Article

Defining end-of-life care from perspectives of nursing ethics

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Abstract

Despite increasing interests and urgent needs for quality end-of-life care, there is no exact definition of what is the interval referred to as end of life or what end-of-life care is. The purpose of this article is to report our examination of terms related to end-of-life care and define end-of-life care from nursing ethics perspectives. Current terms related to end-of-life care, such as terminal care, hospice care, and palliative care, are based on a medical model and are restrictive in terms of diagnosis and prognosis. Using codes of ethics for nurses as a framework, we attempt to identify people to whom nurses are responsible to provide end-of-life care and develop a definition of end-of-life care that is more inclusive and applicable to a broader range of people who would benefit from end-of-life care by nurses and other health-care providers.

Keywords

Code of ethics, end-of-life care definition, nursing ethics, palliative care, terminal care

Introduction

In 2011, Chiba University Graduate School of Nursing in Japan started a new program for end-of-life care in nursing. As founding faculty of the program, we started philosophical, theoretical, and empirical examinations of end-of-life care and nursing roles. Through this effort, we recognized the lack of precise definitions of the meaning of end of life and end-of-life care, and, consequently, nurses' practice and nursing roles in end-of-life care are left for interpretation of each nurse. The purpose of this article is to report our work to define "end-of-life care" as a framework for our program and to explore roles of nurses in end-of-life care from perspectives of nursing ethics.

History and current definitions related to end-of-life care

The term "end-of-life care" is often used interchangeably with various terms such as terminal care, hospice care, or palliative care. Shifts in the preference of terms to use in the last 30–40 years have occurred, and the specific meanings of terms have changed over time. Meanings and definitions of terms vary by organizations and countries as well (see Table 1).

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Table 1. Terms related to end-of-life care

Terms related to end-of-life care	Definition	Organization (country)	Source
Terminal care	The term "terminal care" has lost relevance and should not be used any more, or only to describe the care given during the very last stage (the last few days) of illness.	The European Association for Palliative Care	*European Journal of Palliative Care* 2009; 16(6): 283.
Terminal phase	Terminal phase is when physicians judge a recovery from an illness cannot be expected, no available treatment improves the condition, and death is considered to be unavoidable in the near future.	All Japan Hospital Association, The Japan Geriatrics Society Ethics Committee, and Science Council of Japan	http://www.ajha.or.jp/about_us/activity/zen/090618.pdf *Geriatrics and Gerontology International* 2004; 4: 1–4. http://www.scj.go.jp/ja/info/kohyo/pdf/kohyo-20-t51-2.pdf
Hospice care	A hospice is a comprehensive service provided to people living with and dying from an eventually fatal condition. This may include inpatient medical care, respite care and end of life care for people who are unable to die at home.	Palliative Care Australia	http://www.palliativecare.org.au/Portals/46/docs/PCA%20strategic%20plan%20-%202008-2011.pdf
	Hospice is a concept of care that involves health professionals and volunteers who provide medical, psychological, and spiritual support to terminally ill patients and their loved ones. Hospice stresses quality of life—peace, comfort, and dignity. Hospice services are available to persons who can no longer benefit from curative treatment and have a life expectancy of 6 months or less.	National Cancer Institute at the National Institute of Health (USA)	http://www.cancer.gov/cancertopics/factsheet/Support/hospice

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Table 1. (continued)

Terms related to end-of-life care	Definition	Organization (country)	Source
Palliative care/hospice palliative care	Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.	World Health Organization	http://www.who.int/cancer/palliative/definition/en/
	Palliative care is the active, total care of the patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of social, psychological and spiritual problems is paramount.	The European Association for Palliative Care	*European Journal of Palliative Care* 2009; 16(6): 280.
	Palliative care is specialist care provided for all people living with, and dying from an eventually fatal condition and for whom the primary goal is quality of life.	Palliative Care Australia	http://www.palliativecare.org.au/Portals/46/docs/PCA%20strategic%20plan%20-%202008-2011.pdf
	Hospice palliative care is whole-person health care that aims to relieve suffering and improve the quality of living and dying. Hospice palliative care is appropriate for any patient and/or family living with, or at risk of developing, a life-threatening illness due to any diagnosis, with any prognosis, regardless of age, and at any time they have unmet expectations and/or needs, and are prepared to accept care.	The Canadian Hospice Palliative Care Association	http://www.chpca.net/Home

