Patient Engagement, Involvement, or Participation -- Entrapping Concepts in Nurse-Patient Interactions: A Critical Discussion

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Patient Engagement, Involvement, or Participation — Entrapping Concepts in Nurse-Patient Interactions: A Critical Discussion

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Abstract
The importance of patients taking an active role in their healthcare is recognized internationally, to improve safety and effectiveness in practice. There is still, however, some ambiguity about the conceptualization of that patient role; it is referred to interchangeably in the literature as engagement, involvement, and participation. The aim of this discussion paper is to examine and conceptualize the concepts of patient engagement,
involvement, and participation within healthcare, particularly nursing. The concepts were found to have
semantic differences and similarities, although, from a nursing perspective, they can be summoned to illustrate
the establishment of a mutual partnership between a patient and a nurse. The individualization of such
processes requires the joint effort of engagement, involvement, or participation, represented by interactive
actions of both the patient (asking questions, telling/speaking up, knowledge acquisition, learning, and decision-
making) and the nurse (recognizing, responding, information sharing, teaching, and collaborating). Suggesting
that the concepts can be used interchangeably comes with some caution, requiring that nurses embrace
patients playing a role in their health and healthcare. Further research and practice development should focus
on how patients and nurses receive and respond to each other to establish patient engagement, involvement,
and participation.

1 INTRODUCTION
Over the last few decades, healthcare has shifted from traditional, paternalistic structures to more modern care
models focusing on people as individuals enacting a patient role, comprising their identity and entity as humans
(Coulter & Oldham, 2016; McCance et al., 2011; Nolte et al., 2020; Santana et al., 2018; Slater, 2006). Providers
have been tasked to provide care with patients, not only for patients. Emphasis has been placed on the patient
(and family) care experience and many healthcare organizations routinely survey patients following care to
ensure preferences and needs are being met.

Patient participation in care, also referred to as patient engagement or involvement, has been included in
healthcare improvement models as a strategy to improve the quality of care and patient outcomes (Bombard et
al., 2018; Higgins et al., 2017; Martin Ginis et al., 2017). Yet, there remains some ambiguity in the terms
“engagement,” “involvement,” and “participation,” leading to a lack of conceptual clarity (Eldh, Ekman, et
al., 2006; Eldh et al., 2010). This paper addresses the benefits and challenges of having three concepts to choose
from that all describe the ideal conditions for patient-nurse interactions in healthcare. Decision on what term to
use can depend on the healthcare context and the use of customary terms. The terminology concerning the
patient role in healthcare interactions is blurred: is it linguistically-, policy-, or conceptually driven and how do
the underlying philosophies of nursing care influence term choice?

Nursing theorists have reflected on the patient role and patient-nurse interaction since the Nightingale era
(Nightingale, 1859), with the work by Peplau and Henderson considered novel in terms of the focus on patient-
centered and/or individualized care. More recently, patient- and person-centered care have been reintroduced
with contemporary evidence at hand (Ekman et al., 2011; McCance et al., 2011; McCormack, 2004). Given that
health professionals and decision-makers tend to use the concepts of engagement, involvement, and
participation interchangeably, along with philosophies like patient-centered care, it is often difficult to tease out
what is unique about each concept. With terms undefined (Longtin et al., 2010), there are limited opportunities
to suggest appropriate strategies and outcome measures. The aim of this paper is to examine and conceptualize
the terms patient engagement, involvement, and participation within healthcare and particularly nursing.

2 METHODS
2.1 Design
Discussion paper, informed by both scientific and colloquial principles of concept analysis (Risjord, 2009; Walker
& Avant, 2019): the discussion was based on our contexts and how terms are used as part of colloquial speech
(colloquial) as well as empirical literature (scientific). We did not conduct a full concept analysis, as our aim was
not theory building, but instead recognized that principles of concept analysis allowed us to undertake a critical
discussion by reflecting on and articulating our beliefs and conceptions about existing concepts, considering
contemporary research and semantics.
2.2 Procedure
The discussion originated from three concepts, that we ourselves, and others use to illustrate an ideal condition in healthcare where patients and nurses can benefit individually and professionally: engagement, involvement, and participation. All three terms appear across legislation, policies, guidelines, and everyday dialogues in clinical and academic settings in our countries of origin: Australia, Sweden, and the United States.

