

Review Article

Concepts and Definitions for “Actively Dying,” “End of Life,” “Terminally Ill,” “Terminal Care,” and “Transition of Care”: A Systematic Review

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Abstract

Context. The terms “actively dying,” “end of life,” “terminally ill,” “terminal care,” and “transition of care” are commonly used but rarely and inconsistently defined.

Objectives. We conducted a systematic review to examine the concepts and definitions for these terms.

Methods. We searched MEDLINE, PsycINFO, Embase, and CINAHL for published peer-reviewed articles from 1948 to 2012 that conceptualized, defined, or examined these terms. Two researchers independently reviewed each citation for inclusion and then extracted the concepts/definitions when available. We also searched 10 dictionaries, four palliative care textbooks, and 13 organization Web sites, including the U.S. Federal Code.

Results. One of 16, three of 134, three of 44, two of 93, and four of 17 articles defined or conceptualized actively dying, end of life, terminally ill, terminal care, and transition of care, respectively. Actively dying was defined as “hours or days of survival.” We identified two key defining features for end of life, terminally ill, and terminal care: life-limiting disease with irreversible decline and expected survival in terms of months or less. Transition of care was discussed in relation to changes in 1) place of care (e.g., hospital to home), 2) level of professions providing the care (e.g., acute care to hospice), and 3) goals of care (e.g., curative to palliative). Definitions for these five terms were rarely found in dictionaries, textbooks, and organizational Web sites. However, when available, the definitions were generally consistent with the concepts discussed previously.

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Conclusion. We identified unifying concepts for five commonly used terms in palliative care and developed a preliminary conceptual framework toward building standardized definitions. *J Pain Symptom Manage* 2014;47:77–89.

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Key Words

Actively dying, end of life, systematic review, terminal care, terminally ill, terminology, transition of care

Introduction

Prognostication of life expectancy is of the utmost importance to patients, families, and health care professionals, particularly in the setting of advanced disease. Many important health care decisions, such as those regarding chemotherapy use, hospice referral, advance care planning, discharge planning, and personal finances, are dependent on the expected survival duration. The terms “end of life,” “terminally ill,” and “actively dying” have prognostic implications and are frequently used in clinical communications and published articles;¹ however, the exact meaning of these terms is unclear. This ambiguity results in confusion that may lead to delays and inconsistencies in arranging “terminal care” and facilitating “transition of care.” Ironically, these latter two terms also are poorly defined.¹

In a recent survey conducted by our team, palliative care specialists ranked the terms end of life, terminally ill, terminal care, actively dying, and transition of care highly in regard to both the frequency of use and the relative importance.¹ A better understanding of the defining features and concepts for these five terms could help to standardize them and thus improve communication among clinicians, researchers, and policy makers. The objective of this systematic review was to examine the published literature, medical dictionaries, textbooks, and organization Web sites for concepts and definitions for end of life, actively dying, terminally ill, terminal care, and transition of care.

Methods

Literature Search

This study was approved by the M. D. Anderson Cancer Center Institutional Review Board without the need for full committee review.

Between February 21, 2011, and April 18, 2011, we searched all available records in Ovid MEDLINE, Ovid Embase, Ovid PsycINFO, and EBSCO CINAHL from 1948 to 2011. Our search strategy consisted of Medical Subject Headings and text word or text phrase for actively dying, end of life, terminally ill, terminal care, and transition of care, plus one of the following terms including “defin\$,” “understanding,” “conceptualization,” “terminology,” and “nomenclature.” This methodology has previously been used for other palliative care terms.² We included all original studies, reviews, systematic reviews, guidelines, editorials, commentaries, and letters that specifically defined or conceptualized the terms of interest and excluded non-English articles, dissertations, conference abstracts, and duplicates. The search was updated on September 2012. In addition, we conducted a hand search of the reference lists of all included articles.