(continued)

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Terms related to end-of-life care	Definition	Organization (country)	Source
End-of-life care	No exact definition of end of life; however, the evidence supports the following components: (1) the presence of a chronic disease(s) or symptoms or functional impairments that persist but may also fluctuate; and (2) the symptoms or impairments resulting from the underlying irreversible disease require formal or informal care and can lead to death. Older age and frailty may be surrogates for life-threatening illness and co-morbidity.	National Institutes of Health (USA)	http://consensus.nih.gov/2004/2004EndOfLifeCareSOS024html.htm
	Understood as an extended period of one to two years during which the patient/family and health professionals become aware of the life-limiting nature of their illness. End-of-life care may also be understood more specifically as comprehensive care for dying patients in the last few hours or days of life.	The European Association for Palliative Care	*European Journal of Palliative Care* 2009; 16(6): 282.
	End of life care combines the broad set of health and community services that care for the population at the end of their life.	Palliative Care Australia	http://www.palliativecare.org.au/Portals/46/docs/PCA%20strategic%20plan%20-%202008-2011.pdf

Terminal care

Initially, terminal care was commonly used to describe care for dying patients, particularly in hospital settings. However, over the last 30 years, the use of the term "end-of-life care" has gradually increased and been substituted for "terminal care" in health-care literature written in English. Although "terminal care" is still used as a subheading indexing in health-care literature databases such as PubMed, "end-of-life care" has become the more broadly accepted term in English. The reason behind this transition is not clearly explained, but Kashiwagi speculates that it may be due to the negative connotation of the term "terminal."[1] Over the last 30–40 years in Japan, "terminal care" has been most commonly used to describe care for seriously ill patients who are dying from terminal illness.[1] Although terminal care can include any patients who are dying, historically most of the issues related to terminal care in Japan have focused on care for patients with terminal-stage cancer. Because cancer has been the number one cause of death in Japan since 1981, and one in every three persons in Japan dies of cancer, a diagnosis of cancer implies death and dying. In addition, there are obvious clinical indications when cancer is no longer responsive to treatments and a patient is in the terminal stage of the illness. Therefore, use of the term "terminal care" in the care of dying patients, especially with terminal-stage cancer, is acceptable and common in Japan at present.

Hospice care

The term "hospice" usually indicates a program or a type of care for terminally ill patients. Hospice care emphasizes provision of comfort and relief from symptoms and suffering, and addresses the patient's psychological, social, and spiritual needs.[2] While terminal care could include any care and treatments for patients dying of any kind of serious illness, hospice care is specific to comfort care for dying patients who most of the time agree to forgo active therapies.[3] In Japan, less than 6-month prognosis is required to be admitted to a hospice program, and this is a common hospice criterion across countries.[4,5] Furthermore, national health insurance in Japan limits hospice admission only to patients with cancer or AIDS.[6] In sum, although a philosophical definition of hospice care is applicable to all patients in their end of life, a practical definition limits this service only to patients who have less than 6-month life expectancy in general and to patients with a specific disease who agree to forgo curative treatment in some countries.

Palliative care

Palliative care is another term increasingly used to represent comfort-focused care for patients with life-threatening illnesses. In 2002, the World Health Organization (WHO) revised their definition of palliative care to

> an approach which improves quality of life of patients and their families facing life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.[7]

This current WHO definition emphasizes the importance of active symptom management throughout the continuum of a patient's illness, even before a patient enters the terminal stage of their illness. Introduction of palliative care to patients when they are still receiving curative treatment contributes to improving the quality of care they receive throughout their course of illness and, therefore, their quality of life. Although inclusion of palliative care in the early stage of illness is still rare and is mostly considered as an option for terminally ill patients, the scope of palliative care goes beyond the patient group narrowly designated for hospice care.[8] Palliative care encompasses comfort-focused, holistic care to any patient, including patients receiving curative cancer treatments, patients with HIV/AIDS, and older adults with chronic illness other than cancer.[3] WHO states that palliative care should be offered from the time of diagnosis to the end of life throughout the course of illnesses and that it should not be limited only to the last few weeks of life when no curative treatment is available.[9]

