

## Review Article



## Concept Analysis of End-of-Life Care

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## Abstract

**Introduction:** The inevitability of human mortality encourages the care system to enhance the quality of life (QOL) at the end of life. However, the main problem is that the boundaries of care as end-of-life care (EOLC) have not been defined precisely. Hence, this study aimed to clarify the concept of EOLC.**Methods:** This study was conducted based on Walker and Avant's eight-step approach (2019). A detailed review of the literature was accomplished in the databases including PubMed/Medline, Web of Sciences, Scopus, EMBASE, and Google Scholar from January 2010 to September 2020 using the keywords 'Terminal Care', 'Hospice Care', 'Nursing Palliative Care', and 'End of Life'. Out of a total of 302 articles obtained, 14 articles were included in the study.**Results:** The properties of EOLC included the following items: palliative care; improving QOL; reducing pain and suffering from physical, psychological, and psychological symptoms; and filling the gap between treatment teams and family caregivers through considering ethical issues and respecting patients' independence. Furthermore, through taking a team approach, EOLC helps the family with physical, emotional, social, and spiritual supports. EOLC is a comprehensive and compassionate process that does not hasten or delay death, but respects and comforts the patient.**Conclusion:** The EOLC can be defined as a palliative and humanistic care with a holistic and team-based approach focusing on all dimensions of the patients and their families. It also improves well-being at the end of life or even at the time of death, and helps the families with their grieves.

## Introduction

Death is an inevitable phenomenon for all beings. End of life may be the worst and last unpleasant experience that can happen to a person. This is a disaster for both the individual and the family. Nowadays, with growing life expectancy and technology advances, many people need end-of-life care (EOLC), which is one of the serious concerns of the health systems.<sup>1</sup> However, the inevitability of human mortality encourages care systems to enhance the quality of life (QOL) at the end of life. In this regard several questions may be addressed as follows:

- What does EOLC mean?
- What is the main duty of a nurse while giving EOLC?
- What is the philosophy of care at the end of life?

The answers to these questions should be addressed. But EOLC is considered as a vague and unclear concept in nursing science. One of the primary outcomes of caring for life in any situation should be a good death experience by the patient, family, and healthcare providers.

Nurses play an important role in caring for patients, as they support patients and families and provide ongoing direct care.<sup>2</sup> However, what happens at the end of life and

what care should be taken is still unclear. The concept of "good death" is very controversial, and little research has been conducted on it. Nursing care is defined as a helping, supportive, and facilitator activity to meet the potential and actual needs of the individual or group. The goal of EOLC is to help patients live naturally despite the complications caused by the disease. The approach of integrating care in developed countries is such that palliative care is provided globally and systematically, and it is accessible to all members of society.<sup>3</sup> Palliative care is a teamwork and it is an interdisciplinary task; nurses also play an important role in helping the palliative care team improve patient outcomes.<sup>4</sup>

One of the most important issues in EOLC is the lack of a satisfactory and clear definition for this concept. Given the ambiguous nature of the concept, its use and unique features may not be clearly understood, or what is used in the communication is not coordinated. The correct definition of this concept can be effective in caring for patients and even the type of cares. Therefore, this study aimed to analyze the concept of EOLC through using the method proposed by Walker and Avant.<sup>5</sup>

## Materials and Methods

This study was conducted as a concept analysis with the aim of clarifying the concept of 'care at the end of life'. Concept analysis analyzes the basis, attributes, and relationships of the concept with other meanings, and clarifying concepts is of the utmost importance.<sup>6</sup> In nursing, there are a lot of abstract concepts and phenomena related to psychology. In addition, there are many words and concepts related to psychology and behavioral sciences that cannot be objectively analyzed and quantified, and the characteristics of that phenomenon must be examined to identify it.<sup>7</sup>

Initially, the databases of PubMed/Medline, Web of Sciences, Scopus, EMBASE, and Google Scholar were searched with the keywords "Terminal Care", "Hospice Care", "Nursing Palliative Care", and "End of Life" from 01 January 2010 to 30 September 2020. Our search strategy resulted in the retrieval of a total of 302 articles, 14 of which met the inclusion criteria. Exclusion criteria included abstracts, reviews, and commentaries. The inclusion criteria were as follows: 1- papers containing a definition of EOLC, 2- discussing the history of the concept of EOLC, 3- identifying the relationship between the role of caregivers and related outcomes, and 4- reporting the findings of all studies related to the concept of EOLC or related concepts. The researchers repeatedly examined the studies. Words, phrases, lines, sentences, and paragraphs were searched for meanings and then compared by researchers for similarities and contrasts (Figure 1).