After the initial librarian search, two palliative care specialists independently reviewed the title and abstract of each citation for inclusion. Publications were included if one of their objectives was to provide a definition or conceptualization for the terms of interest. Any disagreements were discussed and a consensus reached. We then retrieved the full article and extracted the definitions and/or key concepts related to each term.

Dictionary Search

We also searched for definitions related to actively dying, end of life, terminally ill, terminal care, and transition of care in six print dictionaries and four online medical dictionaries. The print dictionaries were selected from a list of 26 based on their year of publication and authoritative publishers and included *McGraw-Hill Allied Medical Dictionary* (2008), *Dorland's Illustrated Medical Dictionary* (2007),

Black's Medical Dictionary (2010), *Mosby's Medical Dictionary* (2009), *Stedman's Medical Dictionary* (2006), and *Taber's Cyclopedic Medical Dictionary* (2009).

The Google search engine was used to identify four online medical dictionaries based on criteria outlined by *A Guide for Evaluating Health Web Sites* provided by the National Network of Libraries of Medicine (<http://nnlm.gov/outreach/consumer/evalsite.html>). These included *MediLexicon* (2011), *Medical Dictionary* (WebMD, 2011), *MedlinePlus Medical Dictionary* (2011), and *The Free Dictionary: Medical Dictionary* (2011).

Textbook Search

We identified four commonly used palliative medicine textbooks (*Oxford Textbook of Palliative Medicine*, 4th edition; *Textbook of Palliative Medicine*, 1st edition; *Principles and Practice of Palliative Care and Supportive Oncology*, 3rd edition; and *Palliative Medicine*, 1st edition) and searched for definitions for the five terms of interest.

Organization Web site Search

We also searched 12 palliative care and oncology organization Web sites for definitions related to the five terms of interest, including American Academy of Hospice and Palliative Medicine, American Cancer Society, American

Society of Clinical Oncology, European Association for Palliative Care, European Society for Medical Oncology, Education in Palliative and End-of-life Care, End-of-Life/Palliative Education Resource Center, International Association for Hospice and Palliative Care, Multinational Association of Supportive Care in Cancer, National Comprehensive Cancer Network, National Cancer Institute (NCI) dictionary, and National Hospice and Palliative Care Organization. We also searched the U.S. Federal Code for legal definitions for the five terms.

Statistical Analysis

We summarized the concepts and definitions using frequencies and percentages.

Results

Literature Search

The literature search flowchart is shown in Fig. 1.

Concepts and Definitions for Actively Dying

Only one article addressed definitions related to actively dying (Table 1): "The hours or days preceding imminent death during which time the patient's physiologic functions wane."¹ No definitions were found in dictionaries and textbooks for this term (Tables 2 and 3). Two Web sites provided the same

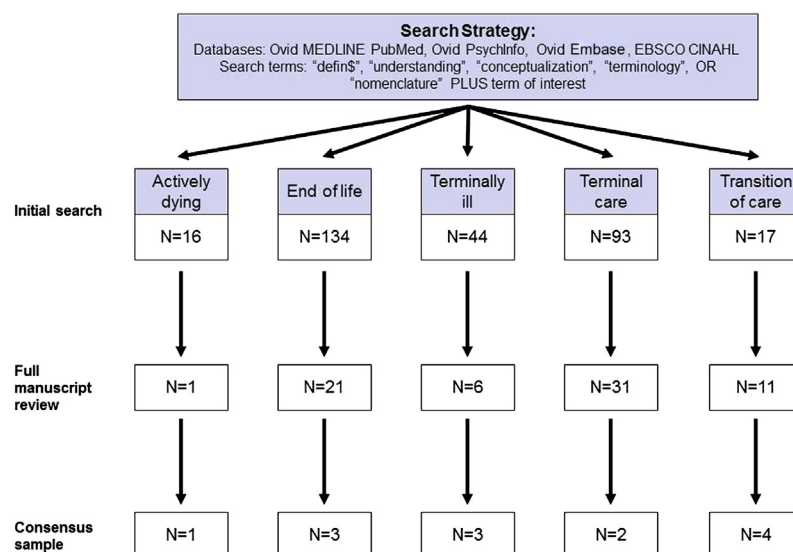


Fig. 1. Search strategy for articles that conceptualized/defined "actively dying," "end of life," "terminally ill," "terminal care," and "transition of care."

