Review Article

Patient's Perspectives on the Notion of a Good Death: A Systematic Review of the Literature

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Abstract

Context. There is no clear definition of what constitutes a good death or its features. Patients, caregivers, physicians, and relatives have different notions of a good death. Discussions have been driven by academic perspectives, with little research available on the patients' perspectives.

Objectives. To explore the notions of a good death from the patients' perspective.

Methods. A systematic literature search was conducted up to November 2017 using CINAHL®, MEDLINE®, EMBASE®, and PsycINFO® databases. Search terms used were "quality of death," "good death," "quality of dying," or "good dying." Scientific empirical studies that included the exploration of the notion of a good death in adult patients with advanced and life-threatening diseases were selected separately by two researchers. Hawker's et al. criteria were used to assess the quality of articles. The analysis was conducted using a thematic analysis.

Results. Two thousand six hundred and fifty two titles were identified; after elimination of duplicates, screening, and final selection, 29 relevant publications remained for analysis. Sample populations included patients with terminal diseases (AIDS, cardiovascular disease, and cancer). Core elements for a "good death" included control of pain and symptoms, clear decision-making, feeling of closure, being seen and perceived as a person, preparation for death, and being still able to give something to others; whereas other factors such as culture, financial issues, religion, disease, age, and life circumstances were found to shape the concept across groups. Studies agree on the individuality of death and dying while revealing a diverse set of preferences, regarding not only particular attributes but also specific ways in which they contribute to a good death.

Conclusions. Although sharing common core elements, patients' notions of good death are individual, unique, and different. They are dynamic in nature, fluctuating within particular groups and during the actual process of dying. Formal and informal caregivers should carefully follow-up and respect the patient's individual concepts and preferences regarding death and dying, while attending to shared core elements, to better adjust clinical decisions. J Pain Symptom Manage 2020;59:152–164. © *2019 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words

Death, attitude to death, patients, terminally ill, terminal care

Introduction

Death and dying play a central role in all societies and cultures, reflecting the social and cultural identity and the individual's embedding in society. With the advances in medicine and technology, the process of dying has become more protracted, with death itself being delayed by longer end-of-life periods.[1]

The term "good death" was primarily used as a synonym for euthanasia (from the Greek word *εὐθανασία*, meaning "good death"), in the context of situations where life was deliberately put to an end.[2] In the

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United States and Europe, the term good death emerged broadly in the 1960s, as a key concept of the incipient palliative and hospice movement.[3–5] It was not until a decade after that the debates on a good death broadened in scope. Although some still used it as a reference for euthanasia, others began to consider the meanings and determinants of a natural good death.[2]

The first approach to define a good death was made by O'Neil in 1983.[6] He considered a death to be good if the individual maintained control and autonomy over the dying process and the timing of death. In its literal sense, the definition referred to a good euthanasia.[2,6] Kellehear investigated the attitudes of dying people in a hospital setting and explored the social conditions characterizing the concept of good death at that time. His findings suggest that a good death in hospitals can be achieved under the following conditions: awareness of dying, preparation for death, abandonment of roles and responsibilities, and saying goodbye.[7] The concept of good death has become established since then as a separate model for helping dying persons, distinct from previous notions of euthanasia.

However, there is no clear definition of what constitutes a good death or what features the term implies. In the scientific literature, similar expressions such as "dying well," "dying peacefully," "appropriate death," "desired death," or "dignified death" are used, sometimes synonymously and sometimes as distinct from each other.[2]

Studies have shown that patients, caregivers, physicians, and relatives differ in their notions of a good death.[8–12] However, discussions on the subject have tended to be driven by academic and clinical perspectives, with little research available on what patients themselves consider to be important at the end of life.[13] This shortcoming indicates that the topic of good death has long being reserved for expert debate.[11,14] Consequently, this review aims to systematically explore the notion of a good death from the patients' perspective.

Methods

A protocol to guide the review was prepared in advance including a scope, a research question, inclusion and exclusion criteria, search strategies, and extraction methods. The research question was, "What are the notions of a good death from the perspective of patients described in the scientific literature?"

Inclusion and exclusion criteria considering population, intervention, and study design were defined (Table 1). Only scientific empirical studies, published in English, that included the exploration of the notion of a good death in adult patients were selected. Although there is abundant literature derived from the humane and social sciences, authors were interested in including original studies that directly explored the patients' views on what constitutes a good death for them. Whenever studies included different populations (e.g. health care staff, family), only the information regarding patients was taken into account.

Studies were identified using the electronic databases CINAHL (from 1961), MEDLINE (from 1946), EMBASE (from 1947), and PsycINFO (from 1967), up to November 2017. Additional studies were identified using cross-reference. The search was conducted using the terms: "quality of death," "good death," "quality of dying," or "good dying." Terms from the natural language were used, given the specificity of the subject which was not accounted for by MeSH terms. The search strategy used was "quality of death"[All Fields] AND ("0001/01/01"[PDAT]: "2017/11/30"[PDAT]); "good death"[All Fields] AND ("0001/01/01"[PDAT]: "2017/11/30"[PDAT]); (quality[All Fields] AND dying[All Fields]) AND ("0001/01/01"[PDAT]: "2017/11/30"[PDAT]); (good[All Fields] AND dying[All Fields]) AND ("0001/01/01"[PDAT]: "2017/11/30"[PDAT]).

The screening and preselection of the studies was conducted independently by two authors (J. J. K. and T. P.), using the title and abstract and according to the eligibility criteria. A third member of the research team was available for supervision of the procedure whenever help was needed to resolve disagreements (A. K.). Full texts of preselected titles were retrieved and read by J. J. K. and T. P. to confirm their inclusion in the study. Data extraction was conducted by J. J. K. following the thematic analysis process by Braun and Clarke.[15] A table containing the following information was prepared: author, year, design, country, setting, sample, aim, primary outcome, results, conclusion, and comments. T. P. checked the extracted data; disagreements were discussed with A.

