

Hospital-to-home transition of individuals receiving palliative care in light of Afaf Ibrahim Meleis' theory

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ABSTRACT

Objective: to reflect on the hospital-to-home transition process of individuals receiving palliative care, based on Afaf Ibrahim Meleis' Transitions Theory. **Methods:** theoretical-reflective study based on publications (non-systematic search) on the subject in Portuguese, Spanish, and English from 2018 to 2023, retrieved from the databases Embase, LILACS, MEDLINE (via PubMed of the National Library of Medicine), and Web of Science, using the controlled descriptors: Transitional care, Patient discharge, and Palliative care. **Results:** the reflections are presented across three thematic axes: facilitating conditions in the hospital-to-home transition process for individuals in palliative care; inhibiting conditions in the hospital-to-home transition process for individuals in palliative care; and therapeutic nursing interventions. **Conclusion:** it is essential that healthcare professionals observe, assess, and plan the transition process, taking into account all facilitating and inhibiting conditions, in order to ensure the continuity of safe care for individuals in palliative care and their families.

Descriptors: Palliative Care; Patient Discharge; Transitional Care; Nursing Theory; Nursing.

INTRODUCTION

Palliative care is defined as holistic care for individuals experiencing severe suffering related to complex clinical conditions throughout the life cycle, particularly for those nearing the end of life with multidimensional needs⁽¹⁾. Individuals in palliative care are entitled to receive care from professionals with specific competencies⁽²⁾, based on the complexity of their condition and needs⁽³⁾, to ensure their quality of life, as well as that of their families and caregivers⁽¹⁾.

These people may experience instability in the face of complex clinical conditions that require changes in care across different levels of healthcare and in various care settings⁽⁴⁾, including the home, hospital units, outpatient clinics, and long-term care facilities, as well as hospitalizations due to worsening of the condition, decline in general health, and exacerbation of signs and symptoms⁽⁵⁾. This movement is known as transitional care and refers to a set of measures aimed at ensuring the coordination and continuity of patient care as these care trajectories unfold⁽⁴⁾.

After controlling signs and symptoms, the patient in palliative care is usually discharged from the hospital⁽⁶⁾. Preparation for discharge should include a transition process from hospital to home health care, developed by a multidisciplinary team, including planning and educational practices for the patient and their family/care-giver⁽⁷⁾.

The hospital-to-home transition process is influenced by personal, environmental, and social factors, including the patient's age, cognitive status, health literacy, and clinical complexity⁽⁸⁾. Most often, the patient relies on a family member to serve as an informal caregiver, which requires training and educational support from

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healthcare professionals to ensure safe care and reduce the risk of hospital readmissions⁽⁹⁾.

To act effectively in this context, nurses must be guided by theoretical frameworks, among which Afaf Ibrahim Meleis' Transitions Theory stands out⁽¹⁰⁾. According to Meleis, transition refers to the process triggered by a change from one relatively stable state or condition to another, requiring the acquisition of new knowledge, behavioral adjustments, and the redefinition of identity⁽¹⁰⁾.

The theory presents four fundamental concepts: nature of transition (type, patterns, and properties), transition determinants, response patterns, and therapeutic nursing interventions⁽¹⁰⁾.

Regarding its nature, transition may be developmental, situational, health-illness-related, or organizational. Transition patterns can be simple, multiple, sequential, simultaneous, related, or unrelated⁽¹⁰⁾. Transition properties include awareness, engagement, change and difference, time span, events, and critical points⁽¹⁰⁾.

Conditions determining transition can be categorized as facilitators or inhibitors and may be personal, community-based, or societal. Personal conditions include meanings, cultural beliefs and attitudes, socioeconomic status, preparation, and knowledge. Community and societal conditions involve social support and relevant information provided by health professionals⁽¹⁰⁾.

Patterns of response encompass process and outcome indicators. Process indicators include feeling connected, interacting, being situated, developing confidence, and coping. Outcome indicators include mastery and fluid integration of identity⁽¹⁰⁾.

Therapeutic nursing interventions favor the reduction of unhealthy transitions, result in positive process indicators, and occur through nursing assessment, reminiscence, role supplementation, creation of a healthy environment, and provision of environmental resources⁽¹⁰⁾.

Several considerations guided the development of the present study; the critical importance of hospital-to-home transitional care in coordinating and ensuring safe continuity of care for individuals in palliative care; and the relevance of Transitions Theory to understand potential influencing factors in the transition process of individuals who require ongoing support and social assistance to meet their needs. Thus, the objective of this study was to reflect on the hospital-to-home transition process of individuals in palliative care based on Afaf Ibrahim Meleis' Transitions Theory.

METHODS

This is a theoretical-reflective study on the hospital-to-home transition of individuals receiving palliative care, based on Afaf Ibrahim Meleis' Transitions Theory⁽¹⁰⁾.