With this definition by the WHO and current efforts expanding palliative care beyond terminal illnesses, palliative care should be seen as partially overlapping but not synonymous with end-of-life care. Palliative care does not necessarily revolve around end of life. This is an important conceptual differentiation of the terms; however, palliative care is still often used interchangeably with hospice care or end of life care in clinical settings and in the society. Most in-hospital units providing hospice care are named as "palliative care units" in Japan because the term hospice implies the strong connotation of a place for dying. "Palliative care teams" in hospital settings in various countries also are providing palliative care mostly to patients whose curative treatment options are limited, and in the United States, there was a trend in the last 10 years to rename organizations using the combined terms "hospice and palliative care" to encompass these services to meet both definitions.[3] More recently, there is another movement in the United States to use "supportive care" instead of "palliative care" because of the belief that the term palliative care still carries a lot of baggage implying a negative death and dying. Although we are aware of the mixed use of these terms in our society, in order to delineate the scope of end-of-life care, we will differentiate palliative care and hospice care in this article as it has been defined above.

End-of-life care

Despite the increased use of the term "end of life" and "end-of-life care" in health-care and nursing literature, over the last 30 years, there is no exact definition of what constitutes the time interval referred to as end of life.[10] The period of time and types of patients who are considered to receive specific "end-of-life care" such as hospice service may be defined by regulatory, policy, or administrative guidelines, but there is no scientific evidence to support the clinical indications characterizing a period of end of life.[10] This lack of clinical evidence is largely due to the difficulty of reliable prognostication.[11,12] To date, there is no clear clinical indicator to predict time of death. Therefore, it is impossible, and may be unreasonable, to mark a date such as 6 months before the predicted death as the beginning day of an end-of-life period.[10]

Researchers and clinicians in end-of-life care found three stereotyped trajectories of the last months and years of patients' lives.[13] One of the trajectories is common among patients with various types of cancer, maintaining good functions with a diagnosis of life-threatening illness for a long time followed by rapid decline over a few weeks or months prior to death. This trajectory is relatively predictable once the tumor becomes nonresponsive to treatments and continues to grow. Therefore, patients in this group are more likely to be able to receive benefits from end-of-life care specific to time frame and prognosis such as hospice. Yet, new treatment options for advanced-stage cancer may become available, thereby postponing death and making more difficult the decision of when patients enter end of life and should forgo treatment. Two other kinds of trajectories that are more typical for patients with organ system failure and dementia/frailty are more difficult to set time frames for their functional decline and death.[13] For those, determining the beginning of their end-of-life stage is unattainable; therefore, introducing end-of-life care may be delayed, or they may not receive any end-of-life care until very near death.

It is interesting that the National Institutes of Health (NIH) report[10] mentioned very broad interpretations of the end-of-life period by stating "people can, in some respects, be considered to be approaching death from the moment they are born" (p. 27). This view of an entire life conceptualized as a dying process may be too broad and impractical to define care for people in the end-of-life period. But we will revisit this philosophical view of death as part of one's whole life later because we believe that this view has the potential to define and expand the nursing role in end-of-life care. A more practical definition of end-of-life period is usually evidenced by (a) the presence of a progressing chronic disease with pronounced symptoms or functional impairments and (b) the presence of symptoms or impairments resulting from the underlying conditions leading to death that require care.[10]