Walker and Avant's approach was used in this analysis.<sup>5</sup> This approach is a simple method of Wilson's eleven-step approach, and it can be applied to top-level results through clarifying the concept. Moreover, it includes eight steps as follows: 1- concept selection, 2- stating the objective of analysis, 3- definitions and uses of the concept, 4- identifying the concept defining attributes, 5- identifying a model case, 6- identifying boundary,

opposing, and innovative cases, 7- identifying antecedents and consequences, and 8- defining experimental representation.

## Concept Selection

The meaning of each concept depends on a range of different factors within the field, as well as the boundaries outside it over time. Therefore, the more the concept is analyzed and clarified, the more it is used, emphasized, and studied.<sup>5</sup> In this analysis, the concept of EOLC was chosen because of its widespread use and importance in the healthcare system. This concept has been addressed by various professional groups, such as law, jurisprudence, ethics, politics, as well as in the healthcare system. Currently, the most serious problem with the concept of EOLC is the lack of defining its boundaries. However, knowing a specific definition of this concept can help the caregivers provide appropriate services to the patients.

## Objective of Analysis

There are many reasons to do a concept analysis, one of which might be examining the intrinsic structures of a complex concept and identifying its constituents to enhance conceptual exploration.<sup>5</sup> In addition to clarifying the vague and confusing concepts, concept analysis can clarify common concepts and distinguish a concept from similar ones.

The phenomenon of death has always occupied people's minds, and aging is associated with increased concerns about death and how to go through life stages; as a result, this causes anxiety among the elderly.<sup>8,9</sup> Also, the increasing prevalence of emerging and incurable diseases in the present century and the increase in medical advances along with the prolongation of life open a new debate about the concept of EOLC. There are inevitable barriers and facilitators in ELOC. These include medical,

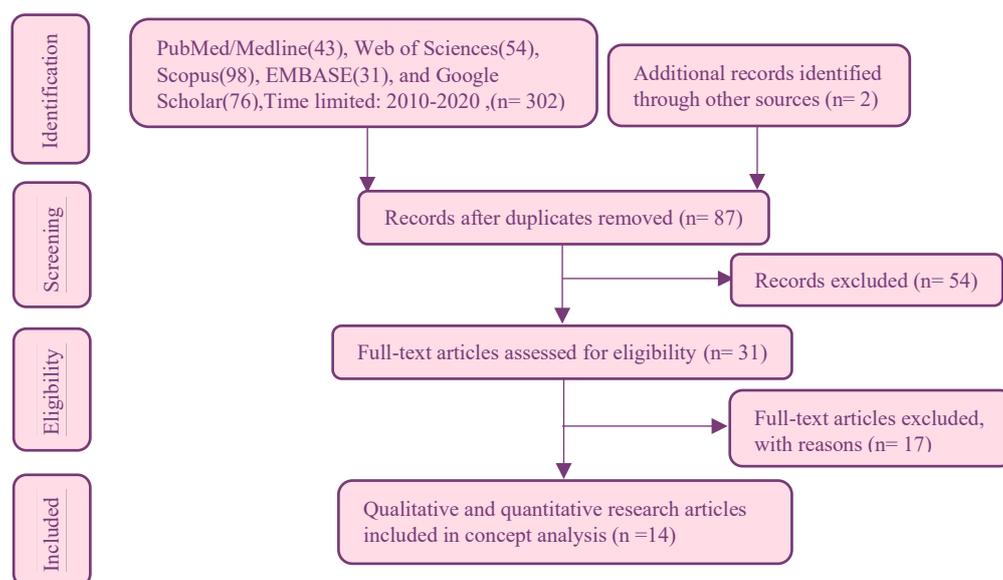


Figure 1. Flowchart of the study selection process of the concept analysis

legal, ethical, and communication issues, along with clinical problems.

This period is also challenging for the patient, family, and nurses. On the other hand, the elderly and their family members have their concerns, and nurses should also be able to apply their experiences to care for these patients.