Table 1
Inclusion and Exclusion Criteria

Selection Criteria	Inclusion Criteria	Exclusion Criteria
Population	Patients with advanced disease	• Children • Health personal • Experts • Family members
Outcome	Quality of dying	• Certificate of death • Epidemiological studies
Study design	Empirical original data (qualitative and quantitative studies)	• Editorial, Letters • Historical reports • Case reports • Reviews • Opinion papers • Conferences

K., and an assessment of the quality of each included article was performed by A. K. and C. M.

Given that qualitative, quantitative studies and mixed studies were selected, the quality of the studies was appraised according to the criteria by Hawker et al.[16] Each study was assessed in a scale ranging from 4 to 1 (4: good, 3: fair, 2: poor, and 1: very poor). Recommendations of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement were applied.[17] None of the articles selected was excluded for quality reasons. The analysis was conducted using a thematic analysis, supported/based on the repeated review of the articles and the information included in the extraction.

Results

A total of 2652 titles were identified with the search strategy, and after eliminating duplicates, 1332 publications remained for further analysis. In the screening, 1189 publications were excluded because of nonconformity to inclusion criteria. Finally, 144 publications were selected and examined in detail based on the full text, 117 were excluded, and four new publications were identified through cross-reference, resulting in 29 relevant publications for analysis.[10,18–20] The data extraction process is shown in Figure 1.

As explained, only data regarding patients were included in the analysis. Overall, the reviewed studies reported the views of 6690 individuals. Most sample populations included patients with advanced stage diseases (AIDS, cardiovascular disease, chronic obstructive pulmonary disease, and cancer) ($n = 16$). Other studies focused exclusively in older adults ($n = 4$); mixed populations including patients, relatives, and health care professionals ($n = 5$); and general population ($n = 3$). Most studies were American or European, with 13 set in the U.S., seven in European countries, two in Japan and China, and one in Canada, Uganda, India, and Kenya, respectively (Table 2 details the sociodemographic characteristics of the population included in each study).

Recruitment settings included community and health care settings (hospitals, outpatient clinics, hospices, and long-term care facilities). Most studies used qualitative methods ($n = 18$), relying on observation, individual interviews, focus groups, and self-report questionnaires. Nine studies used quantitative methods, and two used mixed methods.

All the studies underwent a quality evaluation according to Hawker's criteria, after the selection process. The mean score of the studies was 3.87 (range 2.89−4), and most of the articles had scores above 3.5, indicating that, overall, the reviewed studies had a fair to good quality, thus we decided to include all. Only one article was found to have noticeable weaknesses regarding methodology and data analysis, which affected the quality of the results and, therefore, its conclusions[21]; however, the final score was 2.89 indicating a fair to good quality; therefore, we decided to retain it for analysis. Three articles had slight flaws regarding methodology and data collection.[21–23] Two articles showed fair scores in

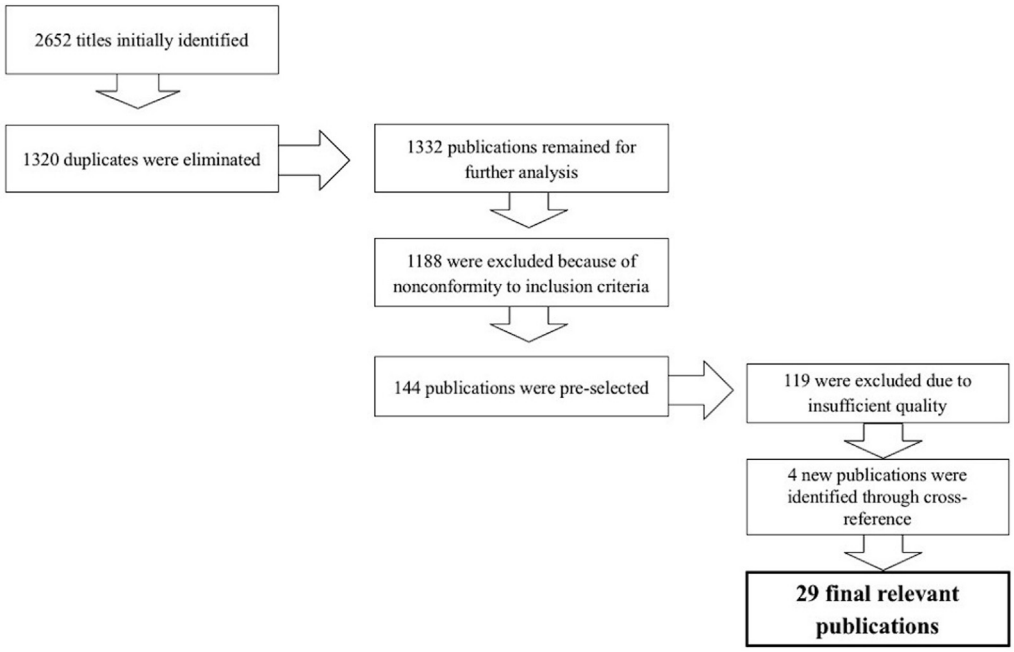


Fig. 1. Data extraction process.