Table 1
Definitions for “Actively Dying,” “End of Life,” “Terminally Ill,” “Terminal Care,” and “Transition of Care”

Reference	Study Type	Definition(s) Proposed or Information Discussed	Citation Source
Articles on actively dying Hui et al., <i>J Pain Symptom Manage</i> , 2012 ¹	Systematic review	Actively dying: “The hours or days preceding imminent death during which time the patient’s physiologic functions wane.”	Kintzel et al. ²³
Articles on end of life Lunney, <i>J Hosp Palliat Nurs</i> , 2001 ⁴	Editorial	End of life: “That financing has contributed to the growth of an important care-delivery service, but its restriction to those with a 6-month-or-less prognosis has only further cemented the notion that the end of life is constrained to a short period of time during which a person is clinically recognized as dying.”	None
Lamont, <i>J Palliat Med</i> , 2005 ³	Review article	End-of-life: “In clinical medicine, the ‘end of life’ can be thought of as the period preceding an individual’s natural death from a process that is unlikely to be arrested by medical care.”	None
		End-of-life: “For insurance purposes, the ‘end of life’ has been operationalized to represent the last 6 months of a patient’s life.”	None
Articles on terminally ill McCartney and Trau, <i>Death Stud</i> , 1990 ⁶	Review	Terminal condition: “What we are suggesting then is the commonsense view, held by at least two appellate courts, that ‘dying’ or a ‘terminal condition’ is ‘a condition caused by injury, disease, or illness from which, to a reasonable degree of certainty, there can be no restoration of health, and which, absent artificial life-prolonging procedures, will inevitably lead to natural death.’”	None
		Terminally ill: “The authors argue that those permanently unconscious are by definition terminally ill and suffering from a fatal pathology, because medical treatment in their cases will not lead to a restoration of health and will prolong the dying process.”	None
		Terminally ill: “We ... argue that people in an irreversible coma (IC) and/or a persistent vegetative state (PVS) are, ipso facto, terminally ill. For the sake of simplicity, we will consider IC and PVS to belong to this same class of terminally ill people and refer to them as permanently unconscious, though we recognize that each group has different, but related, neurological impairments.”	None
Lynn, <i>Duquesne Law Rev</i> , 1996 ⁵	Review	Terminal illness: “The Medicare hospice benefit, for example, is limited to persons whose physicians attest that the patient has ‘a terminal illness with a life expectancy of six months or less.’”	Xact Medicare Services, Medicare Part B Reference Manual, Revision 020, August 23, 1996
		Subjective judgment: “The usual approach regarding living will has been to delegate the determination of whether an individual is terminally ill to a physician, perhaps with some consultation required. Other possibilities abound, including allowing the patient to make the determination, creating a committee for review, requiring judicial review, requiring consensus between the attending physician and named family members, etc.”	Miesel, supra note 1
		Statistical prognosis approach: “... required that public policy (e.g., in defining the population eligible for physician-assisted suicide) adopt a definition that requires that a terminally ill person has ‘less than x% chance to live y time’. The statistical prognosis approach could be more complex, for example, by stating that the patient’s survival must also be less than (x + a)% at some later time (y + b).”	None
		Observable clinical threshold of illness: “A patient with an illness expected to be fatal will be classified as “terminal” if the patient’s health become worse than a stated threshold.”	None