The concept of EOLC is one of many concepts that can be understood, while the concept is complex and needs clarification.<sup>10</sup> Clarifying this concept can provide users with a common understanding, and thus lead to concept development.<sup>11</sup>

## Results

### *Definitions and Uses of the Concept*

According to the definition by the National Cancer Institute (NCI) dictionary, the concept of EOLC is “a program that provides intensive care to people who are in their late stages of life or who have stopped controlling their illness or continued treatment”. These cares provide physical, emotional, social, and spiritual support to patients and their families. The primary purpose of EOLC is to control pain and other symptoms so that patients are as comfortable and alert as possible. These are usually provided at home, but may also at a hospice, hospital be provided or nursing home.<sup>12</sup>

The World Health Organization (WHO) definition palliative care as: “an approach that improves the QOL of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual”.<sup>13</sup> When patients and their families encounter with a life-threatening illness, palliative care is an approach that prevents and relieves suffering through improving the QOL. Other interventions are early identification, evaluation, and treatment of pain and other physical, psychosocial, and mental problems.<sup>14</sup>

This approach supports life and death as a natural process. Relieve pain and improving other symptoms of distress do not intend to hasten or postpone death. It provides a support system to help patients live as actively as possible until death and also helps the family cope with their illness. If available, it uses a team approach to meet the needs of patients and their families, including bereavement counseling. It improves the QOL, and can also affect the disease process. Early in the disease, it may be used in combination with other therapies that are intended to prolong life, such as chemotherapy or radiation.<sup>14, 15</sup> Further research is needed to better understand and manage distressing clinical complications.

Providing good care to the patient in the later stages of life makes it easier for them to live and die with respect in their life-limiting situations. Also, the patient's family should benefit from high-quality care. Decisions at these stages may be clinically complex and emotionally

distressing.<sup>16</sup>

### *Identifying the Concept Defining Properties*

Palliative care is a resource for anyone with a serious illness, such as heart failure, chronic obstructive pulmonary disease, cancer, dementia, Parkinson's disease, etc. It can be helpful at any stage of the disease. In addition to improving the QOL and helping with symptoms, palliative care can help patients understand their choices for medical treatment. Organized services available through palliative care may be useful to any elderly person who has general discomfort and severe disability later in life. This care can be provided with treatment and does not depend on the prognosis. There are several signs, symptoms, and features associated with the end of life: pain, dyspnea, nausea and vomiting, fever, infection, edema, anxiety, delirium, metabolic disorder, and restlessness. This care begins when a new severe illness is diagnosed, and it continues until the time of recovery or death.<sup>16,17</sup>

End-of-life palliative care facilitates traditional religious, spiritual, and cultural traditions or rituals according to the patient's and his or her family's wishes, especially at the time of death and after. Hospice provides EOLC during the final week before death.<sup>10</sup> Palliative care is a science and art that enhances the QOL at the end of life. However, palliative care is not only effective in prolonging life in chronic diseases, but also it is used in EOLC. Therefore, nursing staff should be able to provide adequate care in the palliative care setting. This is a step for nurses to strive to enhance their sense of well-being.<sup>10,14</sup>

The concept of EOLC is a comprehensive and compassionate action to reduce physical, and psychological symptoms of patients with incurable diseases. An important component of this type of care is communication; when the nurse knows the patient's wishes, he/she can support the patient and provide information to other members of the healthcare team. Bridging the communication gap between patients, families, and healthcare team members is a key role of the nurses.<sup>15</sup>

Personal information includes understanding the wishes of the patient and his or her family during a difficult time at the end of life. Nurses coordinate care as part of their daily routine. Routine care coordination activities include assessing risk and identifying patients at risk of poor or readmitted outcomes, accurately communicating needs and priorities, putting the care plan into practice, evaluating outcomes, and assisting in the transition of treatment as the patient moves throughout the care plan. Nurses, as key members of the care team, can work with the patient's and family's knowledge of the goals and share this information with other team members to support the patient's goals.<sup>18</sup>

A condition must be provided for the patient so that he/she can go through the end stages of his/her life comfortably, in which case we say that the patient had a “peaceful death”. Ethics are very important when patients

die, because the patient's human dignity must be respected at this stage, and the treatments given to him/her should be beneficial and not harmful, meaning that additional treatments should be provided to the patient, and any harmful intervention should be avoided<sup>16</sup> (Table 1).

### Identifying a Model Case

The model case will provide an example of using the concept for clarifying the concept's properties in a real and obvious way. Thus, the reader will understand how to interpret or define the concept.<sup>5</sup> In this study, two examples of these models are presented.

