

## CONCEPT ANALYSIS - ENGAGEMENT OF PATIENT AND FAMILY CAREGIVERS IN CARE

Reema Danish<sup>\*1</sup>, Muhammad Ishtiaq<sup>2</sup>, Nasim Banoo<sup>3</sup>

<sup>\*1</sup>Lecturer, Shifa Tameer-e-Millat, Islamabad

<sup>2</sup>Associate Professor, Shifa Tameer-e-Millat, Islamabad

<sup>3</sup>Assistant Professor from City University, Khyber Pakhtunkhwa

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Corresponding Author: \*

Reema Danish

### Abstract

Patient and family caregiver engagement is increasingly recognized as a vital component of patient-centered healthcare. However, the concept is often used inconsistently across the literature, creating challenges in understanding and applying it effectively in clinical practice. This study aims to clarify the concept of patient and family caregiver engagement in healthcare settings using the concept analysis framework proposed by Lorraine Olszewski Walker and Kay C Avant. A comprehensive review of relevant literature was conducted to examine the use of the concept across healthcare disciplines. Following the steps outlined in the Walker and Avant concept analysis method, the defining attributes, antecedents, and consequences of patient and family caregiver engagement were identified. The analysis revealed key attributes including active participation in care, collaborative decision-making, effective communication with healthcare providers, shared responsibility, and empowerment of both patients and family caregivers. Engagement of family caregivers is particularly significant in complex conditions where patients rely heavily on family support. Clarifying this concept may guide nurses and other healthcare professionals in developing interventions that promote meaningful involvement of patients and caregivers in the care process.

### INTRODUCTION

Patient and family Engagement in a healthcare setting is an essential concept and is considered a holy grail in a healthcare setting (Rooke & Oudshoorn, 2020). The concept of engagement goes beyond just not leaving the patient and family in bed or beside the bed; it is essential to engage the voice and decision in the care of the patient. It will promote engagement with the patient and patient representatives to promote quality care and strengthen their skills to support their patients and their health throughout the illness (Carman, et al., 2013).

In developing countries, where the ratio of nurses is not just deficient, formal nursing is also

unavailable; in that situation, introducing the concept of patient and family engagement in the healthcare system could be a better solution for quality outcomes and patient-centered. Moreover, there are such medical conditions that require the continuous engagement of patients and families where patients suffer not just physically but cognitively, psychologically, and behaviorally dysfunctional and unable to comprehend their feelings and needs, such as neurosurgery patients. In that situation, the recovery process gets delayed due to the number of injuries; nurses could ideally position to engage patients and their families and initiate comprehensive

teaching such as feeding, suctioning, range of motion, wound care, tracheostomy care, handling, and other routine activities (Pardee, 1992).

The conceptualization of engagement was introduced many years ago, and relevant literature supports the concept of patient-family engagement and how its application can result in positive outcomes. However, the lack of operational definitions of engagement, different concepts, and insufficient measurable outcomes of patient and family engagement in care still need to be clarified (Krist et al., 2017).

Concept analysis will assist in examining the concept of "Patient and family engagement." A thorough understanding of the concept will make it easy to differentiate it from similar concepts and help clarify it.

#### **Aim of Concept Analysis**

This concept highlights the importance of engaging patients' family caregiver participation in healthcare settings. Its implementation will be the "blockbuster drug of the century," which may not only empower the family caregiver but also improve the outcomes of patient recovery and prevent the patient from further complications such as wound infection, bedsores, aspiration pneumonia, contractures, and cerebral edema. Participating in care can prevent it with sufficient knowledge (Huang et al., 2022). Moreover, this analysis will explain the concept by understanding its key components, antecedents, consequences, and applications in various contexts.

#### **Methodology:**

A systematic PubMed and Google Scholar search was conducted to identify index terms and keywords. Further, after a keen search using all the index terms and keywords in the following different electronic databases, such as CINAHL, SAGE, and Wiley online library, the MeSh words used with the help of Boolean operators; "Engagement" AND "Involvement in care" AND "partnership" AND "Caregiver" AND "partnership" OR "participation" OR "empowerment" OR "family involvement" OR "Comprehensive teaching." The search was broad because of the variety of words used to relate the concept of engagement of patients and family in care.