Because of the lack of specific indicators for the end-of-life time frame, it is not clear what is encompassed in end-of-life care. Frequently, people assume that end-of-life care is providing comfort care and holistic care to dying patients and their family in a time frame of days to weeks when they are actively dying. But if end-of-life care is framed only by the brief time interval before actual death, many patients would be left without receiving adequate end-of-life care because their time frames are not well predicted. In greatly aging societies such as Japan, many older adults are going through one of the two trajectories that make it difficult to determine when they enter the end of life and predict approaching death. How about a relatively healthy older adult who does not have significant life-threatening illness but has concerns about approaching death because of his or her advanced age? Does this person need end-of-life care? Current definitions related to end-of-life care are mostly based on the time to death and stage of illness. But there are many people without a prognosis of how much time is left and who do not think they have terminal illness but are actually facing end of life and need end-of-life care from nurses. Because they may not have an obvious medical diagnosis leading to imminent death, physicians whose focus is treating a specific disease may not be able to provide adequate care that the patient needs regarding end of life. On the other hand, nurses who see a patient's life as a whole are better situated to understand the patient's condition and concerns and guide them to examine and prepare for end of life. In order for nurses to identify these people and provide the care they need, end-of-life care should not be defined from a medical perspective based on the presence of a terminal illness or estimated time remaining but from the nursing perspective based on a broader view of life and journey toward the inevitable end of life.

Nurses' ethical responsibility in end-of-life care

Code of ethics for nurses

According to the international code of ethics for nurses by International Council of Nurses (ICN),[15] nurses are responsible to promote health, to prevent illness, to restore health, and to alleviate suffering. Japanese Nursing Association (JNA) adds to the ICN code "to assist individuals to live fully throughout their life until the end" as the major purpose of nursing.[16] ICN also states "The nurse's primary professional responsibility is to people requiring nursing care,"[15] and both codes state that nurses should provide respectful and equitable care to all individuals, families, and communities needing nursing care regardless of age, color, creed, culture, disability or illness, gender, sexual orientation, nationality, politics, race, or social status.[15,16]

Nurses' responsibility to alleviate suffering resonates with the philosophy of hospice care and palliative care. A difference is that nursing care to alleviate suffering is meant for all individuals, families, and communities who need nursing care and it is not limited to only people who have terminal-stage cancer or who have symptoms due to underlying diseases. The Code of Ethics by JNA specifically states that nurses ought to provide care to assist people to live fully throughout their life until the end, and it does not draw an artificial line determining the time to shift from care to live to end of life.

People who need end-of-life care

Which individuals, families, and communities need end-of-life nursing care? Nurses face death and take care of people who are affected by death regardless of the areas and settings where they work. While most of the Japanese people express their preference of dying at home,[17,18] more than 80% of death in Japan occurred in hospitals in 2009.[19] Because patients' need for end-of-life care is often not addressed until death becomes inevitable and imminent in acute-care hospitals, end-of-life care in hospital settings tends to be rushed and inadequate. It is a consistent finding across many countries that patients are not receiving adequate care at the end of life during and following last hospitalization because their end-of-life care needs are not recognized adequately.[20–26] In addition, unless patients and their family know exactly what they want and are being persistent about expressing their wishes, receiving timely end-of-life care and a peaceful death at home or as they wish does not happen easily.

Death also happens outside of hospitals, so the home-visiting nurses, nurses in long-term care facilities, and public health nurses also provide care to people who are dealing with end-of-life issues. Not only individuals who are facing death but also their family members and people around them would be affected and may need care. In rapidly aging societies such as Japan, where the number of deaths is expected to double within the next 30 years because of the large number of older population, the whole society is facing death of a friend or family member, and the society, as a large community, needs end-of-life care. Narrow and medically oriented definitions of terminal care, hospice care, or palliative care do not provide a broad enough scope to include all people who need end-of-life care.

Ethical issues related to definition of end-of-life care

The lack of inclusive definition of end-of-life care and people who are eligible to receive end-of-life care creates ethical tensions for nurses. As described before, patients who are admitted to hospice palliative care units are limited to those with terminal-stage cancer or HIV/AIDS in Japan. A patient who is suffering from advanced-stage chronic obstructive pulmonary disease (COPD) cannot be admitted to the hospice palliative care unit because of his diagnosis. Nurses taking care of him may recognize his needs for end-of-life care such as good symptom management and assistance to prepare him for death. But nurses may not be able to bring in resources to meet his needs because he does not meet the hospice palliative care criteria. Nurses in this situation would feel moral distress for providing unjust and inequitable care differentiating patients by their diagnosis. Nurses taking care of a young woman who is newly diagnosed with breast cancer may recognize a need of this woman and her husband to talk about death. Although this patient is not terminally ill and probably has a good chance to be cured by chemotherapy, she and her husband may be concerned about death brought to the foreground of their consciousness by the cancer diagnosis. If nurses do not acknowledge their needs to talk about death because the patient is not terminally ill, the nurses are not compliant with the code of ethics providing care to alleviate suffering and assist to live as fully as possible throughout their life. When healthy older persons talk about their thoughts about death and dying to nurses in a day-care center, the nurses may organize an educational session for the community to introduce advance care planning and discuss issues around end of life. Not doing so because nurses do not recognize people who are in need of end-of-life care is ethically unacceptable, and their competency to assess their needs and provide quality care to those who need nursing care is questionable.[27]

