concept. We searched for definitions of related expressions such as patientcentered care, patient involvement, participation, activation and empowerment. Patient-centered care is defined by the Institute of Medicine as "Providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions [14]. Patient involvement, participation, activation and empowerment are often focused on the patient exclusively, rather than the relationship and interaction between provider and patient and are recursive with patient engagement [15] in that they may be both antecedents and consequences of the process of patient engagement. In other words, patient engagement may lead to increased activation, empowerment, participation, or involvement, as well the anticipated health outcomes. But the processes associated with activation, empowerment, increased participation and involvement may also contribute to a state of patient engagement. All of the related terms represent concepts of a more narrow range than that of engagement. Activation is patientfocused and indicates the patient's confidence and skills to engage in their care [16]. The ability to measure patient activation using the Patient Engagement Measure (PAM) supports the personalization attribute by tailoring care based on the patient's score [17]. Empowerment represents the patient's increased desire and ability to participate in care as a function of their confidence of their status within the healthcare system [15] and relates to the commitment attribute of engagement. Participation and involvement are similar but they are strictly behaviors rather than states, and there is some indication that participation involves a greater degree of self-management in care compared to involvement [15].

# 3.2. Selection of literature sources

The initial search yielded 722 articles that used patient engagement in the title, abstract or as a keyword. The majority of the literature on patient engagement was published in the field of medicine (83%). Articles published by authors from the nursing discipline comprised 13% of the overall total; but more than each of the other disciplines: psychology (6%) and social science (8%). Another 8% was published in the public health and policy fields. (Totals do not add up to 100% because articles may apply to more than one discipline.) Use of the term 'patient engagement' was not restricted to the US literature. Slightly more than half of the articles were published in the US while the UK was the second most prolific publisher on patient engagement (14%), followed by Australia (7%)

and Canada (6%). Also publishing on patient engagement were authors from Italy, Switzerland, Germany, the Netherlands, France and Ireland in rank order.

# 3.3. Collection of relevant data

The 722 abstracts (or full text when no abstract was available) were scanned to identify articles that used the term patient engagement as an autonomous concept, independent of the terms and concepts that surround it. For example, patient engagement sometimes served as a placeholder that did not add meaning to a phrase, such as "patient engagement in medication adherence" instead of simply "adherence to medication". Or patient engagement was used as a synonym for participation or retention in care, as in "engagement in care". In these two examples patient engagement was not considered an autonomous concept.

# 3.4. Analysis of the data

Those articles that utilized the concept of patient engagement in an autonomous, contextualized or meaningful way, rather than as a replacement for an active verb as in the examples, were retained, leaving 202 articles. The 202 full text articles were reviewed to identify those that satisfied the inclusion criteria indicated in step 2 leaving 96 articles for analysis. These articles yielded 446 individual attributes. The attributes were characteristics that may or may not have been indicated directly, but could be inferred from the context [18].

#### 3.4.1. Attributes

Attributes were combined by identifying synonyms and clustering related items, which brought the total number of individual attributes to 108. These attributes encompassed three general domains: attributes of process, attributes of behavior, and attributes of the environment. Attributes of process describe the steps taken by the patient, provider or institution that contribute to increasing patient participation in care. Attributes of behavior represent cognitive or emotional states that stimulate participation in care. Attributes of environment included characteristics of clinical institutions or patient/provider resources that facilitate greater participation in care. By combining and categorizing the individual attributes, four overall attributes were identified — 1) personalization of the approach to care, 2) access to necessary resources, 3) commitment to pursuing quality care, and 4) nurturing the relationships between actors in the encounter.

Of the 96 total articles, personalization was explicitly present in 61 articles, access 55 articles, commitment 56 articles, and therapeutic alliance 64 articles. 30 of the articles contained all four of the attributes.

# 3.4.2. Antecedents

Antecedents are phenomena that occur prior to patient engagement and may include events, behaviors, or environmental characteristics that temporally or theoretically precede the appearance of the concept. A total of 34 antecedents present in the 96 articles were identified, collected, organized and collated. They included aspects of the quality of the patient's experience, provider role, and characteristics of the healthcare system. The most frequently identified antecedents included an individual experiencing ongoing illness, pain or care of a chronic condition with some form of enrollment, participation or invitation to obtain care (37 articles). Patient engagement was not explicitly mentioned in literature regarding trauma care, and had little mention in association with health promotion and disease prevention for healthy populations. The patient's status ranged from passive non-involvement in care to active well-informed participation in care.