Table 2
Sample Characteristics of the Studies Included in the Review

Author	Country	Method	Population	Sample Characteristics		Aim
				Sex Distribution	Age (Mean/Range)	
Steinhauser et al.[10]	U.S.	Qualitative Focus group and in-depth interviews	$n = 75$ (physicians, nurses, social workers, chaplains, hospice volunteers, patients, and bereaved family members)	48 female/27 male	46.8/26–77	Identify components of good death from patients, family, and providers
Akechi et al.[18]	Japan	Quantitative Cross-sectional survey	$n = 2595$ sample of general population 466 aged (from 70 up, considered as elderly)	47% female/53% male	40–79	Investigate differences in concepts of good death between elderly and younger populations and to clarify the relevant components of a good death in elderly adults.
Hirai et al.[21]	Japan	Mixed-methods Semistructured interviews	$n = 63$ 13 patients with advanced cancer 10 family members 20 physicians 20 nurses	36 female/27 male	47.52/not informed	Identify components of a Japanese good death
Kikule[22]	Uganda	Quantitative Cross-sectional study	$n = 173$ terminally ill patients registered in home care programs	145 female/28 male	Under 50 years old	Explore the definition of "good death" in Uganda, and identify palliative care needs
Hattori & Ishida[24]	U.S.	Qualitative Ethnography and in-depth interviews	$n = 18$ healthy and active elderly Japanese-Americans	14 female/four male	78/72–90	Identify the pattern of beliefs about a good death
Ko et al.[25]	U.S.	Qualitative Semistructured open-end interviews	$n = 18$ healthy older Mexican-Americans	13 female/five male	77.5/not informed	Identify and describe domains that define a good death from perspective of older Mexican-Americans
Bullock et al.[30]	U.S.	Qualitative Semistructured focus groups and follow-up questionnaires	$n = 102$ African-Americans	Not informed	72/not informed	African American's preferences and perspectives around end-of-life-care characterize domains of a good death
Hughes et al.[38]	U.S.	Quantitative Cross-sectional interview study	$n = 100$ patients with lung cancer	47 female/53 male	72/66–85	Perceptions of good death in patients with lung cancer (short-term survival rate)
Reinke et al.[39]	U.S.	Qualitative Cross-sectional, preferences about death and dying questionnaire (PAAD)	$n = 376$ veterans with chronic obstructive pulmonary disease	11 female/365	69.4/not informed	Determine preferences for death and dying among veterans with chronic obstructive pulmonary disease
Willems et al.[31]	Netherlands	Qualitative Prospective longitudinal multiple case study using qualitative interviews	$n = 31$ patients with heart failure	eight female/23 male	72/46–88	Explore ideas and attitudes of patients with end-stage cardiac failure concerning dying

(*Continued*)

Table 2
Continued

Author	Country	Method	Population	Sample Characteristics: Sex Distribution	Sample Characteristics: Age (Mean/Range)	Aim
Pierson et al.[23]	U.S.	Qualitative Face-to-face interviews	$n = 35$ patients with C3 AIDS	three female/32 male	41/not informed	Identify domains that define "good death" from perspective of patients with advanced AIDS
Mak MH.[34]	China	Qualitative based on grounded theory, semistructured interviews	$N = 33$ terminal cancer	16 female/17 male	67/34–86	
Singer et al.[40]	Canada	Qualitative In-depth, open-ended, face-to-face interviews	$n = 126$ Three patient groups: renal failure in dialysis (48), HIV (40), residents in long-term facility (38).	48 female/78 male	54.73/20–85	Identify elements of quality end-of-life-care from patient's perspective
Gott et al.[36]	United Kingdom	Mixed-Methods Semistructured interviews with qualitative and quantitative questions	$n = 40$ people with advanced heart failure	19 female/21 male	77/not informed	Explore older people's definition of a good death
Rietjens et al.[32]	Netherlands	Quantitative Cross-sectional interview study	$n = 1388$ general public	61 female/39 male	47/20–93	Identify characteristics considered important for a good death, insight into the relationship with broad acceptance of euthanasia
Haishan et al.[41]	China	Quantitative Cross-sectional survey	$n = 513$ 190 healthy participants 323 health care providers	55.8% female/44.2% male	34.8/not informed	Compare the current situation between common people and health care providers' preferences for a good death in the context of Chinese culture
Tong et al.[33]	U.S.	Qualitative	$N = 197$	33% female/57% male	Not informed/14–68	To identify common domains that characterize good death for a range of community-dwelling individuals
Steinhauser et al.[37]	U.S.	Quantitative Cross-sectional, stratified random national survey	$n = 1452$ 340 seriously ill patients, 332 recently bereaved family 361 physicians 429 other care providers	711 female/741 male	57/not informed	Determine the factors considered important at the end of life
Grant et al.[44]	Kenya	Qualitative Semistructured interviews	$n = 32$ with incurable illness	11 female/33 male	54/16–80	Identify what constitutes a good death in sub/Saharan Africa
Chacko et al.[35]	India	Quantitative, descriptive, cross-sectional, comparative approach	140 patients and 40 health professionals.	72 (51%) female/68 (49%) male	Not informed	Explore end-of-life perspectives of patients with advanced carcinoma

						and health care professionals in a tertiary health care setting in India
Ko et al.[28]	U.S.	Qualitative face-to-face interviews	21 homeless older adults	three female/18 male	65/not informed	Explore older homeless adults' perspectives toward good and bad deaths and their concerns regarding their EOL care needs
Gelo Florence et al.[26]	U.S.	Qualitative semistructured open-end interview	$n = 15$ nursing home residents	13 female/two male	84.5/73–96	Identify a good death as envisioned by frail elderly and the impact of formal religious belief
Kastbom et al.[46]	Sweden	Qualitative Semistructured interview (The interviews were analyzed using inductive qualitative content analyses, and no predetermined categories or themes were used)	$n = 66$ participants with cancer were interviewed ($n = 54$ in 1997–1998; n 12 in 2007)	37 (56%) female/29 (44%) male	64/30–90	To explore the perception of a good death in dying cancer patients in Sweden
Toscani et al.[45]	Italy	Qualitative Semistructured interviews	$n = 8$ healthy persons believers and nonbelievers in individual life after death	four female/four male	55/25–74	Identify the influence of believing in individual life after death on good death models
Tong et al.[33]	U.S.	Qualitative Focus-groups	$n = 180$ terminally ill patients	121 female/59 male	69/32–88	Explore preferences of terminally ill patients with cancer
Nosraty et al.[27]	Finland	Qualitative Life-story interviews	$n = 45$ community-dwelling nonagenarians	25 female/20 male	Not informed	Investigate the meaning and content of good and successful aging by the oldest old people, aged 90+
Payne et al.[29]	United Kingdom	Qualitative Semistructured interviews	$n = 18$ persons in a palliative care unit, who explicitly mentioned the word "death" or made explicit reference to dying during the interview.	nine female/nine male	65.6/30–81	Perceptions of a good death in patients with advanced cancer
Vig et al.[19]	U.S.	Qualitative Open- and close-ended interviews	$n = 16$ older adults with a nonterminal heart disease and cancer	two female/12 male	75/67–84	Explore attitudes of older adults about end of life
Leung et al.[20]	Taiwan	Observational study—Prospective	$n = 281$ patients with terminal cancer	135 (48%)/male 146 (52%) female	64.4/not informed	Evaluate the change of quality of life and quality of death over time and between patients of long and short survival in a palliative care unit.

