

REVIEW

End of life care: A concept analysis

Hodan Abdullah*¹, Jessie Johnson², Fadi Khraim²

¹Hamad Medical Corporation, Qatar

²University of Calgary in Qatar, Qatar

Received: February 5, 2021

Accepted: April 25, 2021

Online Published: May 25, 2021

DOI: 10.5430/ijh.v7n2p1

URL: <https://doi.org/10.5430/ijh.v7n2p1>

ABSTRACT

Background: End of life care is crucial to preserve a dying patient's values and dignity. This type of care also works towards fulfilling any last wishes the dying person may have.

Aim: The aim of this paper is to analyze the concept of end of life care using Rodgers' evolutionary method as a guide.

Methods: A systematic search of the literature was conducted in CINAHL, PsycINFO, and Medline databases. After reviewing the literature from 2006 to 2019, 14 articles were selected to be included in this analysis.

Results: The consequences of this concept include a good death, peaceful death, and dying with dignity.

Conclusions: This concept analysis provides attributes that could help to develop a standardized end of life care approach to patients who are dying.

Key Words: Concept analysis, End of life care, Terminal care, Palliative care, Meaning of

1. INTRODUCTION

According to the National Palliative and End of Life Care Partnership (2015-2020),^[1] end of life care should be ubiquitous as nurses support patients to live and die with dignity. End of life care is described as the "choreography of dynamic interaction among wishes, values, culture, religion, acceptance, and the essence of control" that dictates a good death.^[2] According to the World Health Organization (2021),^[3] cancer is the second cause of death globally accounting for 10 million deaths in 2018. The role of the nurse during this time is more important than ever. Nurses who work in areas where death is imminent require knowledge, skills, and expertise to deliver end of life care.^[4] Priorities of care may change in the last weeks or days before death. Thus, end of life care is essential in order that dignity is preserved, and patient's values are maintained and respected.^[5]

Different contexts and cultures can shape the meaning of end

of life care. In nursing science, establishing the meaning of a concept is a necessary criterion for basic research. Thus, the aim of this paper is to analyze the concept of end of life care using Rodgers' evolutionary method of concept analysis.

Background

End of life care is critical for all patients no matter what terminal illness they may have. There have been multitudes of efforts to ensure that end of life care is holistic and congruent with all patients.^[6] The National Institute of Health and Care Excellence defined end of life as "a subset of palliative care focusing on expected impending death within 12 months."^[7] The World Health Organization defines end of life care as the process that helps in improving the quality of life of dying patients and their family members through pain control and symptom management.^[7] Health care providers continually develop end of life care strategies to help advanced, progressive, and terminally ill patients to live their

*Correspondence: Hodan Abdullah; Email:HIbrahim7@hamad.qa; Address: Hamad Medical Corporation, Qatar.

life with quality until they die. This particular care provides supportive and palliative care needed for dying patients and their caregivers. End of life care includes various needs and covers different aspects of patients and families' life. For example, it includes management of pain and other symptoms, provides psychological, social, spiritual, emotional support, and ensures financial security and patients and families preparedness for death.

Providing end of life care with optimum quality is highly important for multidisciplinary health team members, particularly nurses. Nurses' use words like privilege, honor,^[8] and a promise to keep to describe end of life care, and they believe that the care they provide for dying patients and their families is rewarded.^[9] According to Borhani et al. (2013),^[10] nurses view their role in end of life care as a commitment and obligation to care. During end of life care nurses promote dignity and comfort for terminally ill patients. Nurses also provide psychological and emotional support for families and caregivers through facilitating therapeutic communication and providing information.^[7] Conducting a concept analysis that delineates the meaning of end of life care will help nurses understand the true essence of the concept and its associated factors, which will further support their mission to provide best care at the end of life.

2. METHODS

The strengths of Rodgers' method are in the systematic approach and the clear phases used in this method. Rodgers' method also contributes to the clarification, description, and explanation of a variety of concepts through analyzing the uses of a concept in nursing and other sciences.^[11] This method views concepts as context dependent; therefore, it has been chosen to understand the concept of end of life care with inductive and dynamic technique. Rodgers' method for concept analysis involves several phases. These phases include identifying the concept, identifying surrogate terms and uses, identifying and selecting the sample, identifying attributes, identifying references, antecedents, and consequences of the concept, identifying related concepts, and identifying a model case.