From the provider perspective 28 articles included antecedents of disorganization of health information or care coordination (seven articles), an invitation to the patient for enrollment, scheduling or visit preparation (eight articles), or efforts toward improved communication or meaningful patient interaction (13 articles). From the perspective of the healthcare institution, 22 articles included antecedents reflecting an effort towards innovation in technology or procedures (12 articles) or an attempt to satisfy new policy standards (10 articles).

#### 3.4.3. Consequences

The consequences of patient engagement are those anticipated events, behaviors, or conditions that follow execution of the concept. There were 21 intended consequences identified in the literature that manifested in the outcomes of care and the experiences of care. Some consequences for outcomes included: increased patient safety (five articles), reduced costs (three articles), care coordination (five articles) and identification of best practices (12 articles). Consequences of the experience of care included cognitive benefits such as greater understanding and awareness through learning and communication on the part of the patient (30 articles), and job satisfaction on the part of care providers through more meaningful interaction and collaboration with patients and other providers (seven articles). The majority of consequences were references to improved outcomes of care and improved patient satisfaction (33 articles).

#### 3.4.4. Definition

The definition of patient engagement is based on the collected attributes, antecedents and consequences listed above. Based on the thematic reflection in our analysis, four overarching attributes of patient engagement were defined: 1) personalization, 2) access, 3) commitment, and 4) therapeutic alliance (PACT). Personalization is a term that represents the need to tailor interventions or strategies to care according to the unique needs and circumstances of the individual patient. This includes health literacy, defined as the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions, as well as cultural background, attitudes towards health interventions, and availability of caregiver support systems. Failure to accommodate the patient in their specific circumstances would inhibit engagement of the patient.

Access includes the ability of the patient to obtain the necessary informational or institutional resources with some level of confidence in the consistency of their availability. This may include such things as functional literacy status, geographic location, or socioeconomic status.

Commitment represents the cognitive and or emotional factors that stimulate the patient to exploit the resources available. Cognitive/emotional factors include those that drive the patient to seek greater understanding or awareness of their condition and their willingness to take steps on their own or in collaboration with others to satisfy that drive over a period of time.

Therapeutic alliance is a factor that differentiates patient engagement from related terms such as patient empowerment, involvement, or self-management. The therapeutic alliance sustains the patient's connection to the provider within the healthcare system, potentially creating an effective partnership in the pursuit of health goals. This contrasts with the traditional patient-provider relationship based on the authority of the healthcare provider and the normative role of biomedicine [19].

To maximize the potential for patient engagement, the attributes indicate that the process must be personalized, the patient must have access to information and resources, behavior change strategy should be applied appropriately, and a supportive

relationship must exist between patients, providers, caregivers and healthcare institutions that serves to evaluate healthcare options collaboratively and sustain a partnership towards shared goals. The definitions and the quotes provided in Table 1 reflects the defining attributes more explicitly with some illustrative examples.

Based on the findings above, the concept of patient engagement can be defined as the desire and capability to actively choose to participate in care in a way uniquely appropriate to the individual in cooperation with a healthcare provider or institution for the purposes of maximizing outcomes or experiences of care.

# 3.5. Exemplar

After identifying the attributes, antecedents and consequences for the concept, the next step in Rogers' method of concept analysis is to identify an exemplar of the concept within the literature. One article, "Using Mixed Methods for Evaluating an Integrative Approach to Cancer Care: A Case Study", reported a clinical scenario involving chronic care patients participating in a research study [32] and demonstrated all four of the attributes of patient engagement: personalization, access, commitment and therapeutic alliance. The mixed methods study involved cancer patients enrolled in an integrative cancer therapy program. The authors concluded that patient engagement was facilitated by personalized integration of complementary and conventional therapies, access to information and resources, continued commitment through emotional support and hope, and healing partnerships with providers.

For the attribute of personalization, the article cited that a "key aspect of active engagement in care is creating a personalized plan by finding what feels right for the individual, or as one patient described, 'creating your own game' because 'what has worked for me won't work for other people." (p. 11)

In ensuring access, patients were able to access all the information resources in one place, which was crucial to guiding decisions enabling patients to sort through and evaluate the mass of information available . . . "You wouldn't believe all the different information I'm getting out there, and it's very confusing" (p.13). The presentation of information from all sources in one place facilitated access and understanding of the mass amounts of data available.