While concept analyses are considered cornerstones in developing theories and frameworks, it is important to recognize that there are no single, enduring definitions, but language develops because of the people using it (Bergdahl & Berterö, 2016). Over the years, a multitude of concept analyses have been published to illuminate core components of patient engagement, involvement, and participation (Cahill, 1996; Castro et al., 2016; Chadderton, 1995; Halabi et al., 2020; Higgins et al., 2017; Kvæl et al., 2018; Nilsson et al., 2019; Rooke & Oudshoorn, 2020; Sahlsten et al., 2008; Snyder & Engström, 2016). Consequently, we suggest that there is seldom one single definition to any concept, but several routes (and reasons) for attempting to define the terms used. We developed six queries to explore the breadth of the concepts, adapting concept analysis perspectives to fit a critical discourse (Walker & Avant, 2019):

Phase I. The scope of the selected concepts:
- Do you differentiate between the terms patient engagement, involvement, and participation, and in that case, how?

Phase II. Aligning the concepts in nursing:
- Which term(s) do you use, when, and why?
- How does the term you use align with nursing care theories and models?

Phase III. Comparing and contrasting the concepts:
- What is a model case for (each) term, and what similarities (and differences) transpire in the model cases?

Phase IV. Discussing consequences in nursing research and clinical practice:
- Benefits and/or challenges in using more than one term?
- Who should decide and define the term(s) used within healthcare and research?

Our written accounts provided input to a discourse in accord with the overall aim of the paper, comprising previous concept analyses and reviews (as above), our prior and current studies (Årestedt et al., 2019; Eldh et al., 2004, 2010, 2015; Eldh, Ehnfors, et al., 2006; Eldh, Ekman, et al., 2006; Jerofke-Owen & Dahlman, 2019; T. A. Jerofke-Owen et al., 2021; Luhr et al., 2018; Tobiano, Bucknall, et al., 2015, 2016; Tobiano, Marshall, et al., 2016, 2021; Wärdig et al., 2021), and reviews (Jerofke-Owen et al., 2020; McAndrew et al., 2022; Tobiano, Jerofke-Owen, et al., 2021; Tobiano, Marshall, et al., 2015). In this paper, this is reported as a narrative. To conclude, we propose how this may impact clinical nursing and theory development.

3 OUR NARRATIVE ON PATIENT ENGAGEMENT, INVOLVEMENT, AND PARTICIPATION
3.1 Differentiation between concepts
Our discussion found a common ground, in that, when we talk about patient engagement, involvement, and/or participation, we use these concepts to describe an individual who is playing an active role in their healthcare. The perspectives then diverged, particularly as to which term was the broadest. We suggested that the concept “involvement” could be defined by the least amount of interaction on the patient’s end. Yet, was “engagement” and/or “participation” the broadest or active concept?
Turning to the recognized Oxford English Dictionary, we undertook a semantic overview (26 March and 15 April 2021 via URL https://www-oed-com.e.bibl.liu.se/); a full report is provided in Supporting Information: File 1, while details aiding the dialogue were:

- Being engaged is about involvement. Historically, “engage” comes with a sense of having motives, being invited, or being appointed. The notion of engagement incorporates a promise, a guarantee.
- Involvement originally meant a sort of wrapping and nowadays “involve” can still indicate “surrounding with” (a material or substance). However, it also connotes being implied and being engaged (in a matter).
- Participation was formerly considered sharing of something, in a partner- or fellowship. Today, it means sharing in an action or sentiment, taking part, and actively being involved.