Hui et al., <i>J Pain Symptom Manage</i> , 2012 ¹	Systematic review	Terminally ill: "A life expectancy of 6 months or less." Terminally ill: "Beneficiaries who have a progressive incurable illness that will culminate in death." Terminally ill: Two definitions mentioned in this article: "Life expectancy less than three months"; "Life expectancy of less than six months." Terminally ill: "Less than six months to live." Terminally ill: "Death is likely within 6 months."	Meghani²⁴ Buntin et al.²⁵ Proot et al.²⁶ Babgi²⁷ Rondeau and Schmidt²⁸
Articles on terminal care McCusker, <i>J Chronic Dis</i> , 1984 ⁷	Retrospective study	Terminal care period: "Parkes defines ... the 'period of terminal care' as that period from the end of active treatment to the patient's death." Terminal care period: "The period during which there is evidence of progressive malignancy, and in which therapy cannot realistically be expected to prolong survival significantly. Patients enter this period either at time of diagnosis, or following a period of active treatment. The onset of the terminal care period should not be confused with the point at which life-expectation is estimated to be short. A patient might be expected to die within a few months, but have a treatable malignancy. This patient would still be in the active treatment period." Terminal illness: "Calman lists three conditions, all of which need to be met before making a diagnosis of 'terminal' illness in cancer patients: a firm diagnosis, with symptoms and signs relate to progressive malignant disease and not primarily to non-terminal conditions; the recognition that death is not far off; and that conventional anticancer therapy (surgery, radiotherapy, cytotoxic chemotherapy and hormonal therapy) has been used to the full." Type of terminal care period: "Type I: no tumor directed therapy ...; Type II: tumor-directed therapy discontinued ...; Type III: tumor-directed therapy continued during terminal period."	Parkes²⁹ None Calman KC. Physical aspects. In: Saunders CM, ed. The management of terminal disease. London: Arnold, 1978 None
Hui et al., <i>J Pain Symptom Manage</i> , 2012 ¹	Systematic review	Terminal care: "Care of patients with an anticipated prognosis of 3 months or less." Terminal care: "Concerns individuals with a terminal diagnosis, from which death can be expected within 12 months. Palliative terminal care concerns relieving the patients' suffering in the last phase of their lives, and includes, in addition to alleviation of physical symptoms, attention to emotional, spiritual and social aspects."	Napolskikh et al.³⁰ Proot et al.²⁶
Articles on transition of care Miller, <i>Paediatr Nurs</i> , 1996 ¹¹	Review	Themes identified for transition from adolescent to adult care include: timing (gradual, individualized), no specific time, arrangement of clinics (specialized, clinic hours, professionals), information giving (tailored), transition models.	None
Burge et al., <i>BMC Palliat Care</i> , 2005 ⁸	Retrospective study	Transition of care during the end of life: "1) a change in location of where the patient was cared for by the PCP (Palliative Care Program) or 2) a change in which clinical service provided care."	None
Rayson and McIntyre, <i>Curr Oncol Rep</i> , 2007 ⁹	Review	Discussed transitions in the context of 1) changing place of care, 2) changing goals of care, 3) changing teams of care.	None
Reinke et al., <i>J Palliat Med</i> , 2008 ¹⁰	Qualitative study	Themes identified for transitions at the end of life include 1) new or different treatments, 2) no more treatment/curative to palliative care, 3) activity limitations/functional decline, 4) initiation of oxygen therapy, 5) illness exacerbation or hospitalization, 6) improvement from illness.	None

Table 2

Definitions for “Actively Dying,” “End of Life,” “Terminally Ill,” “Terminal Care,” and “Transition of Care” From Print and Online Dictionaries