In order to conduct a concept analysis, researchers must select databases that are appropriate to provide comprehensive understanding of the concept being explored. There are a variety of accessible electronic and printed databases that provide depth and breadth of knowledge for the concept. Tofthagen and Fagerstrom (2010)^[11] reported that Rodgers' method relies on using different databases in order to allow for such depth and breadth. Databases that can be utilized include printed media, professional literature, interviews, or other forms of verbalized language. Tofthagen and Fager-

strom (2010)^[11] also recommended including literature from different disciplines and different scientific methods in order to explore all possible uses of the concept across these disciplines. This inclusion of a variety of databases or resources helps researchers reach the desired data saturation related to the meaning and uses of the concept.

For the purposes of this concept analysis, the following databases were searched CINAHL, PsycINFO, and Medline. The selection of these databases was because they would provide a comprehensive overview for the meaning and the various uses of the concept across a variety of disciplines including but not limited to nursing, medicine, and other allied health professions. In searching these databases, the key terms used were end of life care, palliative care, terminal care, concept analysis, and meaning of. The initial search through these databases yielded 35,000 articles. Therefore, articles selected for this concept analysis were those published in the English language, peer reviewed, published from 2006 to 2019, articles based on inpatient and outpatient participants, and articles that focused on adults. Applying these limiters concluded with 708 articles. These 708 articles were screened further by title and abstract. Through scanning of the titles and quick reading of the abstracts, 27 articles were selected for full-text review. The result of the full text review included 14 articles in the final analysis. The chosen fourteen articles were sufficient to include in this review and analyze the end of life care concept. These articles were written by different disciplines and targeted different audiences. Authors were psychologists, sociologists, health economists, nursing philosophers, nursing scholars, oncologists, and others, while the audiences were nursing practitioners who worked in various settings, physicians from different specialties, social workers, other allied health professions, and hospital administrators.

3. RESULTS

After the initial phase of defining the concept of interest and conducting the databases search, a careful review of the literature was conducted to initiate the first step of the core analysis by identifying the surrogate terms and relevant uses of the concept. The review of this literature identified the common attributes to the concept of end of life care as well as some frameworks and models to confirm the application of this concept. In addition, preceding factors and impacts of end of life care were reviewed through this literature.

3.1 Surrogate terms and relevant uses

This phase begins with finding surrogate terms and relevant uses of the concept. According to Kehl (2006),^[12] surrogate terms are terms that are used interchangeably with the con-

cept of interest and have similar definitions of the concept. The relevant uses of the concept define other uses in the same or different disciplines.^[11] Surrogate terms help to explore the different words in a language that explains the idea of the concept of interest. Defining different uses of a concept helps in facilitating the inter-subjectivity between different sciences.

The term End of life care does not have other synonyms rather its medical meaning. Searching through medical dictionaries and thesauruses available online; revealed definitions for end of life care, such as providing the optimum quality of care for terminally ill patients as well as their families and caregivers. This literature review found the term is not exclusive to medicine and nursing disciplines. It is also used broadly in sociological science to explore culture, politics, and policies' effects on this concept. End of life is also used in psychology to examine the patients' emotional distress from the context of this concept and describe caregivers' burdens. The End of life care concept has been covered in philosophical science through evaluating the epistemological issues related to end of life care decisions. Lastly, the concept is used in medical and nursing education and research to improve the quality of care provided for terminally ill patients.

3.2 Attributes

Concepts consist of unique attributes that contain interpretations and descriptions of the situations where the concepts are used. Attributes are "clusters of characteristics that make it possible to identify situations that can be categorized under the concept."^[11] Attributes for concepts can be physical, mental or social symptoms, time, an individual or relational process, and more. The selected literature emanating from various disciplines reported some attributes for end of life care, such as continuity of care, effective communication, emotional support, and preparing and coping with death.

