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Invited Perspective

Is Successful Dying or Good Death an Oxymoron?

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“Remembering that I’ll be dead soon is the most important tool I’ve ever encountered to help me make the big choices in life.”

—Steve Jobs (1955-2011)¹

Awareness of one’s own mortality is one of the uniquely human attributes. In evolutionary terms, it is believed to have arisen approximately 150,000 years ago.² Death anxiety may be seen in children as young as age 5 years, becomes prevalent at ages 20–40 years, reaches its peak at 41–64 years, and, interestingly, begins to fall after age 65.^{3,4} Kübler-Ross and Kessler⁵ described five stages of dying: denial and isolation, anger, bargaining, depression, and finally acceptance—that is, realization that death is inevitable. Denial of the certainty of one’s own death is common in the youth, whereas the reaction in older age is markedly different. According to Mather and Carstensen’s⁶ socioemotional selectivity theory, as the time horizon shrinks with age,

people become increasingly selective, investing greater resources in emotionally meaningful goals and activities, with a relative preference for positive over negative information in attention and memory.

The Institute of Medicine⁷ has defined “good death” as one that is free from avoidable distress and suffering for the patient, family, and caregivers, and is in general accord with the patient’s and family’s wishes, and reasonably consistent with clinical, cultural, and ethical standards. However, good death or successful dying is rarely a topic of professional or social discussion. Certainly, ours is a death-phobic culture, which, in large part, is a result of the realization that we have little control over death. The United States has been a nation of hope and “can-do” attitude. We take justified pride in how the country has coped with and overcome adversities of various kinds, and still succeed. However, we will never be able to prevent death, although we are doing everything possible to delay it as much as we can. This sense of helplessness and lack of power to conquer death is one of the main reasons for our reluctance to

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discuss it. There are also more personal reasons. Family members may not want to talk about death with their dying loved one for the fear of making her or him feel depressed, although in reality, that is rarely the case. Sometimes, there is even a family superstition that talking about death may hasten the person's death.

Systematic attempts at empirical research on what constitutes a good death only began approximately 25 years ago. In a previous study published in this journal,⁸ our group reported the results of a literature review of English-language peer-reviewed articles on qualitative and quantitative studies that provided a definition of a good death. Stakeholders included patients, prebereaved and bereaved family members, and healthcare providers. Six of these studies originated from the United States, four from the United Kingdom, three from Japan, two each from the Netherlands and Thailand, and one each from Iran, Canada, Saudi Arabia, South Korea, and Sweden. Based on the definitions published, we identified 11 core themes (and 34 subthemes) of good death: preferences for a specific dying process (e.g., dying during sleep or at home), pain-free status, religiosity/spirituality, emotional well-being, life completion, treatment preferences, dignity, family, quality of life, relationship with the healthcare provider, and others. 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%). There were some differences in the core themes among the respondent groups. For example, family perspectives included life completion (80%), quality of life (70%), dignity (70%), and presence of family (70%) more often than did patient perspectives regarding those items (35%–55% each). In contrast, religiosity/spirituality was reported more frequently in patient perspectives (65%) than in family perspectives (50%).

In the study in this issue by Vanderveken et al.,⁹ the investigators translated the 11 core themes and 34 subthemes from the Meier et al.⁸ article, and developed a questionnaire for four groups of subjects in a Belgian setting. The investigators queried 67 nurses, 57 general practitioners, 16 patients, and 8 close relatives from the Belgian Palliative Care Network of local quality groups, nursing homes, and groups of homecare nurses. The study participants scored their answers on a symmetric Likert scale of 0–10,

presented as a visual analog scale. All the groups were unanimous in stating that a pain-free death was a critical attribute of a good death, and also agreed on several other subthemes: support of family, respect for the patient as an individual, being able to say goodbye, and euthanasia in cases of unbearable suffering. Interestingly, religiosity and spirituality were considered less important compared with other themes by all parties. The authors suggested that a possible explanation for this finding may be related to the fact that fewer than 10% of the Belgians consider themselves as practicing Catholics, based on a recent survey. There were some significant differences between nurses' and general practitioners' ratings. Nurses found the following subthemes more critical than general practitioners did: dying during sleep, the patient is not a burden to their close relatives, life well-lived, faith, all available treatments were used, the patient's last phase of life can be lived in a usual and meaningful manner, he or she can talk to their healthcare provider about spiritual beliefs or fears in relation to dying, the presence of pets, and the cost of healthcare. The authors point out that these differences between nurses' and general practitioners' perspectives deserve attention, because patients and family members expect that healthcare providers would work together as a team.