Reference	Actively Dying	End of Life	Terminally Ill	Terminal Care	Transition of Care
Print dictionaries					
<i>McGraw-Hill Allied Medical Dictionary</i> (2008)	No entry	No entry	No entry	No entry	No entry
<i>Dorland's Illustrated Medical Dictionary</i> (2007)	No entry	No entry	No entry	No entry	No entry
<i>Black's Medical Dictionary</i> (2009)	No entry	No entry	No entry	No entry	No entry
<i>Mosby's Medical Dictionary</i> (2009)	No entry	No entry	Terminal illness: An advanced stage of a disease with an unfavorable prognosis and no known cure.	No entry	No entry
<i>Stedman's Medical Dictionary</i> (2006)	No entry	No entry	No entry	No entry	No entry
<i>Taber's Cyclopedic Medical Dictionary</i> (2009)	No entry	No entry	Terminal illness: A final fatal illness.	No entry	No entry
Online dictionaries					
<i>MediLexicon</i> (2011)	No entry	No entry	No entry	No entry	No entry
<i>Medical Dictionary</i> (WebMD, 2011)	No entry	No entry	No entry	No entry	No entry
<i>MedlinePlus Medical Dictionary</i> (2011)	No entry	No entry	No entry	No entry	No entry
<i>The Free Dictionary: Medical Dictionary</i> (2011)	No entry	End of life. (Medtalk) adjective: Referring to a final period—hours, days, weeks, months in a person's life in which it is medically obvious that death is imminent or a terminal moribund state cannot be prevented. End of life. (Cardiac pacing) noun: The point at which a pacemaker signals need for replacement, as its battery is nearing depletion Source: <i>McGraw-Hill Concise Dictionary of Modern Medicine</i> . © 2002	Terminally ill (Managed care): The status of a person expected to die within six months from a specific condition and thus may need hospice care. Source: <i>McGraw-Hill Concise Dictionary of Modern Medicine</i> . © 2002	No entry	No entry

Table 3
Definitions for “Actively Dying,” “End of Life,” “Terminally Ill,” “Terminal Care,” and “Transition of Care” From Palliative Care Textbooks

Palliative Care Textbook	Actively Dying	End of Life	Terminally Ill	Terminal Care	Transition of Care
<i>Oxford Textbook of Palliative Medicine, 4th edition (2010)</i>	No entry	No entry	Terminal phase: The period of inexorable and irreversible decline in functional status before death. This may unfold gradually over days or weeks with a fluctuating but nonetheless ongoing decline in a progressive illness, precipitously following an unexpected and devastating neurological event such as a stroke, or following a planned withdrawal of life-sustaining interventions, such as hemodialysis or ventilatory support	No entry	No entry
<i>Textbook of Palliative Medicine, 1st edition (2006)</i>	No entry	No entry	No entry	No entry	No entry
<i>Principles and Practice of Palliative Care and Supportive Oncology, 3rd edition (2007)</i>	No entry	No entry	No entry	No entry	No entry
<i>Palliative Medicine, 1st edition (2009)</i>	No entry	No entry	No entry	No entry	No entry

definition of actively dying, describing it as a process with unique signs and symptoms before death (Table 4).

Concepts and Definitions for End of Life

Three of 134 articles discussed the concepts for end of life (Table 1). Lamont³ discussed the “challenge of recognizing the onset of this unique period referred to as the end of life” and two key aspects: 1) a disease-centered perspective based on a period of irreversible decline before death and 2) a time-based perspective related to the hospice admission criteria of six months or less of life expectancy. The time-based approach also was mentioned in an editorial by Lunney.⁴

One dictionary (Table 2) and one organizational Web site (Table 4) provided definitions for end of life. Both incorporated elements of disease trajectory and life expectancy in their definitions, although the duration of survival was not clearly defined.

Concepts and Definitions for Terminally Ill

Terminally ill was discussed in three articles, two of which focused on the legal definitions^{5,6} and one on definitions available in the literature.¹ Lynn⁵ discussed the criteria for categorizing terminally ill, including “1) A clear definition of terminal illness so that almost all individuals may be classified correctly; 2) A reasonable survival period of persons who are categorized as terminally ill (to make, effect, and be affected by decisions or to receive benefits); 3) A period of terminal illness recognizable for most lethal chronic diseases; and 4) Competence of persons within the category, at least for part of their time as terminally ill.” The authors further described three approaches to defining this term: subjective judgment, statistical prognosis approach, and observable clinical threshold of illness (Table 2). They also cited the Medicare hospice benefit definition in which a terminal illness was described as a life expectancy of six months or less.