3.2.1 Continuity of care

Continuity of care is essential in nursing practice and has to be focused on providing health information, facilitating access to health care in hospital and community, and coordinating care plans with other health care providers.^[13] The continuity of care during end of life care differs from care provided for other patients. Terminally ill patients may benefit from the continuity of care during end of life to maintain their interests, concerns, and hope. The time is a significant element that has to be presented in permanent situations in continuity of care. This attribute facilitates providing quality of care for dying patients until the very end of their life.^[13] Continuity of care provides patients with an interdisciplinary approach, health education, and integration of care during transition. den Herder-van der Eerden et al. (2017)^[14] re-

ported that continuity of care consists of relational continuity and informational continuity among patients, families, and health care providers. Consequently, patients and their families will be satisfied with the quality of end of life care that is provided.

3.2.2 Effective communication

Effective communication between health care providers and dying patients, their families, or caregivers is another attribute in end of life care. Providing best end of life care involves mutual therapeutic communication.^[10] This facilitates delivering compassionate end of life care and enhances collaboration among health care providers. Canaway et al., (2017)^[15] emphasized the quality of communication is as important as the availability of staff to deliver information. Effective communication provides clarifications regarding the disease progression and the available treatment interventions for the dying patients and their caregivers during their journey.^[14] Effective therapeutic communication contributes to reduce patients' emotional distress and caregiver burden. It also helps in viewing dying patients' preferences and wishes. This view helps in granting their wishes to offer a peaceful journey during their end of life care.^[15]

3.2.3 Emotional support

Death is a challenging situation for patients, families, caregivers, and health care providers that consist of emotional stress. End of life care should be focused on providing emotional support for dying patients and caregivers to cope with death effectively.^[16] Nurses, social workers, and psychotherapists are constantly assessing emotional issues related to care and providing emotional support for dying patients during end of life care. This attribute helps dying patients and their families to improve their experiences with end of life care and the notion of death.^[15]

3.2.4 Preparing and coping with death

According to Canaway et al. (2017),^[15] end of life care is an opportunity for patients and families to cope with the concept of dying. It is also an opportunity to prepare oneself for bereavement. As a result, this is expected to improve their experiences about death and bereavement. This attribute enables dying patients and families to manage their properties, financial assets, and other interests in life before death. It also helps dying patients, their families, and caregivers in adapting appropriate coping mechanisms.^[16] In end of life care, health care providers have to be honest and truthful in preparing patients and their families of what is to come.^[9] Practical support by health care providers is important in end of life care, because providing care for dying patients will help caregivers to have some normality in their life and preparedness for bereavement.^[15]

3.3 References

This step identifies the range of events, situation, or phenomenon to confirm the application of the concept.^[11] There are numerous frameworks and models to confirm the appropriateness of an application of a concept.

Current literature provides various measurements for end of life care. The Person-Centered Preferences to Guide Advanced Illness Care is one measurement for end of life care. It covers six important domains: purpose and connection, physical comfort, emotional and psychological wellbeing, family and caregivers support, financial security, peaceful death and dying.^[17] This measurement tool identifies the effectiveness of end of life care through evaluating the performance of health care providers. In October 2016, the National Quality forum (NQF), which is a nonprofit organization that aims to improve healthcare quality through measurement, provided a simplified measurement framework that was originally developed in 2006 for palliative and end of life care to assess the quality of care provided for dying patients.^[17] The NQF framework for palliative and end of life care placed the patient and family in the center of care. The framework assesses the domains of care, model of care, and types of care. Another framework is the Gold Standards Framework (GSF), which is a method to assess provided care during end of life.^[18] The GSF involves a comprehensive care assessment tool that helps health care providers to identify dying patients, assess their symptoms, needs and wishes, and support patients to live and die where they choose.^[18]

3.4 Antecedents

Antecedents are events or phenomena that related previously to the concept.^[11] Antecedents describe the incidents before the application of the concept. Antecedents of end of life care are approaching death, reduced quality of life, increased dependency, and reduced life expectancy.^[19] Before transition to end of life care, patients have to be progressively ill with an incurable disease that leads them to death. The quality of life may also be reduced for dying patients as a result of their condition, increased pain, and other disease-related symptoms. Dying patients often become dependent in activities of daily living and experience less life expectations.

