

Defining a Good Death (Successful Dying): Literature Review and a Call for Research and Public Dialogue

Emily A. Meier, Ph.D., Jarred V. Gallegos, M.A., Lori P. Montross-Thomas, Ph.D., Colin A. Depp, Ph.D., Scott A. Irwin, M.D., Ph.D., Dilip V. Jeste, M.D.

There is little agreement about what constitutes good death or successful dying. The authors conducted a literature search for published, English-language, peer-reviewed reports of qualitative and quantitative studies that provided a definition of a good death. Stakeholders in these articles included patients, prebereaved and bereaved family members, and healthcare providers (HCPs). Definitions found were categorized into core themes and subthemes, and the frequency of each theme was determined by stakeholder (patients, family, HCPs) perspectives. Thirty-six studies met eligibility criteria, with 50% of patient perspective articles including individuals over age 60 years. We identified 11 core themes of good death: preferences for a specific dying process, pain-free status, religiosity/spirituality, emotional well-being, life completion, treatment preferences, dignity, family, quality of life, relationship with HCP, and other. The top three themes across all stakeholder groups were preferences for dying process (94% of reports), pain-free status (81%), and emotional well-being (64%). However, some discrepancies among the respondent groups were noted in the core themes: Family perspectives included life completion (80%), quality of life (70%), dignity (70%), and presence of family (70%) more frequently than did patient perspectives regarding those items (35%–55% each). In contrast, religiosity/spirituality was reported somewhat more often in patient perspectives (65%) than in family perspectives (50%). Taking into account the limitations of the literature, further research is needed on the impact of divergent perspectives on end-of-life care. Dialogues among the stakeholders for each individual must occur to ensure a good death from the most critical viewpoint—the patient's. (Am J Geriatr Psychiatry 2016; 24:261–271)

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Received May 12, 2015; revised December 18, 2015; accepted January 19, 2016. From the Department of Psychiatry (EAM, JVG, LPMT, CAD, SAI, DVJ); Sam and Rose Stein Institute for Research on Aging (EAM, JVG, LPMT, CAD, DVJ), Moores Cancer Center, Psychiatry & Psychosocial Services, La Jolla, CA; Patient & Family Support Services (EAM, JVG, LPMT, SAI); and Department of Family Medicine and Public Health (LPMT), University of California, San Diego, La Jolla, CA. Send correspondence and reprint requests to Dr Dilip V. Jeste, Stein Institute for Research on Aging, University of California, San Diego, 9500 Gilman Drive #0664, La Jolla, CA 92093-0664. e-mail: djeste@ucsd.edu

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INTRODUCTION

"The truth is, once you learn how to die, you learn how to live."

—Mitch Albom, *Tuesdays with Morrie*¹

Considerable lay literature describes positive approaches to dying. For example, in "Tuesdays with Morrie"¹ Mitch Albom visits with his former Sociology professor, Morrie Schwartz, who provides lessons on acceptance, communication, and love in the midst of his own dying process. Similarly, Viktor Frankl's "Man's Search for Meaning"² describes experiences in a Nazi concentration camp that led to finding meaning during times of suffering and death. Also, in "The Last Lecture,"³ Randy Pausch discusses, after being diagnosed with advanced pancreatic cancer, how to truly live and embrace every moment because "time is all you have. . . and you may find one day that you have less than you think." Finally, in his commencement speech at Stanford University, Steve Jobs,⁴ after a recent diagnosis of cancer, called death "very likely the single best invention of life" and described focusing on what was most important and meaningful to him as he confronted death. These literary examples illustrate various constructs of a good death or "dying well."⁵

Within the healthcare community and, more specifically, in hospice and palliative care, there has been some discussion of the concept of a good death.^{6,7} This concept arose from the hospice movement and has been described as a multifaceted and individualized experience.⁸ According to an Institute of Medicine report published 19 years ago, a good death is one that is "free from avoidable distress and suffering for patient, family, and caregivers, in general accord with the patient's and family's wishes, and reasonably consistent with clinical, cultural, and ethical standards."⁹ This concept has received some critique in several disciplines, including medicine, psychology, theology, sociology, and anthropology.⁶ In particular, concern has been raised that there is no such thing as an external criterion of a good death and that it is more dependent on the perspectives of the dying individual.¹⁰

In this article we use the terms "good death" or "successful dying." Is successful dying an extension of successful aging? Research on successful aging has grown considerably in recent years,¹¹ however, there

is little agreement as to what specifically constitutes a good death or successful dying despite many reviews examining the concept of a good death from sociological and philosophical viewpoints¹²⁻¹⁸ as well as research examining the quality of death and dying, which is defined as "the degree to which a person's preferences for dying and the moment of death agree with observations of how the person actually died, as reported by others."¹⁹⁻²³ However, far fewer studies have specifically defined, rather than conceptualized, what a good death is according to patients, family members, and healthcare providers (HCPs). The goal of this article is to review the literature that examined the definitions of a good death from the perspectives of such patients, their family members, and HCPs.

By examining the perspectives regarding a good death contrasted across different stakeholders, our aim is to identify potential unmet needs of patients and to suggest an approach to achieve a multifaceted and individualized experience for patients approaching death. Because a dearth of literature examines this important topic, our review is limited by the quantity and quality of studies available to evaluate. To our knowledge, no review to date has examined and compiled definitions of good death as defined explicitly by patients, family members, and HCPs or examined the differences among these stakeholders' viewpoints. This is an area of considerable public health significance and impact on the patients, their families, and the overall healthcare system. The present article is also intended to serve as a call to action to highlight the need for more patient-focused research and open public dialogues on successful dying.

METHODS

Data Sources

We searched PubMed and PsycINFO databases from inception through November 2015 using the following terms: (definition of) AND (good OR successful OR peaceful) AND (Death OR Dying); (good) OR (successful OR peaceful) AND ("Death and Dying"); ("Terminal Care"[Mesh] AND "Quality of Life"[Mesh] AND "Attitude to Death"[Mesh]); ("Terminal Care"[Mesh]) AND "Attitude to Death"[Mesh] AND (define OR definition); good death and dignity; good

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