McCartney and Trau proposed that a “terminal condition” is one in which “to a reasonable degree of certainty, there can be no restoration of health, and which, absent artificial life-prolonging procedures, will inevitably lead to natural death.” They further argued that patients in irreversible coma or persistent vegetative state were terminally ill.⁶ In a systematic

Table 4
Definitions for “Actively Dying,” “End of Life,” “Terminally Ill,” “Terminal Care,” and “Transition of Care” From Organizational Web sites

Web sites	Actively Dying	End of Life	Terminally Ill	Terminal Care	Transition of Care
American Academy of Hospice and Palliative Medicine, www.aahpm.org	No entry	No entry	No entry	No entry	No entry
American Cancer Society, www.cancer.org	No entry	No entry	Terminal illness: An irreversible condition that in the near future will result in death or a state of permanent unconsciousness from which you are unlikely to recover. In most states, a terminal illness is defined as one in which the patient will die “shortly” whether medical treatment is given	No entry	No entry
American Society of Clinical Oncology, www.asco.org	No entry	No entry	No entry	No entry	No entry
European Association for Palliative Care, www.eapcnet.eu	No entry	No entry	No entry	No entry	No entry
European Society for Medical Oncology, www.esmo.org	No entry	No entry	No entry	No entry	No entry
Education in Palliative and End-of-life Care, www.cancer.gov/cancertopics/cancerlibrary/epeco	No entry	No entry	No entry	No entry	No entry
End-of-Life/Palliative Education Resource Center, www.eperc.mcw.edu	Actively dying: Virtually, all dying patients go through a stereotypical pattern of symptoms and signs in the days before death. This trajectory is often referred to as “actively dying” or “imminent death.”	No entry	No entry	No entry	No entry
International Association for Hospice and Palliative Care, www.hospicecare.com/ ; www.pallipedia.org/	Actively dying: Virtually, all dying patients go through a stereotypical pattern of symptoms and signs in the days before death. This trajectory is often referred to as “actively dying” or “imminent death.” (From EPERC)	End of life: That part of life where a person is living with, and impaired by, an eventually fatal condition, even if the prognosis is ambiguous or unknown.	Terminal condition: A progressive condition that has no cure and that can be reasonably expected to cause the death of a person within a foreseeable future. The definition is inclusive of both malignant and nonmalignant illness and aging. A person has an eventually fatal condition if their death in the foreseeable future would not be a surprise. The terms eventually fatal or terminal condition are used interchangeably. In reference to the patient, language that refers to living with an eventually fatal (or terminal) condition is recommended.	No entry	No entry

Multinational Association of Supportive Care in Cancer, www.mascc.org	No entry	No entry	No entry	No entry	No entry
National Comprehensive Cancer Network, www.nccn.org	No entry	No entry	No entry	No entry	No entry
National Cancer Institute dictionary, www.cancer.gov/dictionary	No entry	No entry	Terminal disease: Disease that cannot be cured and will cause death.	No entry	Transitional care: Support given to patients when they move from one phase of the disease or treatment to another, such as from hospital care to home care. It involves helping patients and families with medical, practical, and emotional needs as they adjust to different levels and goals of care.
The National Hospice and Palliative Care Organization, www.nhpco.org	No entry	No entry	No entry	No entry	No entry
U.S. Federal Code, uscode.house.gov	No entry	No entry	Terminally ill: An individual who has been certified by a physician as having an illness or physical condition which can reasonably be expected to result in death in 24 months or less after the date of the certification. (26 USC Sec. 101)	No entry	No entry
			Terminally ill: An individual has a medical prognosis that such individual's life expectancy is nine months or less. (5 USC Sec. 8714d)		
			Terminally ill: The person has a medical prognosis such that the life expectancy of the person is less than a period prescribed by the Secretary. The maximum length of such period may not exceed 12 months. (38 USC Sec. 1980)		
			Terminally ill: The individual has a medical prognosis that the individual's life expectancy is 6 months or less. (42 USC Sec. 1395x)		

review, Hui et al. identified six definitions related to terminally ill from various palliative oncology publications. Four of these definitions involved a life expectancy of six months or less (Table 2).