3.2 Which concept used, when, and why

Our discourse suggested that the usage of a concept can be contextual. For instance, the term involvement seemed to be the most informal term, used in conversations with lay people who may have different health literacy levels. Engagement and participation on the other hand may be more formal terms, reserved for policies and scholarly conversations. In addition, involvement was suggested to come with the least connotation on mutuality, compared with engagement and participation. According to our semantic base for discussion, there are reciprocal resemblances between engagement and involvement, and between participation and involvement. Yet, semantically, we have not been able to detect a similar original connotation between participation and engagement. This suggests that the employment of these terms requires a more careful conceptualization, recognizing end-users perspectives like patients and providers.

To delineate and model the concepts of patient engagement, involvement, and participation from a nursing perspective, it was noted that differences in the authors’ definitions of the terms may be rooted in their native languages (English and Swedish, respectively). Engagement, in a native English-speaking sense, is associated with a psychological mindset or a “state” of being, although there was no obvious semantic source for this suggestion. While the term “engagement” has been associated with a mutual relationship, in Swedish, a connotation of sharing is most strongly associated with the term “participation.”

Patients were considered to most commonly use the terms “involve” or “participate” when describing what they do in relation to their healthcare and health. Yet, when terms such as “involvement” or “participation” are used by providers, they are often used to describe what the patient is doing. It was suggested that patients are less likely to use the term “engagement” when describing how they become active in their own healthcare. Rather, “engagement” is used to describe actions providers take to motivate patients to play an active role in their health and healthcare issues.

3.3 How the concepts align with nursing care theories and models of care

The choice of terms aligns with philosophies of care, standards of nursing practice, and theories. Philosophies of care like patient-centered care, person-centered care, fundamentals of care, and shared decision-making were viewed as transformative movements that had patient engagement, involvement, or participation as central principles. Furthermore, these philosophies of care appeared to filter down to clinical practice, evident in local hospital professional practice models and guidelines.

Codes of ethics for nursing outline patients’ rights for engagement, involvement, or participation, making it mandatory in nursing practice. These codes also discuss related concepts like patients’ right to have their preferences respected, self-determination, shared and informed decision-making, and being respected as a unique individual and members of the team. The presence of terms like “patient-centered care” in these codes
of ethics further strengthened the relationships between previously mentioned philosophies of care with the terms patient engagement, involvement, or participation.

In addition, there are several nursing theories from the last century that align closely with the three terms, taking for example the patient role, the individual’s commitment to health, and the patient-nurse interaction. However, few theories explicitly address patient engagement, involvement, or participation, but these concepts are rather components of a greater perspective. Overall, our discussions highlighted the similarities across philosophies of care, codes of ethics, and theories, including a need to recognize patients as individuals. Furthermore, patient preferences are to be acknowledged and respected, and patients should have opportunities to play an active role in their healthcare, in accord with their capability. This is regardless of whether this is called patient engagement, involvement, or participation.

3.4 Model cases
Our model cases spanned across contexts, including for example primary healthcare visits and hospital visits, which were contexts familiar to the authors. A model case for primary healthcare nursing was characterized by a person with a long-term condition. The person attends primary healthcare visits, but the frequency of these visits has decreased due to their ability to self-manage their disease. During the visit, the person shares their experiences of managing self-care and treatment in everyday life, and the nurse shares information like laboratory results and research evidence. The nature of this dialogue is successful because it is respectful, mutual, and clear goal setting has occurred. In the community, this person actively takes part in information-seeking and physical activities.

During a hospital admission, patient engagement, involvement, or participation was characterized by a patient who is able and willing to be active in their care, either in seeking or sharing verbal information or physically taking part in activities. Acuity was a factor for the patient capability to be active which likely changes over time. In a model case, patients were asked about their preferences for engagement and involvement or participation while in hospital. Furthermore, they were a part of the healthcare team, with a role in daily rounds and bedside handovers, and actively prepared for these interactions. To prepare for self-management and recovery at home, the patient sought information during the hospital stay, and practiced skills needed to self-manage, recognized the facilitation provided by the nurses. In the community, patients monitored their signs and symptoms, managed their recovery, and knew when and where to seek further help.