#### **Search Results**

With the help of a search strategy, we retrieved 49 articles, of which 17 were from PubMed, 28 were from Google Scholar, one was from CINAHL, 02 was from SAGE, and one was from Wiley online library. While considering the criteria, the screening was done by reading each article's topic and its abstract, and full-text screening was done to filter relevant literature. Thirty articles were excluded because of irrelevancy, duplicate topics, outdated studies, and topics considering leadership and management aspects more than the concept. However, 19 articles were selected for the concept analysis, emphasizing the importance of family caregivers' engagement in clinical settings, and discussing the concept attributes, consequences, and antecedents. Furthermore, a description of inclusion and exclusion criteria for selecting articles is in the PRISMA in Figure 1.

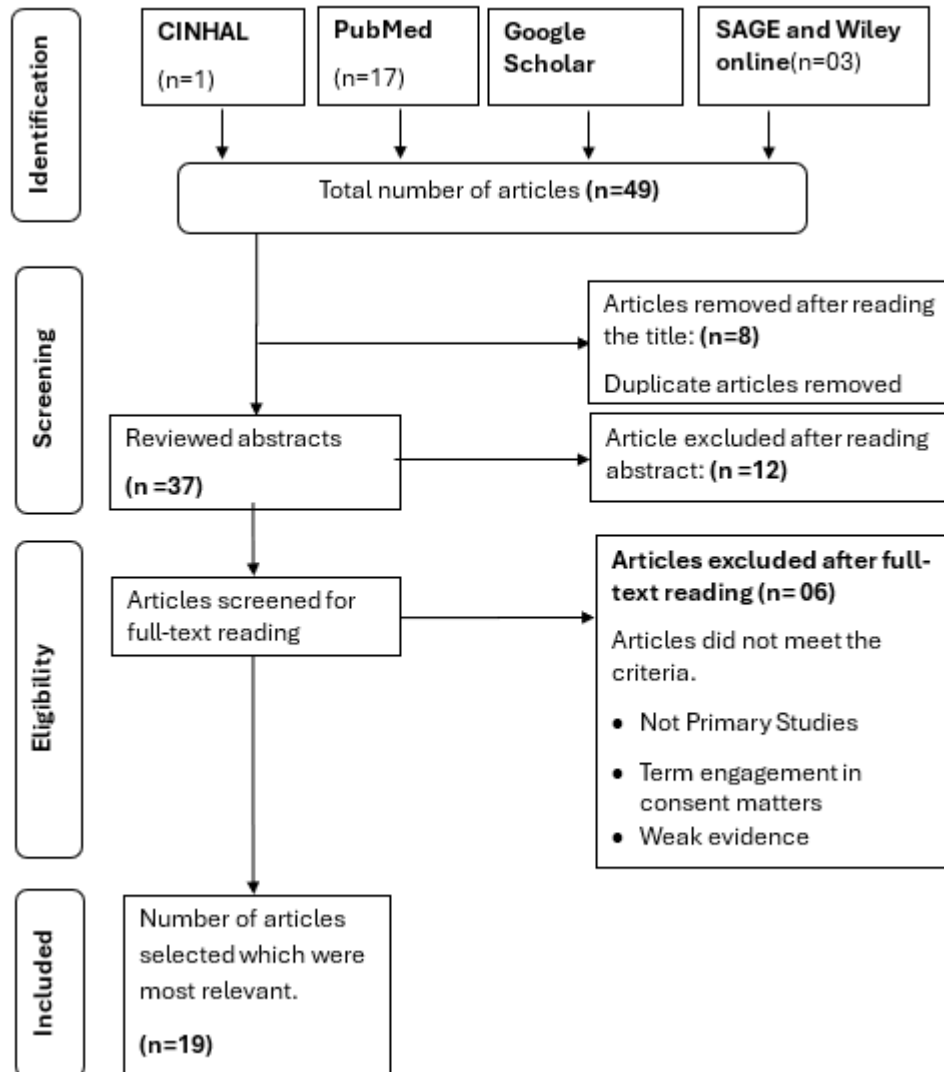


Figure 1  
PRISMA-Published Articles.

Walker and Avant's method was used for concept analysis. To better understand the operational definition of the concept, a search was initiated from different dictionaries, such as Merriam-Webster Dictionary, Google Dictionary, Oxford Dictionary, and Cambridge Dictionary. However, no results were shown. A further search was conducted by separating the phrase into three words: Engagement, patient, and family.

### Engagement

Engagement is the state of being engaged/emotional involvement or commitment (Merriam-Webster's Collegiate Dictionary, n.d.). According to Cambridge Dictionary 2024, it is an arrangement to do something, whereas according to Oxford Learner's Dictionary (n.d.), it is being involved in something to understand it.