Please note that only data regarding patients' views were included in the analysis.

data analyses,[21,22] and noticeably, five articles had shortcomings regarding ethical aspects[22,24–27] (failed to indicate if the study was approved by an ethical committee or if informed written consent was required for participation). Regarding results, five articles were found to have some limitations,[19,21,23,28,29] which, in turn, reflected methodological shortages. Details of the assessment are shown in Table 3. Caution regarding transferability, generalizability, and implications for practice is recommended in relation to the mentioned articles.

When conducting the analysis of the data extracted from the articles, two-level categories were identified: core elements for a "good death" and main themes or factors that shape the concept. A lot of the patients' descriptions of a good death fall within a series of core elements, which entail individual attributes of a good death, denote personal and more private experiences that impact the person as a whole, are universal, and were commonly found across groups; these include control of pain and symptoms,[8,10,18–22,24,28,30–35] clear decision-making,[31,32] feeling of closure,[21,25,33] being seen and perceived as a person,[10,19,22,33] preparation for death,[10,14,18,33,36] and being still able to give something to others.[10,18,21,33] The main themes that were considered factors that shape the concept tend to differ across groups and include culture and society, financial issues, religion and spirituality, disease, age, and life circumstances (Figure 2).

The findings regarding core elements will be described within each category of the main themes previously mentioned, with the intent to integrate the information and, at the same time, show how each theme shapes the common concepts regarding a good death.

Culture and Society

Steinhauser et al.[37] conducted a qualitative and quantitative study among patients, bereaved family members, and caregivers in the United States, which is often cited as a reference.[18,19,25,30,38,39] The themes, identified as important, consist of the following aspects: pain and symptom management, clear decision-making, preparation for death, contributing to others, affirmation of the whole person, and completion. Most authors agree that a good death includes but is not limited to the six themes by Steinhauser et al.[10,14,23,25,31–33,36,38–41]

Culture shapes the meaning people give to illness, suffering, and dying.[18,19,21,22,24,34] It is defined as an integrated system of learned behavior patterns, which are characteristics of a group of members of society.[42] Thus, differences regarding the notion of a "good death" may differ across cultures.

Concomitant with the rise of individualism in some countries, independence and autonomy seem to be central in the perception of a good death.[36,40] The theme of "completion" raised by Steinhauser may be primarily a process of individual life review, whereas in other cultures, it may be more a matter of community and family.[10] Seale argues that care of the self is nowadays considered an individual project in the Western, anglophone medico-psychological discourse.[43] However, this is not the case for most patients, even in Western countries. As found by Gott et al.,[36] views about death and dying were both influenced by personal and family concerns. Particularly, in some cultures, there is greater trust and increased willingness to allow family members and others to care for them and participate in decision-making.[18,25]

This finding by Gott is consistent with studies conducted in Asian cultures, such as Japan and China. Japanese patients with cancer do not consider autonomy to be essential for a good death. Rather, they prefer a passive decision-making style.[18,19] In their recent study, Akechi et al.[18] found that elderly Japanese people regarded "trusting my physician" to be the most important component of a good death. The least commonly supported themes for a good death were knowing what to expect in one's future and knowing how long one has until death.[17] These findings emphasize the importance of the Japanese entrusting pattern of *Omakase*, which means entrusting the decision to a medical expert.[18,19]

Furthermore, in the Japanese, as well as in the Chinese cultural context, good family relationships are considered key requirements for a good death. Although the importance of family support at the end of life is emphasized and expected, the dying also has a strong desire not to be a burden on the family.[18–21]

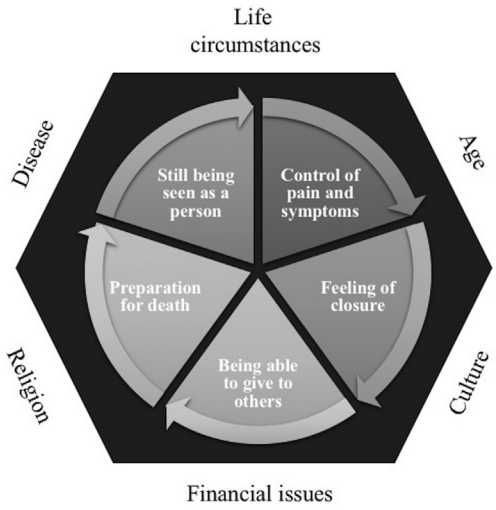
Although the importance of some attributes of the good death differ between U.S., Europe, and Asian cultures, there is considerable agreement about concordance with others, pain and symptom control, preparation for death, completion, and contributing to others, not being a burden to others and maintaining hope.[18–20,32,33]

The concept of a good death shows some variations among subgroups, given their ethnic, cultural, and socioeconomic characteristics.[22,24,34] Thus, the multicultural nature of many societies shapes the experience of dying in a complex way.[40]

Among patients of ethnic-minority groups in the U.S., there is an agreement on the importance of maintaining an open view regarding diverse notions of a good death, which may not be shared by health staff or the majority of patients. Some consider it crucial to a good death and hope that clinicians and others in the health care system acknowledge and adapt to their cultural traditions including, for