3.5 Consequences

The consequences in the concept analysis are the outcomes after applying the concept in a situation.^[11] Consequences of the end of the life care concept are good death, peaceful death, and dying with dignity.

3.5.1 Good death

A Good death is one of the outcomes of end of life care. The Institute of Medicine defined a good death as a result

of absence of emotional distress and suffering for patients, families, and caregivers as well as granting patients and families' wishes while following the clinical, cultural and ethical standards.^[12] The good death is manifested by the dying experience. According to Granda-Cameron et al. (2012),^[20] good death requires appropriate preparation, symptoms control, social support, and spiritual support during end of life care. To achieve a good death during end of life care, health care providers have to deliver optimum quality of care that is patient and family-centered and based on patient's preferences. In end of life care, health care providers focus on comfort care rather than aggressive measures to promote a good death.^[12]

3.5.2 Peaceful death

Another consequence of end of life care in the literature is peaceful death. Approaching end of life is a personal experience; however, nurses while providing end of life care are obligated to assist dying patients to experience as peaceful a death as possible.^[16] In end of life care, nurses are able to provide peaceful experiences by observing and interpreting patients' cues that reflect being or not being in a peaceful state. It has been reported that in order to achieve a peaceful death during end of life care, nurses have to manage pain, ensure a sense of comfort, maintain privacy, and ensure family and significant closeness.^[16] Borhani et al. (2014)^[10] explored nurses' perspectives of end of life care in an Islamic context. They found that nurses promote peaceful deaths for Muslim patients by performing specific Islamic rituals during the dying phase. For example, they ensured that someone is beside the patient to prompt them to shahadatine (saying Declaration of Faith) or recite verses of the holy Qur'an.

3.5.3 Dying with dignity

According to Hemati et al. (2016),^[19] dignity has many potential meanings and applications. These authors stated that dignity consists of two features, human dignity and social dignity. Human dignity is an independent concept that cannot be measured or compared. It is also an intrinsic and inseparable value of each person. While social dignity is a consequence of human dignity, which is the acknowledgment of an individual. The value of the individual and the social acknowledgment are significant even for patients who are dying. Therefore, in nursing science maintaining dignity of the dying patient is essential in their practice.^[21] In addition, during the provision of end of life care, maintaining dignity in final moments of life is important. One of the vital roles of nursing, is delivering holistic care for dying patients and their families while maintaining their cultural and social beliefs. It is also important to respect patients and families' choices and decisions related to end of life. Accordingly, the goal is to ensure dying patient have death with dignity.

3.6 Related concepts

Related concepts are terms that share some commonalities with the main concept, yet they have different characteristics.^[11] Some related concepts that may be used interchangeably with the end of life care concept are quality of care at the end of life and needs of dying people. The concept quality of care at the end of life defines the process of care delivered for dying patients.^[12] This concept focuses on the provided care rather than the dying patient's experience. On the other hand, the needs of dying people defines the type of care these patients require.^[12]

4. MODEL CASE

Model cases in concept analysis provide clarifications and define the characteristics of the concept. Including a model case that has similar attributes in concept analysis enhances the strength of concept clarification. The following case provides an example of a case in end of life care.

A 46 years old female was transferred from an acute medical unit to a long-term care unit. She was diagnosed with advanced, progressive, incurable Parkinson's disease. After a few days of admission, her attending physician consulted with multidisciplinary team members and conducted a case conference to discuss her transition to end of life care. I attended the case conference as her primary nurse and ensured that the patient and her family were included in the decision making for the care plan. After the news was delivered, and the patient accepted the decision; she and her family were involved in planning the end of life care. I interviewed the patients and her sister who was her primary caregiver in order to know her care preferences during end of life phase and her wishes before death. One main request was to maintain constant privacy until the end of her life. She also requested to make her decision as sole priority over her sister or physicians in the treatment plan. She asked to provide measures that would maintain her independence and dignity to ensure a good quality of life. Finally, her wish was to have a peaceful death.