3.5 Benefits or challenges to using multiple terms
Both scholars and clinicians seem to use the three terms discussed here interchangeably, to denote the enactments that any person in need of healthcare services can take (Castro et al., 2016; Kvæl et al., 2018; Nilsson et al., 2019). While the use of three terms enables vivid language, it is not without concerns; as noted, the concepts are not altogether equivalent. Particularly in research, there needs to be deliberate employment of concepts, based on a conceptualization that is comprehensive and fair. If not, it makes literature searches less reliable, and reviewing papers becomes difficult. This is a particular issue when the terms used do not match concepts or keywords. Furthermore, validity and transferability of study outcomes are hampered by a lack of careful measures, in this case sensible use of concepts. Additionally, tools not accurately or evidently tied to concepts may add further ambiguity in terms of measures and outcomes.

This also renders challenges, particularly for researchers with English as a second or third language: the native word needs to match both semantically, contextually, and conceptually to provide for a reliable translation. However, it may also be helpful to translate and back-translate terms, to take nothing for granted in terms of matching the right word for what is to be expressed.
For clinical practice, where patients and staff meet in everyday encounters and communicate using a mix of lay and professional language, there is likely less trouble to amalgamate patient engagement, involvement, and/or participation. The main threat, in this case, is that definitions do not correspond to a full conceptualization, including all stakeholder perspectives and providing for a common understanding.

3.6 Who should decide and define concepts
Ideally, there would be one term that could become common language, consistent across diverse cultures and languages. The description would include the interplay between the provider and the patient, representing “active partnership,” as it is the mutuality between the provider and the patient that is of interest. Yet, for now, there are three terms to consider.

While scholars have the right to pick the concept preferred, we suggest this requires a deliberate and informed choice. Any hasty decision may not only affect the current research but can also add to the confusion. As for clinical practice, it may be of less trouble if a combination of engagement, involvement, or participation is used for communication. However, it is important that the partners of the healthcare contact know that they propose or communicate about the one and same aspect, although using different terms. Misconceptions pose a risk for person- or patient-centered care.

However, in healthcare, engagement, involvement, and participation are classified by decision-makers and policy-makers. Although they seem to originate from the larger societal changes in the Western world advancing around the 1960s, there seems to have been a gap where patients have not been a part of deciding which concepts optimize their lived experience. This is somewhat contradicting the focus on the autonomy of the individual and the right to speak for oneself, which was the main purpose of the transfer from more paternalistic healthcare to partnership and collaboration. Yet nowadays, there is increasing awareness of the necessity to provide healthcare services with, rather than for, patients and to recognize both clients and their next of kin as teammates. After all, engagement, involvement, and participation aim to provide efficient and humanistic care and services for the benefit of health to more.

4 REFLECTIONS ON OUR NARRATIVE
While we suggest that the three concepts—that is, patient engagement, involvement, and participation—can be used interchangeably in nursing, given that they represent the same core elements, this employment comes with some caution. We will provide explanations of why and when these terms can be used interchangeably, returning to the empirical literature to compare our views of factors and processes to others’ viewpoints.