Table 3
Assessment of Articles Included in the Review

Author (Reference)	Year	Abstract and Title	Introduction and Aims	Method and Data	Sampling	Data Analysis	Ethics and Bias	Results	Transferability or Generalizability	Implications and Usefulness	Average
Steinhauser et al.[10]	2000	4	4	4	4	4	4	4	4	4	4.00
Akechi et al.[18]	2012	4	4	4	4	4	4	4	4	4	4.00
Hirai et al.[21]	2006	4	4	2	4	2	4	2	2	2	2.89
Kikule et al.[22]	2003	4	4	3	4	3	3	3	4	4	3.56
Hattori & Ishida[24]	2012	4	4	4	4	4	4	4	4	4	4.00
Ko et al.[25]	2013	4	4	4	4	4	3	4	4	4	3.89
Bullock et al.[30]	2005	4	4	4	4	4	3	4	4	4	3.89
Hughes et al.[38]	2008	3	4	4	4	4	4	4	4	4	3.89
Reinke et al.[39]	2013	4	4	4	4	4	4	4	4	4	4.00
Willems et al.[31]	2004	4	4	4	4	4	4	4	4	4	4.00
Pierson et al.[23]	2002	4	4	4	4	4	4	4	4	4	4.00
Mak[34]	2001	4	4	4	4	4	4	4	4	4	4.00
Singer et al.[40]	1999	4	4	2	4	4	4	3	4	4	3.67
Gott et al.[36]	2008	4	4	4	4	4	4	4	4	4	4.00
Rietjens et al.[32]	2006	4	4	4	4	4	4	4	4	4	4.00
Haishan et al.[41]	2015	4	4	4	4	4	4	4	4	4	4.00
Tong et al.[33]	2003	4	4	4	4	4	4	4	4	4	4.00
Steinhauser et al.[37]	2000	4	4	4	4	4	4	4	3	4	3.89
Grant et al.[44]	2003	4	4	4	4	4	4	4	4	4	4.00
Chacko et al.[35]	2014	4	4	4	4	4	4	4	4	4	4.00
Ko et al.[28]	2015	4	4	4	4	4	4	4	3	4	3.89
Gelo et al.[26]	1997	3	4	4	4	4	3	3	4	4	3.67
Kastbom et al.[46]	2016	4	4	4	4	4	4	4	4	4	4.00
Toscani et al.[45]	2003	4	4	4	4	4	4	4	4	4	4.00
Vig & Pearlman[48]	2004	4	4	4	4	4	4	4	4	4	4.00
Nosraty et al.[27]	2015	4	4	4	4	4	1	4	4	4	3.67
Payne et al.[29]	1996	4	4	4	4	4	4	4	3	4	3.89
Vig et al.[19]	2002	4	4	4	4	4	4	3	3	4	3.78
Leung et al.[20]	2010	4	4	4	4	4	4	4	4	4	4.0
Total		3.93	4.00	3.82	4.00	3.89	3.75	3.79	3.79	3.93	3.87



The inner circle illustrates the personal attributes of a good death and the outer hexagon indicates the aspects that shape the concept

Fig. 2. Categories of analysis (core elements or personal attributes of a good death and factors that shape the concept).

instance, issues related to food and feeding or the treatment of the body after death.[22,24,25,30,34,41]

The concept of a good death for Japanese-Americans greatly reflects the concept of Japanese living in Japan, with important attributes being emphasis on family relationships, not being a burden, trusting the physician and pain and symptom management.[18,21,24] However, it was found that this shared meaning could vary between generations. According to Hattori et al., the second generation of Japanese-Americans had more traditional Japanese views on death, compared with the third generation, which was more "Americanized."[24]

Financial Issues

In high-income countries, where basic human needs are secured, the emphasis for a good death lies on either psychological or social aspects.[10,18,19,37,40] In low-income countries, in contrast, the perception of a good death may be also shaped by issues related to subsistence income and the satisfaction of basic human needs.[22,35,44] This suggestion is reinforced by a study conducted in Uganda, where the health care infrastructure there has very limited resources and 34% of the population lives in absolute poverty. Terminally ill patients thus perceive financial assistance as critical for a good death, not only to cover for medical care but also for basic needs such as food, shelter, and school fees for their children. As pain medications are not readily available, many patients also stress their concern to die free from pain and other distressing symptoms.[22]

Similarly, in India, a great majority of participants attached a great importance to financial arrangements at the end of life. People felt to be a financial burden to their family and expressed the need for financial assistance to pay for treatment costs.[35]

But also, within countries like the U.S., a lot of people are structurally disadvantaged and underprivileged. The concomitant discrimination and social disadvantages influence the respective attributes of a good death. Findings by Ko et al.[28] show that homeless older adults in the U.S. were worried about dying unnoticed and alone on the street. Dying that way for them "confirmed rejection, marginalization, and negligence by society." Furthermore, people were afraid of dying by violence or in an accident, which reflects that homeless people are a vulnerable group that is at greater risk of victimization and violence.

Religion and Spirituality

Religious beliefs affect the conception of a good death, as religion and spirituality are essential elements in the practices and concepts about life, health, illness, and death.[34,45,46] For African-Americans and Mexican-Americans, spiritual support is as important to a good death as symptom management.[25,30]

For Catholic Mexican-American patients, religiosity and spirituality are essential aspects that lead to a good death. Many believe that God is the only one who has control over birth and death, and hence, death should not be fought against with life-extending measures.[25]

Similarly, patients in a nursing home devoted to formal Christian belief regard religious faith and prayers as very important for dying well.[26] Given that God determines the time of death in their belief, many disapprove of medical interventions at the end of life as well as life-prolonging treatment. Furthermore, religious patients seem to have little fear about dying, implying that both religious beliefs and religious practices could decrease anxiety about death.[24–26,34]

Disease and Dying Trajectories

Several authors highlight the influence that the disease exerts on the perceptions patients have of a good death.[23,31,36,38,39] Different dying trajectories and the point of the trajectory in which patients are may be responsible for the heterogeneity of attitudes toward a death and dying.