During her hospitalization, health care members provided comprehensive quality of care that maintained her beliefs and preferences. The multidisciplinary team emphasized the importance of providing measures to maintain the patient's hope for better days with fewer problems until her death. The social worker constantly followed the patient and her sister to provide emotional support by reducing the patient's distress and relieving her sister's burdens. She also offered coping strategies for the patient and her sister, and periodically assessed their coping mechanisms.

The patient gradually progressed and became occasionally

unconscious; nevertheless, health care providers and her sister protected her privacy. Her independence was ensured at the beginning of her condition through providing occupational and physical therapy to preserve her strength and functions. She was also prescribed pain and symptom management interventions and treatment. After six months she had her night bath with assistance from her sister and she went to sleep, and that was her final day. Her sister later shared her thoughts that her sister's wish of having a peaceful death was granted. This model case demonstrates identifying the attributes of end of life care, which are effective communication, continuity of care, providing emotional support, and preparing and coping.

5. CONCLUSION

Exploring and clarifying concepts are important to facilitate conceptual understanding among different disciplines of science. In nursing science and practice, it is significant to avoid ambiguity of concepts. Rodgers' evolutionary concept analysis method aims to serve the goal of clarifying and interpreting nursing concepts.

Rodgers' method suggests that concepts are subject to change, and this paper contains analysis of the end of life care concept guided by this method. While the end of life care concept has no different linguistic uses rather than in health care science and practice, health care providers have shared conceptual understanding of this concept. The end of life care concept has also been used within different disciplines such as sociology, medicine, nursing, education, philosophy, and many more. The application of this concept contributes to the human purpose in actual situations. There is a deficit in the literature of exploring the meaning of end of life care; therefore, this concept analysis provides for nursing practice important attributes that facilitates developing standardized and effective end of life care. It is also recommended that nursing curricula use a standardized concept of end of life care that is part of palliative care.

This paper provides a description of the boundaries that demarcate the concept of end of life care as it concerns various healthcare providers, researchers, and scientist. Knowing the meaning, attributes, and consequences of end of life care would be of particular benefit to researchers interested in studying this phenomenon. It is imperative that researchers aiming to study end of life care among various patient populations understand the boundaries of this concept, so they have a better sense of direction of where to start and what to look for in their studies. This is particularly important when other terminology such as *quality of care at the end of life* and *needs of dying people* are used interchangeably by researchers to describe end of life care. Doing so may lead to

misinterpretation or misrepresentation of research findings.

CONFLICTS OF INTEREST DISCLOSURE

The authors declare no conflicts of interest.