#### Model Case 1

Mr. J; who retired from the US Air Force, was diagnosed with lung cancer at age 70. As the disease progressed, his breathing became more difficult. He sought for experimental treatments to reduce the disease progression. He was treated through "palliative care" provided by the Veterans Health Department. He received the emotional care and support to cope with health problems. The End-of-Life Palliative Care Program also helped organize the affairs of his home and family. Other support was provided to his wife to facilitate caring at home. His severe respiratory distress developed when experimental treatments no longer helped. He enrolled in the hospice. His symptoms improved with the psychological support, semi-Fowler's position, and oxygen therapy. Restlessness and fears improved. He died a week later while speaking hard, and a funeral was held.

#### Model Case 2

Mr. K, 60, has been undergoing chemotherapy and

radiotherapy for two years after being diagnosed with colon cancer. Over the past three months, the symptoms have been worsened and his physician has noticed numerous metastases, including lymph node and lung metastasis. He has been re-treated with high-dose radiotherapy but has been hospitalized a week ago after suffering from a serious illness and lack of oral nutrition, pain, and weakness. The patient recovered somewhat. On the second day, the patient underwent cardiopulmonary arrest. After 20 minutes of a successful cardiopulmonary resuscitation, the patient was transferred to the intensive care unit and the patient was ventilated on Synchronized Intermittent Mandatory Ventilation (SIMV) mode. Nasogastric Tube (NGT) was administered to the patient, and intake and output were monitored and recorded. Glasgow Coma Scale (GCS) was six and pupils were reactive. The patient's blood pressure was controlled by drip dopamine at a dose of 13 µg/kg. The patient's position in bed was changed every two hours for the prevention of bedsores. On the third day, there was no urine output and dialysis was performed. The nurse was repeatedly questioned by the wife and her daughter about the patient's condition. On the fifth day, unfortunately, he became agitated and suffered a cardiac arrest.

### Identifying Boundary, Opposing and Innovative Cases Borderline Cases

Boundary cases contain some and not all conceptual features. Identification of boundary cases aids features that are essential prerequisites for modeling cases and reduces the ambiguity of boundaries between cases.<sup>11</sup>

Adriana suffered from anemia while undergoing treatment for breast cancer. A palliative care specialist suggested that she receive one unit of packed red blood

**Table 1.** Defining attributes

Defining attributes	Sources
Support (patients and families)	
Physical (practical)	
psychological (emotional, spiritual)	
Social	
Financial	References & articles: (Mitrea et al <sup>15</sup> ; NCI Dictionary of cancer Terms <sup>12</sup> ; Usher et al <sup>19</sup> ; Shahnazari <sup>16</sup> ; Ferguson <sup>18</sup> ; Jabbari-Beyrami et al <sup>20</sup> )
Ethical (respect to human dignity, reduce moral distress)	
Planning (identification, assessment, provide information, communication)	
Families cope	
Treatment & Care	
Control pain	
-Physical symptoms (pain, dyspnea, nausea and vomiting, fever, infection, edema, metabolic disorder).	References & articles: (Mitrea <sup>14</sup> ; NCI Dictionary of cancer terms <sup>12</sup> ; Shahnazari <sup>16</sup> ; Button et al <sup>17</sup> ; Palliative Care <sup>13</sup> ; Ferguson <sup>18</sup> ; Jabbari-Beyrami et al <sup>20</sup> )
-Psychological symptoms (anxiety, delirium, and restlessness)	
Routine care	
Quality of life (QOL)	
Improves the QOL (patients& families)	
Enhance of well-being	References & articles: (Koh et al <sup>10</sup> ; Mitrea <sup>14</sup> ; Shahnazari <sup>16</sup> ; Jabbari-Beyrami et al <sup>20</sup> ; Schenell et al <sup>21</sup> ; Dehi Aroogh et al <sup>22</sup> )
Peaceful death	

cells to relieve anemia and some of the fatigue. Controlling her symptoms helped Adriana continue her chemotherapy treatment. Treating her anemia is part of palliative care.

### *Opposing Cases*

None of the main attributes of the concept are included and the introduction defines what the concept under consideration is, and the difference is so obvious that most people can confidently say that this example is not our intended concept.<sup>5</sup>

A 44-year-old female patient with breast cancer underwent a mastectomy in the “in situ” stage. The patient complained of severe pain. Pethidine prescribed 25 mg Pro Re Nata (PRN). But she could eat, walk, and do her daily activities. She hoped to recover and return home as soon as possible.