### **Patient**

There are different definitions of patients, such as the person receiving treatment (Oxford Learner's Dictionary, n.d.), the person receiving medical care (Cambridge University Press, n.d.), or an individual under treatment (Merriam-Webster's Collegiate Dictionary, n.d.).

### **Family**

Similarly, there are various definitions of family, such as a group of domestic people related to each other by a bond of blood, sexual mating, or legal ties (Oxford Learner's Dictionary, n.d.). At the same time, a family is a group of people related to each other, such as a mother, a father, and their children (Cambridge University Press, n.d.). The basic unit in society traditionally consists of two parents rearing their children (Merriam-Webster's Collegiate Dictionary, n.d.).

### **Patient and Family Engagement**

All the relevant definitions were included, and the same definitions of patient, family, and engagement were provided, except Cambridge, which described engagement in a frail manner. While there are numerous definitions of patient-family engagement in the literature, the core meaning is that the nurses partner with the patient and patient representatives to promote quality care and strengthen their skills to support their patients and their health throughout the illness (Carman, et al., 2013). Furthermore, many places use engagement words for patient and family participation. As Jewel (1996) stated, active patient participation in care could be philosophically and practically, in which "individual or holistic care plans are discussed with the patient and family for better outcomes. However, Patient-family engagement is also described as a relationship between patients and healthcare workers to support and promote active participation to strengthen their opinion toward healthcare decisions (Coulters, 2011)

### **Attributes of concept:**

Some attributes are primarily used with this concept of engagement.

### **Holistic care**

The term holistic care is prominent and possesses excellent significance in the healthcare system. Engagement of patient and family in care is the supporting component for holistic care, as it will focus on physical, psychological, behavioral, and mental health and helps to achieve desired outcomes in health (Leach, et al., 2010).

### **Partnership**

It is the nurse's relationship between a patient and a family while providing care and preparing the family to engage efficiently during the hospital stay after discharge. Patient and family caregivers who get opportunities to participate in decision-making and work collaboratively with the nurses will feel empowered and motivated. Moreover, sometimes, too much assistance from healthcare workers results in patients' demotivation and reluctance to perform physical activity (Kvæl et al., 2018)

### **Knowledge Exchange**

By considering the health literacy concept, it is necessary to explain the patient and family caregivers' proper knowledge about the diseases and their treatment to avoid confusion after discharge. Although nurses are beside patients around the clock, the patient only can tell what is going on inside their body better than anyone, so it is essential to share knowledge so that patients and family caregivers recognize adverse symptoms and interpret them in time. (Riegel et al., 2021).

### **Establishing Interdisciplinary Approach**

The goal of an interdisciplinary approach in a healthcare setting is patient safety and a better understanding of the patient's situation in every aspect of health (Lancaster et al., 2015). Involving different service lines to better understand the patient's situation assists in positive outcomes and avoids misinterpretation of symptoms. Moreover, combined efforts will increase the positive impact on patient's health.

### **Antecedents**

#### **Active Participation**

There are times when patient and family caregivers bringing their patient to the hospital assume that now their role is finished, and they are the healthcare worker's responsibility to look after the patient. At that point it's important to initiate awareness regarding the engagement of patient and family regarding self-management and its importance will help in the long run as after discharge, the family can deliver the appropriate care and avoid mismanagement to their loved ones who are already suffering and suffering can be exaggerated due to lack of disease knowledge (Krist et al., 2017).

#### **Organizational Culture**

For the better utilization of the patient and family caregiver concept, a positive attitude and availability of supporting healthcare providers are significant for engagement (Castro et al., 2016). In addition, It is important to have a clear understanding of individual roles in a collaborative environment will decrease the chances of error and individuals know their role in patient recovery (Lancaster et al., 2015).

#### **Biopsychosocial Approach**

It is essential to regard the patient as a whole body rather than physically, taking the patient as

a biological, psychological, and social being who has unique care needs, which can be delivered with an understanding of their needs and engaging the patient and their family in assessing their perspective regarding their health and well-being (Davis et al., 2008).

#### **Patient-Centeredness Approach**

Patient-centeredness is a common phenomenon in inpatient care, and this approach is effectively implemented when family and patient are considered the main stakeholders in their patient's or own health. It will enhance not only the knowledge of the patient and family caregivers but also their skills, behaviors, and health status (Hamilton et al., 2019).

#### **Decision Making**

It is an essential component and crucial in terms of patient autonomy. Engaging patients in decision-making platforms is mandated and essential in the Nuremberg Code of Ethics. Other than that, patients who are aware of their diseases and willingly participate in care and decision-making have better knowledge and realistic expectations from treatment (Krist et al., 2017).