The dying trajectory for cancer might be more clearly defined.[38,47] By contrast, other disease courses are hard to predict, and patients may live for a long time without openly acknowledging the imminence of death.[23,31,36,39] For instance, lung cancer has a relatively short survival time, confronting patients with a rather fast and imminent death. Patients with lung cancer have been found to want to die peacefully,

quickly, and during their sleep, which implies a wish to be as unaware of dying as possible.[38] A specific symptom they are concerned about is breathlessness, leading to the worry of "suffocating to death."[38] This specific concern is shared by patients with heart failure and chronic obstructive pulmonary disease.[36,38]

Within heart failure, dying trajectories vary and sudden death is common.[31,36] Most of the patients only think about dying during an exacerbation, whereas the thought of death disappears when there is no more direct threat to life. Gott et al. argue that this fact may benefit patients with heart disease, enabling them to continue living as normally as possible.[36] This suggestion is reinforced by the fact that patients regard "retaining some usefulness" as a key requirement for a good death. This also relates to the wish of not being a burden for the family.[31]

Also, the point of time in the dying trajectory influences the patient's notion about a good death. Leung et al.[20] found that patients with terminal cancer with long survival had higher scores in awareness of terminality, acceptance of death, timeliness of death, and comfort, but differences between patients with long (above three months) vs. short survival times disappeared as death became imminent. Vig & Pearlman[48] in their study with patients with an life expectancy of six months found no uniform view of a good death, but some common factors included during sleep, painless, quick, without suffering, in peace with God, peaceful, and without awareness. Only one identified attribute was consistent with the six themes proposed by Steinhauser et al., whereas in another study by Steinhauser et al.,[37] patients with advanced illnesses who had been hospitalized in the prior year expressed that factors associated with a good death were being aware, planning for funeral, feeling of completion, not being a burden, being able to help others, coming to peace with God, and praying. These differences may be due to changes occurring during the disease/dying trajectory.

Age and Life Circumstances

The age of patients has been studied as a factor that shapes behaviors and thoughts about death. In connection with older age, patients tend to place greater trust in authority and allow family members to make decisions for them.[36] As distinct from concepts of a good death of younger patients, Gott et al. found in their study that older patients with heart failure did not place value on autonomy and individuality.[36] In contrast, findings by Nosraty et al. show that nonagenarians place great value in retaining their autonomy and preserving their personality in the process of dying.[27]

Further studies among older heart failure and hospice patients show that they preferred a sudden "easy death," rather than a conscious death.[8,27] According to Gott et al., this might enable them to avoid the feared dying process and maintain an intact personhood up to the end.[36] However, in another study involving older patients from The Netherlands[31], awareness of death was important for a good death, reflecting not only age differences, but also cultural ones.

All the aforementioned studies agree on the individuality of death and dying. They reveal a diverse and variable set of patient's preferences in and around death.[8,19,27,31,33] Not only is there variability in the attributes identified as important but also in the way how a specific attribute contributes to a good death.[18,19,33,48] For example, some patients feel that dying in one's sleep would lead to a good death,[19,23,38,48] whereas others prefer to be awake and aware at the time of death.[31,34]

Discussion

The aim of the aforementioned studies was to explore the notion of a "good death" from the patient's perspective and to define key elements to understand the concept. When analyzing the results, two-level categories were identified: core elements for a "good death" and main themes or factors that shape the concept. The first level includes a series of recurrent topics that most people consider important for a good death and that are mainly personal attributes: pain and symptom control, preparation for death, the subjective feeling of closure at the end of one's life, clear decision-making, and contributing to others.[10,18,19,40] However, what patients consider to be a "good death" is strongly influenced by culture, religion, age, life circumstances, disease, and financial issues. These aspects were considered a second-level category labeled "factors that shape the concept."

There are considerable variations, and sometimes contradictions, in the preferences and issues that concern people, even when they belong to similar attributes.[31,32,38] This means that, although some subjects are of particular importance to most, there are some aspects that influence and shape them resulting in a good death or in an experience of suffering when confronting death. For example, control of pain and physical symptoms is universally considered to contribute to a good death. However, in cultural contexts where financial aspects limit the access to health care or medicines, patients tended to put an emphasis on this core element and expressed great concern about it,[22,35,44] whereas in contexts where health access is secured, more importance was placed in aspects such as being able to participate in treatment decisions than in pain control.[31,32] Consequently, we found that what constitutes a good death for each person is highly individual,

changeable over time, and based on personal perspectives, cultural contexts, and experiences gained in the course of their life histories. In concordance with this view, other authors have found that although some themes may be common to the notion of a good death, important variabilities exist between groups on how they relate to them or the degree to which it impacts on a good death.[19,20,33,49]

On the other hand, although the variability and disparity in concepts of good death are evident, there is a strive for a standard concept that helps define the conditions for good death and allows appropriate care to be provided.[11,19,20,49] The very different notions that individuals have of good death raises the question as to how much sense it makes to define concepts of good death. Hart et al.[11] show that current definitions of good death specify a social ideology of death and dying. They point out the risk that an ideology of good death can lead to labeling of "good" and "bad" dying and thus to "good" and "bad" patients who are dying. There is cause for concern that an ideology of the good death may legitimate a new form of social control within which socially approved dying and death are characterized by proscribed and normalized behaviors and choices. This would mean that dying people are not free in their wishes and choices, but instead, that nursing staff, physicians, and relatives intervene intensely in managing the end of life. Dying would be strongly shaped and controlled by society.

Similarly, focusing on achieving "acceptance of death" may imply that the patient should accept the dying process, while death denial could be repressed or negatively viewed. It could prescribe a specific way of dying resulting in controlled dying.[50,51] Palliative care should concentrate on alleviating suffering rather than eliminating any denying of death and dying.[51] Nevertheless, modern medicine possibilities demand "planning" for the future and discussing "end-of-life decisions" such as where to die, whether or not to be resuscitated, fed, or hydrated, which consequently may create an imperative for patients to openly discuss and "accept" that they are dying.[50]

In an Australian study in hospices, health staff considered a death to be good or bad when, in addition to factors such as acceptance, adjustment, and awareness, they were satisfied with the patient's response to treatment, interactions, and choices. Good death was mostly attributed to good care and support by the hospice staff while bad deaths were described as problematic and dissatisfying and were a topic of team discussions. The reasons were more likely to be ascribed to the patients, the families, or more generally to social circumstances.[12] On the other hand, giving the chance to patients to express their experience regarding aspects related to a good death at different point in the illness/dying trajectory may help improve the quality of the care they receive and thus contribute to an overall quality of death.[20]