There are acknowledged limitations to this study, such as limited amount of data on patients and close relatives. Additionally, sample sizes of the patient and family member groups were small, and the results may not generalize to the Belgian population as a whole. However, the investigators should be complimented on undertaking a comparison of the Belgian group's perspectives with those of an international group of studies⁸ using the themes and subthemes reported to be commonly associated with good death in the latter group. Collectively, the findings from Belgium versus other countries raise interesting questions regarding relevant but understudied issues relating to cultural variances regarding the concept of good death.

Examples of such differences pertain to societal attitudes toward suicide and euthanasia. Although suicide is discouraged, and in some countries deemed anti-religious and illegal (i.e., suicide attempts are legally punishable), in certain cultures it is encouraged under specific circumstances. Sad examples of the latter are women who used to commit suicide

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after being widowed.¹⁰ Recent instances of suicide bombers and other terrorists who seek to reach martyrdom in their specific religious sects through violent suicides¹¹ are also illustrations of differing, and grossly dysfunctional, beliefs surrounding the concept of a good death. Euthanasia is a controversial topic as well. European countries like Belgium and the Netherlands legalized euthanasia years ago. In the United States, there are considerable differences in the policies and laws of different states. California now allows physician-assisted suicide, but only under severely restricted circumstances. Another hotly debated topic pertains to maintaining a brain-dead person on life support for long time periods when there is no clear advanced directive.

Not infrequently, sociocultural attitudes toward good death change over time. Therefore, increasing availability of palliative care and hospice services has led to a shift away from continuing curative treatments in people with terminal illnesses. Another case in point is the ongoing controversy over painkillers, specifically opioids. The societal and medical pendulum tends to swing from allowing their use for any level of pain to banning opiates outright. A rational balance between those two extreme positions is essential.

The article by Vanderveken et al.⁹ reinforces the need for well-designed studies to qualitatively and quantitatively examine the concept of successful dying from multiple stakeholders' perspectives—especially those of the patients themselves. It is also important to investigate how addressing the core themes of good death, both convergent and discrepant among stakeholders, may influence patient-related outcomes.

It is crucial that the healthcare system expand end-of-life care beyond treating only the patient's physical symptoms and pain, and more closely address psychological, social, and religious/spiritual themes for both patients and families. Patients view the end of life as encompassing not only the physical components of death but also psychosocial and spiritual concerns. There are both negative and positive psychological characteristics that are seen at the end of life. On the negative side, loneliness becomes more severe in some older adults.¹² However, wisdom tends to increase with aging in many others. Qualitative interviews of people in hospice care showed a dynamic balance of actively accepting their current

situation while simultaneously striving for galvanized growth.¹³ That delicate tension seemed to motivate the patients to live each day fully, yet consciously plan their final legacy.

Today, the healthcare system has made personalized medicine with the goal of promoting patients' well-being as its main focus. This should include personalized successful dying (good death) as a part of the process. If we make the quality of life and a feeling of dying successfully the primary aim of end-of-life healthcare, good death will no longer be considered an oxymoron. Although death should never become a life goal, a good death can be a desirable outcome in later life or with terminal illnesses.

The way to change the cultural attitudes of the society and the healthcare system is through education. There should be an emphasis on educating the population as a whole as well as the involved professionals including physicians, nurses, social workers, and other clinical care providers. For example, medical students, residents, and full-fledged physicians should receive training in talking about death. They will then be in a better position to educate their patients and the families. The family will be ready to embark on this path once they know that 1) the dying person is likely to feel relief at the end of this discussion; 2) such a discussion is in the interests of both the patient and the family; and 3) it may lead to making concrete plans for ensuring a successful dying process for the individual (e.g., dying in hospital versus dying at home, use of pain killers, and others) as well as for continuing the dying person's legacy after his or her death.

There is a critical need for professional and lay communities to accelerate open dialogues regarding death and dying. The discrepancies among patient, family member, and healthcare provider perspectives on successful dying indicate a need for such a dialogue among all stakeholders involved in the care of each individual patient. Furthermore, as a society, we must begin to address the question of how people want to die and what they actually need and want at the end of their lives, so that more people can have a good death, reaching their full potential with dignity and whole-person well-being. Every older adult deserves a good death for her or his own sake and for the sake of the family, and the society and the healthcare system must strive to make that goal a reality.

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