First and foremost, obtaining, dealing with, understanding, and employing information is an essential driver of patient engagement, involvement, and participation. For patients, influencing factors include health literacy (Carman et al., 2013), which nurses can and should enable and sustain by means of evidence from scientific discovery and clinical experience; by sharing knowledge, the nurse can help inform clinical judgment and improve patient outcomes (Wu et al., 2018). A patient’s physical and mental capability to engage in health behaviors will play a role in such a process (Centers for Disease Control and Prevention, 2021; Graffigna et al., 2015), while the clinical and pedagogical skills of the nurse can impact the establishment of nurse-patient relationships and the quality of care delivered (Molina-mula & Gallo-estrada, 2020). Individual experiences will also drive the process. On the patient side, factors such as the acuity of the illness (Arnetz et al., 2008), duration of illness (Eldh et al., 2010), type of illness (Latimer et al., 2014), and prior or current health issues and healthcare experiences can influence the patient’s care preferences or beliefs (Jerofke-Owen & Dahlman, 2019). Patient-centric policies that highlight the importance of understanding and responding to patients as individuals are imperative to quality healthcare (Harrison et al., 2019).
Patients' values and beliefs can be linked to theoretical and philosophical models of care, which often focus on patient autonomy, self-determination, and interpersonal relationships. A belief that everyone has a fair and just opportunity to promote their health with a focus on addressing avoidable inequalities is critical to healthcare (United States Department of Health and Human Services, 2022). The nurse’s role is influenced by their competence, skills, and expertise, illustrating both core competencies and the adoption of theories (Molina-mula & Gallo-estrada, 2020). The joint effort of engagement, involvement, or participation is represented by interactive actions of both the patient (asking questions, telling/speaking up, knowledge acquisition, learning, and decision-making) and the nurse (recognizing, responding, information sharing, teaching, and collaborating). Patient engagement, involvement, and participation does not necessarily display in an activity. Rather, apprehending and adopting information shared by the nurse may constitute being engaged and involved, as well as an active sharing of information, in particular when indicating an increased health literacy (Eldh, Ekman, et al., 2006; Eldh et al., 2010). Ideal conditions involve an interactive process during which time nurses assess patients' willingness and capability to understand how and in which activities they can participate and patients speak up and share their needs, questions, and concerns (Eldh, Ehnfors, et al., 2006).

In hospitals worldwide, we are increasingly implementing policies and procedures designed to promote investment in patient engagement, involvement, and participation. For example, collaboration and decision-making can be facilitated through bedside handovers, where the shift-to-shift handover is moved from a private office to the patient's bedside (Tobiano et al., 2018). However, implementing these activities does not alone ensure patient presence, neither when it comes to emotional nor physical investment (Tobiano et al., 2018). There needs to be drive, motivation, investment, and energy from both the nurse and patient, a deliberate force if you will (Street et al., 2021). We need to transcend nurses from their detached role of observer and task-deliver, to achieve the more connected role of investing in and recognizing patients as being engaged, involved, and participants (Dempsey & Reilly, 2016) and providing opportunities for patients to do so.

Previous researchers suggest that nurses may play a key role in facilitating interactions (Oxelmark et al., 2018), represented by a welcoming environment, dialogue, interpersonal relationships, and trust. Fostering a “welcoming environment,” through relational tactics like using humor, initiating introductions, and informal conversation to build rapport, leads to patients feeling “invited” to engage, be involved, or participate (Bundgaard et al., 2012; Chan et al., 2012; Larsson et al., 2007; Thorarinsdottir & Kristjansson, 2014; Tobiano, Bucknall, et al., 2015). Two-way dialogue is frequently cited as a facilitator to patient engagement (Tobiano, Marshall, et al., 2015), although often nurses initiate the dialogue (Tobiano, Marshall, et al., et al., 2016). How the nurse responds to the efforts of the patient will influence the formation of a mutual partnership (Ferguson et al., 2013), also shaping the future interactions between the nurse and the patient (Wiggins, 2008). Plans to overcome barriers to effective partnerships such as systemic power imbalances, lack of trust from patients, and cultural differences must be integrated into all efforts to promote partnerships (Center for Health Care Strategies, 2021). A true desire to consider the patient's environmental and social circumstances and how those are interwoven in health is critical to the success of the process (Baah et al., 2019).