Nursing staff exert an influence, with their own notions of good death, on the lives of dying people.[11,12,52] There may be limits to the socially accepted range of behaviors on the part of dying patients. Health care staff should be aware of their own value system and the risks of imposing them to the concept of good or bad death. For instance, one nurse, quoted by McNamara et al.,[12] said, "We have to take a step back and respect the different ways of dying." Discussions about the extent to which the ideal of a good death is reconcilable with the institutionalization, bureaucratization, and the predominance of mainstream medicine in hospices are open.[11,12,52]

Finally, some studies in the review define death and dying as a process and others as an event. The two perspectives imply different kinds of responses when dealing with people who have reached the end of their lives.[4,9,10,12,40,49,53,54] If dying is understood as a process, then active shaping of that process by the dying person and the nursing staff acquire greater importance. McNamara understands death as "a complex set of relations and preparations."[12] From this perspective, the good death is not a final event, but a series of social events. This definition also agrees with the fact that wishes and notions of death may change in the course of a protracted dying process. End-of-life support and care should continually respond in flexible and dynamic ways to the notions and wishes of the individual person.

The present study has a series of limitations to consider. First, our review relied on the notions that patients have about a good death and the factors that they consider important for achieving it. This approach tends to capture the individual's experiences and considerations but not necessarily what, in fact, helped them achieve a good death. Further research should take into account not only the patient's view but also the views of other participants (family, caregivers) and other objective variables (access to medicines, opportunities to receive help from significant others, the resolution of specific problems, the level of participation in decision-making, etc.) to identify predictors or determinants of a good death. This last approach would be indeed essential for clinical decision-making toward alleviation of suffering. And second, we only included studies written in English, which limits the possibilities to capture the notions of a good death in contexts were articles are published in other languages (e.g. Latin America, Asia).

Conclusion

Descriptions of good death from the patient's perspective in this systematic review were found to

agree in the following core elements: control of pain and symptoms, clear decision-making, feeling of closure, being seen and perceived as a person, preparation for death, and being still able to give something to others. Also, these elements were found to be shaped by aspects such as culture and society, financial issues, religion and spirituality, disease, age, and life circumstances. Both these core elements and aspects that shape the concept of a good death may be important and in the interest of dying patients and the people providing care and treatment.

At the same time, our review reveals how individual, unique, and different our notions of good death are. They vary not only within particular groups but are also dynamic in nature and undergo changes during the actual process of dying.[19,20,33,49] Thus, a careful follow-up of preferences regarding death and dying should be included along the disease trajectory to better adjust clinical decisions to patient's wishes, whenever possible.

Concepts of good death also provide legitimization for a form of social control over people who are dying. The socially accepted range of behaviors and decisions on the part of dying patients appears to be influenced and limited by normative images of good death.[11,50–52] As a consequence, all constructions of good death are and remain eclectic, highly individualized, or localized in special subgroups.

Findings on the notion of a good death suggest that health care workers are left with little alternative but to focus their attention on the respect for the individual rights and wishes of dying patients, on the basis of generalizable knowledge about the basic prerequisites for good death and, when doing so, to subject their own notions and expectations to critical examination. Even more important: when providing care and support for the dying, efforts should always be made to enquire into the particular societal conditions, problems, conflicts, and social inadequacies that prevent people from dying the way they want to. Dying is like living, to the extent that both are shaped and determined by social contingencies.[49] Rather than postulating some ideal image of dying that people are supposed to comply with in the last days of their life, the search should be for ideal conditions under which everyone can live and die with social security and free of existential worries.

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References

1. Heintz APM. Quality of dying. J Psychosom Obstet Gynaecol 2007;28:1–2.

2. Kehl KA. Moving toward peace: an analysis of the concept of a good death. Am J Hosp Palliat Care 2006;23:277–286.

3. Saunders Y, Ross JR, Riley J. Planning for a good death: responding to unexpected events. BMJ 2003;327:204–206; discussion 206-207.

4. Kübler-Ross E. On death and dying. New York: The Macmillan Company, 1969:25.

5. Mak JM, Clinton M. Promoting a good death: an agenda for outcomes research–a review of the literature. Nurs Ethics 1999;6:97–106.

6. O'Neil R. Defining "a good death". Appl Philos 1983;1:9–17.

7. Alan Kellehear S. Good death: the social life of the dying person. [Sydney]. University of New South Wales, 1986:32.

8. Payne SA, Langley-Evans A, Hillier R. Perceptions of a "good" death: a comparative study of the views of hospice staff and patients. Palliat Med 1996;10:307–312.

9. Bosek MSD, Lowry E, Lindeman DA, Burck JR, Gwyther LP. Promoting a good death for persons with dementia in nursing facilities: family caregivers' perspectives. JONAS Health L Ethics Regul 2003;5:34–41.

10. Steinhauser KE, Clipp EC, McNeilly M, Christakis NA, McIntyre LM, Tulsky JA. In search of a good death: observations of patients, families, and providers. Ann Intern Med 2000;132:825–832.

11. Hart B, Sainsbury P, Short S. Whose dying? A sociological critique of the "good death". Mortality 1998;3:65–77.

12. McNamara B, Waddell C, Colvin M. The institutionalization of the good death. Soc Sci Med 1994;39:1501–1508.

13. Broom A, Cavenagh J. Masculinity, moralities and being cared for: an exploration of experiences of living and dying in a hospice. Soc Sci Med 2010;71:869–876.

14. Granda-Cameron C, Houldin A. Concept analysis of good death in terminally ill patients. Am J Hosp Palliat Care 2012;29:632–639.

15. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006;3:77–101.

16. Hawker S, Payne S, Kerr C, Hardey M, Powell J. Appraising the evidence: reviewing disparate data systematically. Qual Health Res 2002;12:1284–1299.

17. Liberati A, Altman DG, Tetzlaff J, et al. The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate healthcare interventions: explanation and elaboration. BMJ 2009;339:b2700.

18. Akechi T, Miyashita M, Morita T, et al. Good death in elderly adults with cancer in Japan based on perspectives of the general population. J Am Geriatr Soc 2012;60:271–276.