We identified three definitions from dictionaries (Table 2), one definition from textbooks (Table 3), and seven definitions from organizational Web sites (Table 4) for terminally ill. Seven of these definitions included the concept of irreversible fatal illness. Nine included a reference to a limited life expectancy, ranging from “24 months or less,” “12 months or less,” “9 months or less,” “6 months or less,” “days or weeks,” “shortly,” and “within a foreseeable future” to “unfavorable prognosis.” The U.S. Federal Code alone provided four different definitions of terminally ill.

Concepts and Definitions for Terminal Care

Terminal care was defined in two articles (Table 1). In the study by McCusker,⁷ they cited the three criteria for a terminal diagnosis, including 1) firm evidence of progressive disease, 2) termination of active cancer therapies, and 3) “death is not far off.” However, “not far off” was not elaborated further. Others defined the terminal care period as ranging from three months to six months to 12 months.^{1,7} Terminal care was not defined in dictionaries, textbooks, or Web sites.

Concepts and Definitions for Transition of Care

We identified four articles aiming to conceptualize transition of care. Three discussed transition in the context of end-of-life care^{8–10}

and one focused on transition from adolescent to adult care¹¹ (Table 1). All three studies on end-of-life transitions addressed three aspects of transition: 1) place of care (e.g., hospital to home and vice versa), 2) level of care professions providing the care (e.g., oncologists to palliative care teams), and 3) goals of care (e.g., curative to palliative treatments and no further active treatments). The pediatric study also discussed the first two aspects.

We did not identify any definitions from dictionaries or textbooks for transition of care (Tables 2 and 3). The NCI Web site definition of transitional care coincides with the three aspects of transition of care discussed previously (Table 4).

Discussion

This systematic review revealed a paucity of references aimed at conceptualizing or defining actively dying, end of life, terminally ill, terminal care, and transition of care. These terms have previously been identified to be commonly used in both clinical and research settings.¹ Among the available definitions, we identified a number of unifying themes. The first four terms involved diagnosis of progressive irreversible disease with a limited prognosis, although there was no consensus on the exact time frame. Transition of care was defined as evolving place, level, and goals of care. Based on our findings, we developed a preliminary conceptual framework (Fig. 2) to help build standardized consensual definitions.

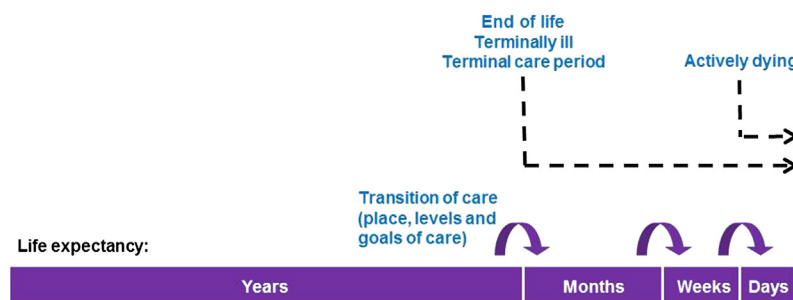


Fig. 2. A conceptual framework toward understanding “actively dying,” “end of life,” “terminally ill,” “terminal care,” and “transition of care.” Based on our systematic review, end of life, terminally ill, and terminal care period are synonymous and apply to patients with progressive disease with months or less of expected survival. Actively dying is related to patients with days of survival, and transition of care is related to changes in the place of care, level of care, and goals of care.