REFERENCES

- [1] National Palliative and End of Life Care Partnership. Ambitions for palliative and end of life care: a national framework for local action 2015-2020. 2015. Available from: <http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf>
- [2] Pattison N, Carr SM, Turnock C, et al. 'Viewing in slow motion': patients', families', nurses' and doctors' perspectives on end-of-life care in critical care. *Journal of Clinical Nursing*. 2013; 22(9-10): 1442-1454. PMID:23506296. <https://doi.org/10.1111/jocn.12095>
- [3] World Health Organization. Cancer. 2021. Available from: <https://www.who.int/news-room/fact-sheets/detail/cancer>
- [4] Libo-On IL, Nashwan AJ. Oncology nurses' perceptions of end-of-life care in a tertiary cancer centre in Qatar. *Int J Palliat Nurs*. 2017; 23(2): 66-73. PMID:28245161. <https://doi.org/10.12968/ijpn.2017.23.2.66>
- [5] Banjar AK. Till death do us part: The evolution of end-of-life and death attitudes. *Canadian Journal of Critical Care Nursing*. 2017; 28(3): 34-40.
- [6] Wachterman MW, Pilver C, Smith D, et al. Quality of End-of-Life Care Provided to Patients With Different Serious Illnesses. *JAMA Internal Medicine*. 2016; 176(8): 1095-1102. PMID:27367547. <https://doi.org/10.1001/jamainternmed.2016.1200>
- [7] Ong KK, Ting KC, Chow YL. The trajectory of experience of critical care nurses in providing end-of-life care: A qualitative descriptive study. *Journal of Clinical Nursing*. 2018; 27(1-2): 257-268. PMID:28514505. <https://doi.org/10.1111/jocn.13882>
- [8] Ranse K, Yates P, Coyer F. End-of-life care in the intensive care setting: a descriptive exploratory qualitative study of nurses' beliefs and practices. *Australian Critical Care: Official Journal of the Confederation of Australian Critical Care Nurses*. 2012; 25(1): 4-12. PMID:21565520. <https://doi.org/10.1016/j.aucc.2011.04.004>
- [9] King PA, Thomas SP. Phenomenological study of ICU nurses' experiences caring for dying patients. *Western Journal of Nursing Research*. 2013; 35(10): 1292-1308. PMID:23797098. <https://doi.org/10.1177/0193945913492571>
- [10] Borhani F, Hosseini SH, Abbaszadeh A. Commitment to care: a qualitative study of intensive care nurses' perspectives of end-of-life care in an Islamic context. *International Nursing Review*. 2014; 61(1): 140-147. PMID:24382147. <https://doi.org/10.1111/inr.12079>
- [11] Tofthagen R, Fagerström LM. Rodgers' evolutionary concept analysis—a valid method for developing knowledge in nursing science. *Scandinavian Journal of Caring Sciences*. 2010; 24 Suppl 1: 21-31. PMID:21070310. <https://doi.org/10.1111/j.1471-6712.2010.00845.x>
- [12] Kehl KA. Moving toward peace: an analysis of the concept of a good death. *The American Journal of Hospice & Palliative Care*. 2006; 23(4): 277-286. PMID:17060291. <https://doi.org/10.1177/1049909106290380>
- [13] D'Angelo D, Mastroianni C, Hammer JM, et al. Continuity of Care During End of Life: An Evolutionary Concept Analysis. *International Journal of Nursing Knowledge*. 2014; 26(2): 80-89. PMID:24898036. <https://doi.org/10.1111/2047-3095.12041>
- [14] den Herder-van der Eerden M, Hasselaar J, Payne S, et al. How continuity of care is experienced within the context of integrated palliative care: A qualitative study with patients and family caregivers in five European countries. *Palliative Medicine*. 2017; 31(10): 946-955. PMID:28659022. <https://doi.org/10.1177/0269216317697898>
- [15] Canaway A, Al-Janabi H, Kinghorn P, et al. Development of a measure (ICECAP-Close Person Measure) through qualitative methods to capture the benefits of end-of-life care to those close to the dying for use in economic evaluation. *Palliative Medicine*. 2017; 31(1): 53-62. PMID:27260168. <https://doi.org/10.1177/0269216316650616>
- [16] Kongsuwan W, Touhy T. Promoting peaceful death for Thai Buddhists: implications for holistic end-of-life care. *Holist Nurs Pract*. 2009; 23(5): 289-296. PMID:19713787. <https://doi.org/10.1097/HNP.0b013e3181b66ce6>
- [17] Burstin H, Johnson K. Next-generation quality measurement to support improvement in advanced illness and end-of-life care. *Generations*. 2017; 41(1): 86-93.
- [18] Shaw KL, Clifford C, Thomas K, et al. Improving end-of-life care: a critical review of the Gold Standards Framework in primary care. *Palliative Medicine*. 2010; 24(3): 317-329. PMID:20156934. <https://doi.org/10.1177/0269216310362005>
- [19] Hemati Z, Ashouri E, AllahBakhshian M, et al. Dying with dignity: a concept analysis. *Journal of Clinical Nursing*. 2016; 25(9-10): 1218-1228. PMID:27001200. <https://doi.org/10.1111/jocn.13143>
- [20] Granda-Cameron C, Houldin A. Concept analysis of good death in terminally ill patients. *The American Journal of Hospice & Palliative Care*. 2012; 29(8): 632-639. PMID:22363039. <https://doi.org/10.1177/1049909111434976>
- [21] Ho AH, Leung PP, Tse DM, et al. Dignity amidst liminality: healing within suffering among Chinese terminal cancer patients. *Death Studies*. 2013; 37(10): 953-970. PMID:24517523. <https://doi.org/10.1080/07481187.2012.703078>