We suggest that patient engagement, involvement, and participation in nursing are equally represented by “mutual partnership.” Nursing care delivery with partnerships at its center is a natural course, given many nursing theories have had partnerships at their core (e.g., Newman’s health as expanding consciousness theory) (Petiprin, 2020). The term mutual and mutuality is present in previous descriptions of facilitators, antecedents, and attributes of patient engagement/involvement/participation (Angel & Frederiksen, 2015; Sahlsten et al., 2008). Mutuality has two defining attributes: 1) there is a synchronous co-constituted relationship with response interdependence, intersubjectivity, shared commonality, and equity within the relationship; and 2) through the relationships, participants develop greater self-awareness and self-understanding which contributes to their personal becoming (Curley, 1997). The first defining attribute highlights that the process is co-produced
and must occur between patients and nurses to ultimately achieve the outcome of “partnership.” Interestingly, earlier work on patient engagement/involvement/participation used terms like equal and equality when describing the nurse–patient partnership (Sahlsten et al., 2008; Thorarinsdottir & Kristjansson, 2014). We would argue that achieving equality in partnerships is challenging. Patients bring experimental knowledge, gained through experiences of maintaining health and adapting to illness. Nurses bring knowledge and expertise learned through professional practice and formal education (Ashworth et al., 1992). The notion that these two parties come to the partnership with equal footing does not fit well, as they do not have the same resources or opportunities. Instead, mutuality recognizes that the patient and nurse have different circumstances, and they need dialogue to understand what each person brings to the partnership, providing role clarity. To conclude, our critical discourse provides an overview of patient engagement, involvement, and participation, as illustrated in Figure 1.

**FIGURE 1** Conceptualisation of patient engagement, involvement, and participation in nursing.

5 RECOMMENDATIONS

We presume that our discussion has implications for research and clinical practice; as such, it provides a starting point for further academic reflection and healthcare debate.

Our critical discussion encourages research designs that examine the interactions between patients and nurses, moving beyond a singular focus on engaging behaviors of one of these actors without regard to the other.

For researchers, our paper highlights that the terms patient engagement, involvement, and participation can be used interchangeably if the person’s understanding of the term is consistent with the conceptualization we provide. Thus, we could make more judicious use of time by focusing on implementing patient engagement, involvement, or participation into practice, and building evidence of outcomes, rather than debating terminology.

This illustration was summoned by nurse researchers, not only for other researchers but also for nursing practice. Other disciplines are encouraged to reflect upon patient engagement, involvement, and participation within their discipline, and consider how terms are used in their context. The critical discourse and its outcomes, along with our reflections on elements and processes (as summarised in the figure) provide guidance for embedding patient engagement, involvement, and participation in practice while highlighting gaps in current practice. For instance, previous research suggests that nurses lack the motivation to engage patients in their care (Chegini et al., 2021), while patients may not recognize their right to engage, be involved, or participate (Bombard et al., 2018; Longtin et al., 2010). This highlights the importance of building patient and nurse motivation for a mutual partnership.

6 CONCLUSION

In this paper, we have explored the concepts of patient engagement, involvement, and participation. We began with these central aspects, recognizing that academic and clinical nursing requires a better understanding of the
concepts, and in turn the phenomena. Defining terms in healthcare should incorporate contextual information and semantics along with reference to careful concept analyses which include lived experiences of patients. In summary, the core of ideal nurse-patient interactions should focus on the establishment of mutual partnerships, regardless of using the terms patient engagement, involvement, or participation. To date, some of the literature on healthcare fails to recall that the much-needed, mutual partnership is about sharing (Oxford University Press, 2022): a sharing of and sharing in health encounters. This requires mutual recognition of the various perspectives representing experiences and preferences (provided by the individual patient) and the evidence, expertise, and perspective brought by the RN (Blaum et al., 2018; Burman et al., 2013; Lindhiem et al., 2014), and a coproduction of knowledge, to suffice a joint venture (Segevall et al., 2021). It is critical to include patients in all steps of care, to address and overcome barriers to health equity. Acknowledging the unique backgrounds of both the patient and nurse and their physical and emotional presence are drivers of the partnering process. We propose further attention focusing on the actions of both the patient and the nurse; how they receive and respond to each other during the process to establish patient engagement, involvement, and participation.

CONFLICT OF INTEREST
The authors declare no conflict of interest.

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