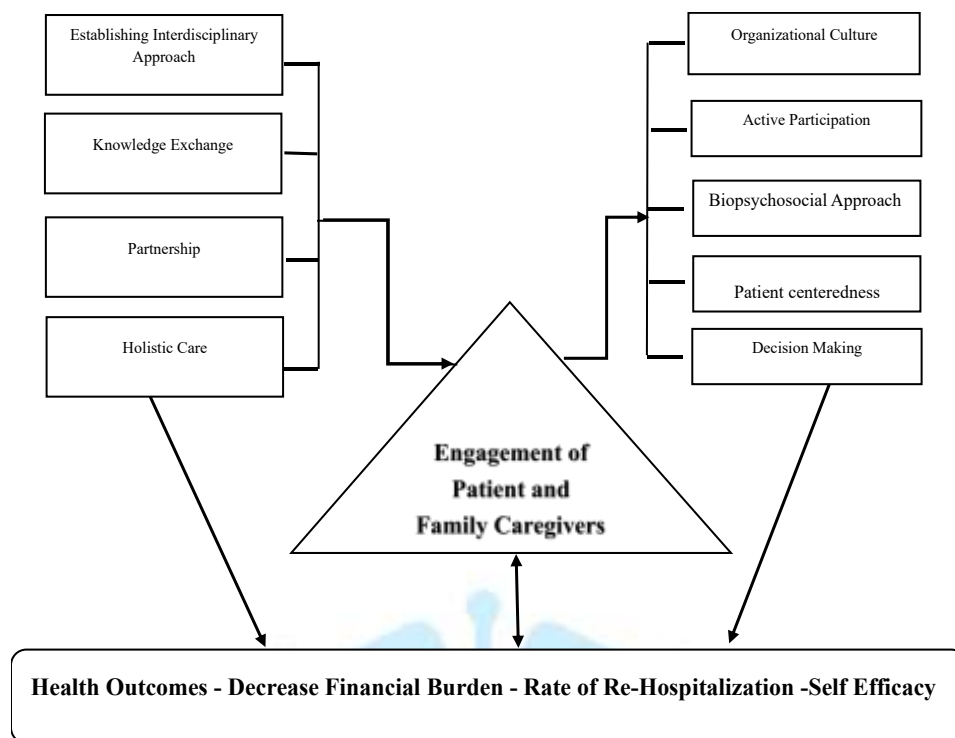


Figure 2

Conceptual Model for understanding the Engagement of patient and family caregivers in care.

### Consequences

Applying the concept of patient and family engagement in care in the healthcare sector can result in numerous positive consequences. It may also cause negative consequences, but those are few.

### Health Outcomes

In a healthcare setting, patient and family caregivers are both untapped resources. Families are directly in contact with their patients, and patients feel comfortable with their attendants. In that situation, availability and engaging family in care help achieve better outcomes (Aadal et al., 2018).

### Decrease Financial Burden

Currently, 8.5 percent of the world's population is 65 years of age and above, a number that may increase by 17% in 2050 (He, Goodkind, & Kowal, 2016). In developing countries, where

workforce shortages and staff unavailability are common issues, it results in care delays, and financial burdens on family caregivers, hospital resources, and human resources.

However, this can be overcome by introducing the concept of family caregiver engagement, which may reduce hospital resources and financial burden (Morelli et al., 2019).

### Self-efficacy

The participation of patients and their families increases the satisfaction level by considering patients' and families' preferences and perspectives. It also helps them improve self-efficacy and hands-on practices, which will benefit them in recovery and at home after discharge (Goldfarb et al., 2020).

### Rate of Re-Hospitalization

Family caregivers play a significant role in patients' lives by sharing knowledge and

interventions to help them while caring for them at home (Thakur et al., 2019). Moreover, suppose nurses provide comprehensive education to patients and their families. This would help to reduce incidences such as aspiration, infections, bedsores, and so on, hence reducing the rate of hospitalization.

#### **Negative Consequences**

There may be some negative consequences that can't be ignored, such as the difficulty of measuring family caregiver engagement in a hospital environment, the literacy level of family and patient, the Lack of human and financial resources, and the mishandling of family caregivers while delivering care to patients.