To support this reflection, a search was conducted for studies on the subject in Portuguese, Spanish, and English between 2018 and May 2023. The literature review was conducted in May 2023, based on a non-systematic search of the following information sources: Embase (Elsevier), Latin American and Caribbean Health Sciences Literature (Lilacs), Medical Literature Analysis and Retrie-

val System Online (MEDLINE) of the National Library of Medicine (via Pubmed) and Web of Science, using the following controlled descriptors: "Transitional care," "Patient discharge," and "Palliative care," combined using the Boolean operators AND and OR.

After identifying the relevant literature, the included studies were selected and read in full by two reviewers to assess whether the results addressed the hospital-to-home transition of individuals in palliative care. Data extracted from the articles were entered into Microsoft Word (Version 2019, Microsoft Corporation, United States) and grouped according to the elements of the Transitions Theory⁽¹⁰⁾, using a deductive analysis conducted by two reviewers. Any disagreements were resolved through a consensus meeting with the other researchers involved in the study. During this process, two concepts from the Transitions Theory emerged prominently: transition conditions and nursing interventions, which served as the basis for the themes around which the current reflections were developed.

RESULTS AND DISCUSSION

Thirteen studies with different methodological approaches — qualitative^(6,11-14), quantitative⁽¹⁵⁻¹⁸⁾, mixed-methods⁽¹⁹⁾ and literature review/update⁽²⁰⁻²²⁾ — were selected to support the reflections, which were organized into three thematic axes: facilitating conditions in the hospital-to-home transition process for individuals in palliative care; inhibiting conditions in the hospital-to-home transition process for individuals in palliative care; and therapeutic nursing interventions.

Facilitating conditions in the hospital-to-home transition process for individuals in palliative care

Among the factors that facilitated the transition of people in palliative care from hospital to home, a prominent one was the feeling of happiness associated with returning home. This was highlighted in a mixed-methods study conducted in two Canadian hospitals with palliative care patients and their caregivers⁽¹⁹⁾. A similar result was found in a study conducted in Belgium, in which patients receiving palliative care expressed a preference for receiving care at home⁽¹¹⁾. These findings suggest that returning home can promote feelings of comfort, well-being, and belonging, as it is a familiar setting that allows for interaction with close people.

Psychosocial factors, such as faith and spirituality, are additional facilitating conditions that provide comfort to patients and their families⁽¹⁰⁾, and should be valued during the hospital discharge process. The understanding that patients and their families have regarding palliative care and the care responsibilities at home⁽²⁰⁾ can positively influence the hospital-to-home transition. This was supported by a mixed-methods study conducted in Canada, which found that understanding the responsibilities to be assumed at home was a key facilitating factor⁽¹⁹⁾.

The perception of feeling prepared for hospital discharge by individuals in palliative care and their family members/caregivers

is an indicator that the transition will be safe. The preparation of family caregivers to provide care at home is a facilitating factor for this transition⁽¹⁰⁾. It is essential to consider the perceptions, preparedness, and knowledge of both the individual and the family/caregiver regarding palliative care when developing a discharge plan that is coherent and tailored to their unique circumstances and needs.

In addition to aspects related to the person receiving palliative care and their family, factors linked to the community and society can also interfere in this process⁽¹⁰⁾. A sense of community, the availability of sufficient caregivers, and the provision of necessary equipment to meet patient needs⁽¹⁹⁾, along with socioeconomic stability and family and community support, all contribute positively to the transition⁽¹⁰⁾.

Furthermore, awareness of the availability of follow-up care by a home-based palliative care team every day of the week⁽¹¹⁾ contributes to a sense of relief among family caregivers⁽¹²⁾. Access to this kind of healthcare system is a facilitating condition for the hospital-to-home transition⁽¹⁰⁾ and, in the context of complex palliative care, ongoing support from a multidisciplinary team following hospital discharge is essential, whether through primary healthcare services or home health care programs.

Inhibiting conditions in the hospital-to-home transition process for individuals in palliative care

The hospital-to-home transition can be a stressful time for patients and their families, as it requires acquiring new knowledge for providing care and adapting to the home environment⁽¹⁶⁾. Limited knowledge and a lack of preparation on the part of patients and families increase the barriers to assuming responsibility for transitional care at home^(6,10,19).

Throughout this process, new feelings, meanings, and coping mechanisms may emerge, leading to insecurity, discomfort, fear, and loneliness considering the symptoms, impaired daily activities, and lack of continuity of care by caregivers⁽¹¹⁾.

Furthermore, according to healthcare professionals, as patients and families transition from intensive care to community settings, limited understanding of the diagnosis and prognosis of severe illness⁽²¹⁾ along with difficulty managing pharmacological treatments⁽¹⁹⁾, can negatively affect the transition process, turning it into a context of uncertainty for both the patient in palliative care and their family members/caregivers⁽¹⁰⁾.