It was just good because I had done a lot of reading. I'd been looking, I did a bit of Internet, I have a lot of books. I've been talking to everybody I know and then when I came into the Introductory Program all of a sudden all that information was in one place. (41-year-old woman, cervical cancer, p.13)

Rather than strictly prescribing a regimen according to a standard protocol, the physician empowered patients to take an active role in treatment decisions by facilitating exposure to knowledge resources and offering guidance in evaluating alternatives. "The individual in an integrative cancer program is empowered to explore numerous options and encouraged to play an active role in treatment decisions." (p.6). This stimulated patients' active involvement in determining the course of their care and reinforced their confidence. The patient's commitment to their care over time was also strengthened through social support mechanisms. Commitment to the care model in the institution was clear through patient comments such as

There's a whole feeling also that you're part of a community of people that are going through the same thing and that you're not alone. My first response when I got my diagnosis was just to feel so separated from everybody. Coming here gave me a different group to be part of, a very supportive group to be part of. (p. 14)

The relationship between client and physician was described as a healing partnership, a connection made possible through lengthy initial visits with unlimited follow-ups made available for the client. Patients reported a sense of belonging and hope fostered not only by the resources offered by the program, but the caring and supportive services provided by both practitioners and fellow patients. A therapeutic alliance was forged between patients and practitioners who were consistently available and included patient preferences and circumstances in treatment decisions. "I've found that the support from [a physician] was unbelievable . . . (saying) we'll try to do the very best that we can to accommodate and help you out. And that in itself was pretty important for me as a patient to hear" (47-year-old man, colorectal cancer, p.13).

This exemplar offers an illustration of a clinical setting in which all of the four attributes of patient engagement are present. It also demonstrates that the four attributes are not isolated components of engagement but are interrelated, and that one activity may manifest more than one attribute.

Implications for further development of the concept are describe in the Discussion Section below.

#### 4 Discussion

# 4.1. Discussion

The large number of attributes assigned to each of the three domains (processes, behaviors, environment) suggests that the concept of patient engagement touches upon myriad dimensions of healthcare delivery. The concept influences relationships between actors in healthcare who execute processes, impact individual patient behaviors, and drive institutional practices. Many of the articles reviewed were published by interdisciplinary teams, with co-authors from medicine, nursing, public health, and psychology, reinforcing the need for a common definition. Further, the concept of patient engagement is referenced throughout the variety of healthcare disciplines and outside of the US, including non-English-speaking countries [33–35], indicating a shared effort across cultures to arrive at an understanding of what patient engagement means and how this may influence healthcare delivery.

This concept analysis was limited because it included only those articles in which the term 'patient engagement' was explicitly used; there might be other terms which express the same concept. Nonetheless, the attributes identified captured the essential nature of the concept throughout the range of applications even though specific articles sometimes focused on only one aspect.

# 4.2. Conclusion

Patient engagement encompasses levels of participation/involvement in care according to individual desires and capabilities, partnering with providers and institutions vice maintaining the power hierarchy, and increasing the confidence and skill levels of patients. When all four of the attributes are present – personalization, access, commitment and therapeutic alliance – then the full import of the meaning of patient engagement may be brought to bear throughout the range of healthcare settings.

# *4.3. Practice implications*

The four defining attributes deserve further scrutiny to explore their specific role in patient engagement in various contexts, determine how to enhance their role if appropriate, and how to measure their impact on individual engagement levels. It may be hypothesized that proper collection and management of patient data and cultural competence may increase personalization,