Defining end-of-life care from nursing ethics perspectives

Limitations of terms currently used to describe end of life and end-of-life care constrain nursing care to those who are in need of end-of-life care and cause ethical tensions between what nurses should do and can/would do. As the NIH report[10] mentioned, all people, in some respects, are approaching death from the moment they are born. And death will come whether or not the person or health-care providers know when it is coming. Although advancement in medical technology sometimes gives us an illusion of death as an option, death is not medically treatable or avoidable and it should not be addressed solely from a medical treatment standpoint. Death as the end of life needs to be addressed in a more holistic manner throughout the course of life. Because nursing employs a holistic view of persons and their life beyond medical conditions and aims to provide holistic care, nurses can see people and judge when end-of-life care is needed from the vantage point of broader scope of entire life of the person. Furthermore, nurses serve not only patients in hospitals but also residents in long-term care facilities, people living in communities, and people who are relatively healthy and independent as well as those who are sick and dependent. Therefore, nurses are well situated to identify people who need end-of-life care and provide care when it is needed.

We propose the definition of end-of-life care as "to assist persons who are facing imminent or distant death to have best quality of life possible till the end of their life regardless of their medical diagnosis, health conditions, or ages." In this definition, the end of life is a discreet time period when a person is aware of the end of life, not a medically determined period of time before death. Regardless of health conditions, if a person reflects on his or her or other's life and has concerns about death and the end of life, this person, in a sense, is facing death and may benefit from care defined as end-of-life care. The awareness about end of life can be raised from a patient's own insight or result of medical assessment without the patient's awareness. In the latter case, which happens commonly in many health-care settings, it is the health-care providers' responsibility to address the need for end-of-life care with the patient and his or her family at the earliest opportunity. Because there is a broad range of literature relevant to the ethics of end-of-life care communication in health-care settings and it is beyond the scope of defining end-of-life care, we will not discuss any communication strategies or specific care for this situation in this article.

One of the characteristics of the definition we propose here is that it encompasses ethical responsibilities that nurses owe to the larger society from promoting health to alleviation of suffering related to life and end of life. It also encompasses all individuals, families, and communities that nurses are responsible for, to provide care related to end of life. Furthermore, the scope of this definition is not limited to nursing. This is applicable to a medical model to expand their end-of-life care to patients with frailty or chronic illnesses other than cancer. Public health also can adapt this definition to educate communities and develop policies to assure quality end-of-life care to members in the community.

Conclusion

By aligning the definition of end-of-life care with the code of ethics for nurses and expanding the scope of end-of-life care beyond the narrowly defined medical conditions mostly in hospital settings, this definition has the potential to increase the number of nurses involved to end-of-life care. This definition makes nurses working in diverse settings aware about their ethical responsibility to serve people who are in need of end-of-life care. It also resolves some of the ethical conflicts and moral distresses many nurses face in current end-of-life care. This definition has potential to expand roles of nurses in end-of-life care from bedside direct care providers to educators and policy makers in their community to assure quality end-of-life care to all people. Because of our values and philosophy aligning well with end-of-life care, nurses have much to offer and lead to improve the quality of end-of-life care.

Our definition of end-of-life care is still in draft. We, as faculty in a newly started program "End-of-Life Care in Nursing" in Japan, explored literature and our nursing values and drafted this definition to use as a framework for our program. To have a clear and empirically valid definition, we will continue to examine it from a variety of perspectives. We also look forward to hear from readers of *Nursing Ethics* to have conversations about end-of-life care and nursing roles.

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Conflict of interest

The authors declare that there is no conflict of interest.

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