This model shows that it does not have any of the attributes offered and it is easy to understand that it is not EOLC.

### *Identifying Antecedents and Consequences*

Predictions are events that need to be revealed before the concept emerges and the consequences are the events that follow the manifestation of the concept.<sup>5</sup>

EOLC antecedents include “having an incurable disease by failing to respond to treatment and reducing the chance of survival, as well as aging with no physiological return to life and no self-care”.

The operational definition of the elderly at the end of life from a nursing perspective, as a person 60 years or older who is with deteriorating health, loss of independence, and complete irreversible dependence on biological, psychological, economic, and social perspectives. This person needs family support and care, as their human needs may gradually increase and be severely affected.<sup>19</sup>

Consequences: EOLC leads to an increase in QOL and a reduction in moral distress, emotional exhaustion, a decrease in psychological and social stress, imposing lower costs on the family and the health system.

### *Experimental Manifestation*

From the authors’ point of view, experimental manifestations are related to classes and groups related to real phenomena, which shows how the concept in question occurs and is understood. However, according to Walker and Avant, sometimes the level of abstraction of the concept is so high that even defined features are abstract and therefore cannot be good empirical indicators.

They consider empirical references to be recognizable features of the concept, the emergence of which is a sign of the very existence of the concept itself.<sup>5</sup> In this regard, qualitative studies show different themes for EOLC.

Jabbari-Beyrami et al conducted a study with a phenomenological approach to explain patients’ experiences of EOLC. The findings of this study included 7 main themes as follows: 1- lack of special education

for healthcare providers, 2- preferences, 3 - financial problems, 4- health care quality, 5-lack of providing information to patients and their families, 6- restrictions in life due to disease, and 7- burdens to EOLC for family.<sup>20</sup>

### **Discussion**

In the current study, we analyzed the concept of EOLC based on Walker and Avant’s approach. Their method, which is a modified and simplified form of Wilson’s method of concept analysis (1963), provides a relatively simple, understandable, and comprehensive understanding of the concept. Based on a review of existing studies, some of the special attributes of the concept of EOLC included: End-of-life palliative care, improved QOL, reduction of pain and suffering from physical, mental, and psychological symptoms, communication between treatment team and family, and sufficient explanation about care. It is about moral issues and respect for the patient’s independence. Following an increase in the aging population, an increase in incurable diseases, such as malignancy and advanced Alzheimer’s disease can place a burden upon caregivers. However, medical and technical advances prolong the death process.

Spiritual care, as a whole, is one of the four pillars of EOLC alongside medical, psychological, and social care. It also provides a way for nurses and volunteers, regardless of their religious beliefs, to provide patients with end-of-life spiritual care. At the end of life, the patient needs more human attention and care than medication. Humanistic care is a holistic approach. End-of-life clinical management should maximize the QOL of both the patient and the caregiver and, if possible, provide appropriate physical, mental, and social support. Nurses, as the most consistent caregivers, use their experiences to evaluate and diagnose problem, and validate the patient’s perceptions. They also help individuals find meanings in life and have a comfortable end of life.<sup>21,22</sup>

### **Conclusion**

A holistic approach in EOLC leads to a clear understanding of the care of the patients. It helps them provide the best type of care based on values and supports. It seems that this method of care can lead to a good feeling of care for nurses and peaceful death for patients.

EOLC does not intend to accelerate or delay death. Rather, it establishes a peaceful and respectful death with support. Thus, training the specialists should include the development of teamworking, collaborating, and communication skills that contribute to the critical and inevitable management of death.

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### **Authors’ Contributions**

AH contributed to the main idea and design of the study. HA performed the search, data collection, data analysis, and drafting

## Research Highlights

### What is the current knowledge?

- Nowadays, with growing life expectancy and technology advances, many people need EOLC and it is one of the health system concerns. This concept does not have a satisfactory and clear definition. The correct definition of this concept can be effective in caring for patients.

### What is new here?

- We provide a clear definition of EOLC, which is a holistic approach focused on all dimensions of the patient. Also, clinical management should maximize the QOL of both the patient and family/caregivers.

of the manuscript. The final version was read and approved by both authors.

### Conflict of Interests

No conflict of interest has been expressed by the authors in this study.

### Data Accessibility

The datasets are available from the corresponding author on reasonable request.

### Ethical Issues

None to be declared.

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