#### **Model Case**

Mr. X was admitted to the hospital due to a road traffic accident whose primary diagnosis was a traumatic brain injury. As the temporal region of the brain was affected, the patient could not comprehend and swallow effectively. As a result, Doctors and Nurses counseled the patient's family regarding the patient's prolonged recovery and the importance of family participation for quick recovery and preventing nosocomial infections from avoiding extended stays in the hospital. Nurses assigned to that patient started to engage patient and family caregivers from day one in feeding, positioning, sponging, mouth care, and activity of daily living. Moreover, Nurses assisted physiotherapists and speech therapists in involving patients and families during the range of motion and swallow exercises. At the time of discharge, the patient and family caregiver felt confident in providing daily routine care even after the patient started to perform his range of motions. This case study uses partnership, communication, interdisciplinary approach, and knowledge exchange to achieve better patient outcomes.

#### **Borderline Case**

A 55-year-old patient was admitted with an A-com aneurysm. It is an intracranial rupture of the cerebral artery that causes severe headaches till surgical intervention, and medication does not

subside the pain completely. The patient was screaming with severe headaches. Meanwhile, the patient's family asks the nurse to do something. The nurse was assigned to lower the patient's bed to 20 degrees, attach the drip, and close the light without explaining anything. After 15 minutes, the patient again complained of pain, and then the nurse replied that the medication had already been given and to wait for the medication's response. The patient's family asked if they could give the patient the mobile to distract her, but the nurse avoided the family's request. Throughout the shift, the patient was suffering from pain, and the family worried. On the night shift, the patient again complained of severe pain. Then, the nurse explained to the family that they should lower the bed to avoid low-pressure headaches caused by sitting and closing the lights to prevent worsening pain. In this case night shift nurse exchange knowledge about the symptom and how to prevent it. However, attributes such as partnership, communication, and interdisciplinary approach are missing.

#### **Contrary Case**

A 24-year-old patient admitted with a gunshot injury in the lumber region was diagnosed with spinal cord injury and quadriplegia. Doctors explained the patient's prognosis and injury-relevant complications in medical jargon, but the family was unable to understand the knowledge shared by the doctors. Instead of clarification from doctors, the family asked nurses when our patient started to walk and perform his task; the assigned nurse replied, please wait in the visitor's area. Furthermore, while giving positioning, bed sore care, or other activities of daily living, the nurse preferred that the family stay outside while delivering care. When the family caregiver asks to participate in the patient's care, the nurse says, "It's my duty, I will do it. Such circumstances also occur when nurses feel uncomfortable or disturbed by the presence of attendants. In this case, the attributes of communication, Partnership, Interdisciplinary approach, and knowledge exchange are missing.

### Empirical Referents

The final step of concept analysis is identifying the empirical referents. These will help measure the concept and support the phenomena of engagement. Although the concept was introduced long ago, there is still an absence of validated scales that can show the exact effectiveness of patient participation in the health system. Various scales are available to measure a patient's activation to participate in healthcare decision-making. Such as Patient Activation Measure, Observing Patient Involvement in Decision-Making Scale, and the Shared Decision-Making Questionnaire. However, hospital policies restrict this phenomenon from being implemented to measure patient engagement. Hence, recognizing the engagement activation and effectiveness seems complicated at some point.

The effectiveness of patient engagement strategies and understanding that highly engaged patients lead to better system outcomes are essential. A particular scale should ensure that all attributes, such as power, communication, information sharing, and collaboration, remain at the forefront while delivering care. Using tools that measure the engagement level of family and patient in care can help in evidence-based practices for effective patient engagement strategies instead of the "trial and error" approach that currently seems to exist. It will improve health system outcomes, financial burden on hospital and family caregivers, patient's symptoms, and decreased recovery process.

### Conclusion

Today, patient-family engagement faces numerous obstacles, especially in developing countries where the ratio of nurses is deficient. More knowledge is needed regarding the positive impact and results of engagement of patient and family caregivers.

Most studies used a qualitative research design, but a few were quantitative. Because of the limitations of studies and settings, most researchers mentioned the findings in narrative form. The study could not conduct research on a large scale due to the hospital's restriction policy

and inability to describe engagement meaningfully.

This concept aims to highlight the significance of engaging patients and their family caregiver participation in healthcare settings, and its implementation will be the "blockbuster drug of the century," which may not only empower the family caregiver but may resolve multiple concerns (Carman, et al., 2013). However, there are organizational restrictions relevant to patient visit policies, nurses' limitations, and family unwillingness to engage, making implementing the concept of engagement challenging. The following consequences increase the patient's family's anxiety, and reluctance to discharge their patient, and the factors behind the reluctance to discharge are not confident enough to look after their patient safely. Hence, implementing this concept in a healthcare setting may bring positive changes.

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