Individuals in palliative care often experience doubts about what will happen the next day, how the disease will progress, whether there is any possibility of cure or how the dying process will unfold⁽²³⁾. Uncertainties for family members/caregivers during the hospital-to-home transition may relate to the patient's condition, symptoms, and the level of support they will receive from healthcare professionals, the community, and support groups⁽¹⁵⁾.

Other factors, such as financial insecurity, lack of social and community support networks, poor communication by hospital staff, inadequate home health care^(11,13), lack of service integration, premature discharge⁽¹¹⁾ and delayed discharge planning⁽¹⁴⁾ are also

recognized as inhibiting conditions for the transition from hospital to home⁽¹⁰⁾.

An ethnographic study conducted in Brazil and France identified weaknesses in counter-referral and communication between hospital teams and primary care in the Brazilian setting. In France, there was government support with financial resources for hiring caregivers to provide assistance in the household, in addition to the provision of medical-social facilities for the institutionalization of people at the end of life⁽⁶⁾.

The reality that palliative care services within primary care are not yet widely available across Brazil⁽⁶⁾ leads many patients to frequently seek emergency services.

With regard to communication between hospital and primary care teams, the electronic health record has proven to be a valuable tool for ensuring continuity of care and for evaluating and monitoring ongoing treatment. However, its implementation faces operational challenges, such as the use of multiple systems in different formats across institutions and levels of care⁽²²⁾.

Discharging patients without access to a support network, the necessary equipment and resources, or training on how to use them; failures in communication between services; and inadequate educational efforts to fill gaps in the information and guidance provided to patients, families, and caregivers, all represent inhibiting conditions to a safe hospital-to-home transition.

Therapeutic nursing interventions

Therapeutic nursing interventions should facilitate the transition process from hospital to home⁽¹⁰⁾, in which the inclusion and participation of patients and families in decision-making are essential to develop a care plan tailored to their needs⁽¹⁷⁾.

Among the nursing interventions, educational actions stand out, particularly those aimed at the proper handling of medical devices, nutrition, and medication administration. It is essential to prepare a comprehensive discharge plan detailing the care to be performed at home, including referral to the appropriate healthcare unit and arrangements for follow-up after discharge⁽¹⁸⁾.

Based on the discharge plan, effective communication and integration with the home health care team can be established, which allows family members to prepare the household for the patient's return⁽¹⁴⁾. Sharing the medical record with the home health care team and providing written instructions, such as leaflets for patients and families, are strategies that support a smoother transition process⁽¹³⁾.

The provision of palliative care at all levels of health care is a challenge, since this care is still concentrated in hospitals, especially high-complexity facilities⁽²⁴⁾. In Brazil, home health care is provided by the Home Care Service (SAD or *Serviço de Atenção Domiciliar*, in Portuguese), which is not available in all municipalities⁽²⁵⁾. To improve the hospital-to-home transition process, it is essential to expand palliative home health care to cover the entire Brazilian territory.

To ensure a safe return home, the multidisciplinary healthcare

team must pay close attention to both the facilitating and inhibiting factors influencing the hospital-to-home transition. This process should be guided by principles of humanization and open dialogue, respecting the uniqueness, values, and choices of the person receiving palliative care and their family⁽³⁾.

It is essential that professionals within Family Health Strategies and Basic Health Units (program offered by the Brazilian Unified Health System) are well-prepared to care for individuals in palliative care and their families. Nursing interventions are key to strengthening the support network for patients in palliative care at home and minimizing the factors that hinder the hospital-to-home transition process.

Although this reflection has pointed out elements that may contribute to broadening the horizons of understanding of nursing and other health professionals about the transition process in light of a theoretical framework, the approach of only two of the four foundations of the Transitions Theory proposed by Afaf Ibrahim Meleis constitutes a limitation of the present reflection, as does the non-inclusion of studies in other languages.

CONCLUSION

It is essential that healthcare professionals observe, assess, and plan the transition process by considering all facilitating and inhibiting conditions to ensure the continuity of safe and effective care for individuals in palliative care and their families.

In the palliative care context, inhibiting conditions for the hospital-to-home transition include limited knowledge, lack of preparation, financial insecurity, and poor service integration, which contribute to intensifying feelings of insecurity, discomfort, fear, and loneliness, challenging the opportunity to reframe life and accept finitude as part of the human condition. On the other hand, facilitating conditions include feelings of happiness, comfort, and belonging associated with returning home. Therapeutic nursing interventions to facilitate the transition process have predominantly involved educational actions aimed at preparing patients to receive care at home.

Although Meleis' Transitions Theory is still underutilized in Brazilian palliative care research, it has significant potential to explore the conditions that encompass the various dimensions of the human experience and influence the transition toward the end of life.

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