19. Vig EK, Davenport NA, Pearlman RA. Good deaths, bad deaths, and preferences for the end of life: a qualitative study of geriatric outpatients. J Am Geriatr Soc 2002;50:1541–1548.

20. Leung K-K, Tsai J-S, Cheng S-Y, et al. Can a good death and quality of life be achieved for patients with terminal

cancer in a palliative care unit? J Palliat Med 2010;13:1433–1438.

21. Hirai K, Miyashita M, Morita T, Sanjo M, Uchitomi Y. Good death in Japanese cancer care: a qualitative study. J Pain Symptom Manage 2006;31:140–147.

22. Kikule E. A good death in Uganda: survey of needs for palliative care for terminally ill people in urban areas. BMJ 2003;327:192–194.

23. Pierson CM, Curtis JR, Patrick DL. A good death: a qualitative study of patients with advanced AIDS. AIDS Care 2002;14:587–598.

24. Hattori K, Ishida DN. Ethnographic study of a good death among elderly Japanese Americans. Nurs Health Sci 2012;14:488–494.

25. Ko E, Cho S, Perez RL, Yeo Y, Palomino H. Good and bad death: exploring the perspectives of older Mexican Americans. J Gerontol Soc Work 2013;56:6–25.

26. Gelo Florence LO, O'Connor B. Nursing home residents' perception of the "good death". J Religious Gerontol 1997;10:19–27.

27. Nosraty L, Jylhä M, Raittila T, Lumme-Sandt K. Perceptions by the oldest old of successful aging, Vitality 90+ Study. J Aging Stud 2015;32:50–58.

28. Ko E, Kwak J, Nelson-Becker H. What constitutes a good and bad death?: perspectives of homeless older adults. Death Stud 2015;39:422–432.

29. Payne S, Hillier R, Langley-Evans A, Roberts T. Impact of witnessing death on hospice patients. Soc Sci Med 1996;43:1785–1794.

30. Bullock K, McGraw SA, Blank K, Bradley EH. What matters to older African Americans facing end-of-life decisions? A focus group study. J Soc Work End Life Palliat Care 2005;1:3–19.

31. Willems DL, Hak A, Visser F, Van der Wal G. Thoughts of patients with advanced heart failure on dying. Palliat Med 2004;18:564–572.

32. Rietjens JAC, van der Heide A, Onwuteaka-Philipsen BD, van der Maas PJ, van der Wal G. Preferences of the Dutch general public for a good death and associations with attitudes towards end-of-life decision-making. Palliat Med 2006;20:685–692.

33. Tong E, McGraw SA, Dobihal E, Baggish R, Cherlin E, Bradley EH. What is a good death? Minority and nonminority perspectives. J Palliat Care 2003;19:168–175.

34. Mak MHJ. Awareness of dying: an experience of Chinese patients with terminal cancer. Omega (Westport) 2001;43:259–279.

35. Chacko R, Anand JR, Rajan A, John S, Jeyaseelan V. End-of-life care perspectives of patients and health professionals in an Indian health-care setting. Int J Palliat Nurs 2014;20:557–564.

36. Gott M, Small N, Barnes S, Payne S, Seamark D. Older people's views of a good death in heart failure: implications for palliative care provision. Soc Sci Med 2008;67:1113–1121.

37. Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. JAMA 2000;284:2476–2482.

38. Hughes T, Schumacher M, Jacobs-Lawson JM, Arnold S. Confronting death: perceptions of a good death in adults with lung cancer. Am J Hosp Palliat Care 2008;25:39–44.

39. Reinke LF, Uman J, Udris EM, Moss BR, Au DH. Preferences for death and dying among veterans with chronic obstructive pulmonary disease. Am J Hosp Palliat Care 2013;30:768–772.

40. Singer PA, Martin DK, Kelner M. Quality end-of-life care: patients' perspectives. JAMA 1999;281:163–168.

41. Haishan H, Hongjuan L, Tieying Z, Xuemei P. Preference of Chinese general public and healthcare providers for a good death. Nurs Ethics 2015;22:217–227.

42. Hoebel EA. Anthropology: the study of man, 4th ed. New York: McGraw-Hill, 1972:37.

43. Seale C. Social and ethical aspects of euthanasia: a review. Prog Palliat Care 1997;5:141–146.

44. Grant E, Murray SA, Grant A, Brown J. A good death in rural Kenya? Listening to Meru patients and their families talk about care needs at the end of life. J Palliat Care 2003;19:159–167.

45. Toscani F, Borreani C, Boeri P, Miccinesi G. Life at the end of life: beliefs about individual life after death and "good death" models - a qualitative study. Health Qual Life Outcomes 2003;1:65.

46. Kastbom L, Milberg A, Karlsson M. A good death from the perspective of palliative cancer patients. Support Care Cancer 2017;25:933–939.

47. Teno JM, Weitzen S, Fennell ML, Mor V. Dying trajectory in the last year of life: does cancer trajectory fit other diseases? J Palliat Med 2001;4:457–464.

48. Vig EK, Pearlman RA. Good and bad dying from the perspective of terminally ill men. Arch Intern Med 2004;164:977–981.

49. Meier EA, Gallegos JV, Thomas LPM, Depp CA, Irwin SA, Jeste DV. Defining a good death (successful dying): literature review and a call for research and public dialogue. Am J Geriatr Psychiatry 2016;24:261–271.

50. Zimmermann C. Acceptance of dying: a discourse analysis of palliative care literature. Soc Sci Med 2012;75:217–224.

51. Zimmermann C, Rodin G. The denial of death thesis: sociological critique and implications for palliative care. Palliat Med 2004;18:121–128.

52. Semino E, Demjén Z, Koller V. 'Good' and 'bad' deaths: narratives and professional identities in interviews with hospice managers. Discourse Stud 2014;16:667–685.

53. McNamara B. Good enough death: autonomy and choice in Australian palliative care. Soc Sci Med 2004;58:929–938.

54. Emanuel EJ, Emanuel LL. The promise of a good death. Lancet 1998;351(Suppl 2):SII21–SII29.