**Table 1**Definitions and Descriptions of Defining Attributes.

Attribute	Definition	Examples
Personalization:	Assures that the interventions conform as closely as possible to the unique desires and circumstances of the patient. This includes efforts at shared decision making and tailoring information and resources to the patient's level of receptivity based on interests, capabilities and life circumstances	
Access:	Refers to the ability of the patient to obtain information, guidance, and tools to secure consistent, high quality appropriate care. This includes patient functional literacy as well as institutional resources adapted to the patient's geographical location, cultural background, and socioeconomic level.	<ul> <li>Reply to challenges regarding choice of a measure of patient engagement in a study: "Real engagement may require concerted and focused outreach that is outside the care delivery system [23]</li> <li>On role of HIT in patient-centered care under section entitled Patient Engagement: ' patients will increasingly supply and have access to important non-clinical data such as communication and decision making preferences, online social supports, and consents or authorizations for certain uses of their data enable more patients to participate in online communities, obtain online information and support, activate PHC notifications, seek research opportunities, and receive or provide coaching services to others identify resources of interest such as relevant clinical trials, top-tier specialists for their medical problems, or selected individuals who share common health concerns.' [24]</li> <li>AHIMA (HIT) brief on enabling patient engagement: "Many barriers prohibit full engagement, including: limited access to healthcare, low health literacy, health disparities, financial disincentives in the healthcare system, limited EHR portal access " [25]</li> </ul>
Commitment:	Pertains to the cognitive and emotional factors that empower the patient to exploit health resources available. Commitment is demonstrated by the patient efforts over time, and is more inclusive than simple motivation that may waiver according to changing circumstances. It is driven by intrinsic cognitive or emotional forces that may be stimulated through social support, intellectual resources, or any means that encourages behavior change that leads to practices that improve the patient's status	Development of self-management strategies for COPD: " aimed to develop and test an intervention that focused on patient engagement for behavior change merges both self-management education and motivational interviewing; the latter with the intention of facilitating the resolution of ambivalence, fostering engagement in self-management, and encouraging behavior change." [26]  In studying an intervention for older adults with co-morbidities: "engagement in healthcare, should generate extrinsic motivation by making patients feel like they can do what is asked of them, feel like their health behaviors are autonomous and lead to outcomes that are personally relevant." [27]  On health coaching for diabetes patients: "In recognizing the motivational and interactive role required to manage a chronic illness, interventions have increasingly focused on the health care provider as 'coach.' [28]
Therapeutic Alliance:	Incorporates elements of the patient-provider relationship including quality of the clinical interaction, communication, empathy, or mutual understanding	On inpatient nursing care: "Engagement is the ability of the nurse to overcome the clinical situation and actually connect with the patient as a unique individual (Eriksson 1997). Part of engagement is the sharing of suffering, recognizing loss, and acknowledging the human need to be loved and to love (Cantell 1985; Logan 2006)" [29]  — From a qualitative study on patient engagement in primary care: "Engagement means building a relationship on the basis of social, cultural and clinical knowledge use the term 'engagement' to describe the process and outcomes leading to interpersonal communication within the consultation and the primary health care system that supports it." [30]  — On diagnosing mental health issues in primary care: "patient engagement as a set of reciprocal tasks by both patients and clinicians, built upon strong relationships among patients, physicians and the care team " [31]

eHealth tools may improve access, behavior change theory may serve to inform providers on how to encourage and support patients, and communication tools may strengthen the therapeutic alliance [36,37]. Cultural competence, defined as the ability of systems to provide care to patients with diverse values, beliefs and behaviors including tailoring delivery to meet patient's social, cultural and linguistic needs [38], impacts all four attributes. Personalization requires adaptation to individual needs and expectations, access is limited by linguistic and technological abilities, commitment varies according to appropriateness of social

support mechanisms, and therapeutic alliance is modulated by the degree of shared decision making desired by the individual patient.

The definition of the concept of patient engagement in healthcare may enable clinicians, healthcare administrators, and researchers to devise methods that guide behaviors and create settings that support the concept and influence the quality of care for patients. Making explicit the meanings expressed by the concept will improve communication between healthcare entities through a shared understanding of the core aspects and variations of patient engagement. Further, knowledge of the attributes of

patient engagement will help inform the development of health information technology in an endeavor to facilitate patient interaction with health services. Theory development surrounding patient engagement in medicine and nursing may advance based on a well-understood concept of patient engagement. Lastly, understanding of the concept may inform curriculum in the education of healthcare personnel concerning the actions and behaviors that may serve to engage patients in the management of their own health needs.

Distinguishing the defining attributes of patient engagement is only a start. The attributes may be adapted or expanded in time or context. The inductive approach used here sought to avoid preconceived expectations in the analysis and attempted to create a foundation or "state of the art" for the concept as prescribed by Rogers. Our findings suggest that patient engagement exists within a network of related concepts that are also evolving and need clarification, such as shared decision making and empathy. It is hoped that the results may provide foundational coherence and serve as a heuristic with which further development of the concept may occur, both in terms of operational variables or further qualitative exploration of the meaning of the attributes discussed here for different patient populations. The theory, policy and practice behind implementing patient engagement in a patientcentered healthcare system merits further attention, especially in light of the increasing reliance on health information technology as an adjunct to care. Health information technology can be used as an enabler to promote patient engagement in care with attractive and functional design [39-41], yet those elements must correspond to the attributes of patient engagement that are demonstrated to maximize patient involvement in care [42.43]. The patient engagement attributes offered here provide greater concreteness and specificity for use of this concept in healthcare.

# **Conflict of interest**

The authors declare that they have no actual or potential conflict of interest including any financial, personal or other relationships with other people or organizations within three years of beginning the submitted work that could inappropriately influence, or be perceived to influence, their work.

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