The National Institutes of Health (NIH) State-of-the-Science Conference Statement on Improving End-of-Life Care states that “there has been a lack of definitional clarity related to several concepts and terms,” which included end of life and transition of care.¹² This lack of clear definitions for these terms represents a barrier to research on care. Indeed, terms such as end of life were found in one-third of the palliative cancer care literature and ranged from “end-of-life discussions” to “end-of-life care.”¹ The ambiguity with this term is illustrated by two research publications with end of life in their titles. One of these articles discussed end of life in terms of years,¹³ whereas the other implied days of survival.¹⁴ Interestingly, we also found that the U.S. Federal Code provided four different survival durations (less than 24 months, 12 months, nine months, and six months) for the term terminally ill in four different sections. Because the duration of expected survival is an important determinant of goals of care and treatment decisions,^{15–17} it is important to standardize the use of these terms in the literature. This study represents our attempt to bring some clarity to a confusing area.

Actively dying has not been well defined. One definition described it in terms of the last hours or days of life, and the other discussed the presence of unique signs and symptoms preceding death. There is a paucity of studies on the signs of impending death.¹⁸ Further studies are needed to examine specific signs that may signal that the patient is actively dying and to allow clinicians to educate family members and make appropriate recommendations toward maximizing comfort and minimizing aggressive end-of-life measures.

Based on our literature review, the terms end of life, terminally ill, and terminal care share similar meaning: progressive life-limiting disease with a prognosis of months or less. How the terms differ is in their application: end of life is used to define a particular time frame, terminally ill is used to describe a patient’s condition, and terminal care is used to characterize care delivered for terminally ill patients. The NIH State-of-the-Science Conference Statement added two other dimensions to the definition for end of life, namely impaired function and increased symptom burden requiring higher levels of

care, both of which are related to a shortened survival and progressive disease.¹²

Part of the challenge with these prognostic terms is that both our science and language of prognostication are imprecise. Because death is often mediated by catastrophic events such as myocardial infarction and pneumonia, it is difficult to know exactly how long a patient is going to live. Thus, general time frames such as “months,” “weeks,” or “days” are recommended when communicating with patients about their prognosis.^{19,20} In this study, we also propose that end of life, terminally ill, and terminal care use be limited to patients with months or less of expected survival. Fig. 2 presents a conceptual framework detailing the meaning of these terms.

Our study revealed that transition of care has three key dimensions: place of care, level of care, and goals of care. The concept of goals of care was recently reviewed by Kaldjian et al.²¹ and classified under six major domains: cure, prolonging survival, optimizing function, improving comfort, achieving life goals, and supporting family/caregiver. Although transition of care occurs throughout one’s life, transitions are particularly common during the end-of-life period, such as being hospitalized and subsequently discharged, meeting the palliative care team, stopping life-prolonging therapies, enrolling in home hospice, transferring to inpatient hospice, and focusing on comfort care. Schofield et al.²² conducted a systematic review discussing the communication process of transition from curative cancer treatment to palliative care.

Although we conducted an exhaustive search of the literature, it is important to recognize that, in this systematic review, we only examined articles that aimed to conceptualize or define the terms rather than all definitions mentioned in all articles. We previously extracted all available definitions from a sample of the palliative oncology literature over a 12 months period.¹ Furthermore, our search strategy was specific and did not include other distinct but related terms. For example, “imminent death” was not included for actively dying, which may have limited our ability to uncover relevant resources for definitional data. We also did not review the gray literature, abstracts, or statutory laws from countries other than the U.S. and limited our search to

the English language only. Further studies are needed to examine the use of these terms in other languages.

The conceptual framework developed here may help to put the five terms in context with each other, with the aim of an increased understanding. Our findings highlight the urgent need to develop consensus definitions for these terms to facilitate daily communications related to clinical care, scientific research, education, and public policy. This may be achieved through Delphi processes or expert workgroups. Surveys of patients, clinicians, and researchers about their definitions for these terms also may provide additional insights. Until these terms are clearly defined and universally understood, it is important to provide a definition for these terms whenever they are used.

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