# Dying with dignity: The good patient versus the good death

Kathryn Proulx, RN, MS, CS
Cynthia Jacelon, PhD, RN, CRRN-A

## Abstract

*Death is a unique experience for each human being, yet there is tremendous societal pressure on a dying person to be a "good patient" while trying to experience the "good death." These pressures shape patient, caregiver, and family choices in end-of-life situations.*

*The purpose of this literature review was twofold: first, to develop an understanding of "dying with dignity" to enhance the end-of-life care received by dying patients, and second, to contribute to a concept analysis of dignity to improve the clarity and consistency of future research related to dignity in aging individuals. Articles pertaining to dying with dignity from the disciplines of nursing, medicine, ethics, psychology, and sociology were reviewed using a matrix method.*[1]

*A dichotomy surrounding dying with dignity emerged from this review. The definition of dignity in dying identifies not only an intrinsic, unconditional quality of human worth, but also the external qualities of physical comfort, autonomy, meaningfulness, usefulness, preparedness, and interpersonal connection. For many elderly individuals, death is a process, rather than a moment in time, resting on a need for balance between the technology of science and the transcendence of spirituality.*

*Key words: end-of-life care, hospice, quality of life, death with dignity*

## Introduction

The concept of "dying with dignity" may be a theoretical ideal that detracts from our understanding of the process of dying as unique for each individual. It is clear that concepts such as "dying with dignity," the "good death," and the "good patient" are highly subjective and cannot be captured quantitatively.[2-6] Dignity itself rests in a dichotomy in that there is an internal and an external component. The internal aspect of dignity recognizes that all persons hold inherent human worth, which is uniquely expressed by their life stories.[7-9] The external aspects of dignity vary with what matters to a particular individual and includes such values as physical comfort, freedom from pain, autonomy, meaningfulness, preparedness, spirituality, interpersonal connectedness, and dying at home.[5,10-14] Since no two people share the same life story and personal values, it is not possible to develop a universal, best way to die that honors and upholds dignity for all.

In reviewing the literature, the authors identified several dichotomies surrounding the experience of dying in the American culture. For example, euthanasia is viewed as both an immoral crime and an act of moral compassion.[15-21] Dying is conceptualized not only as the single moment in time when life ends, but also a transitional process, the onset of which is rarely clear.[3,4,8] Often, healthcare providers and families of dying patients are reluctant to accept that a dying individual's priority may be spiritual guidance, rather than technologically advanced medical care.[3-5,8,14,16,22] Some Americans seem to expect elderly dying patients to defer to the recommendations of their families and healthcare providers, sacrificing their own personal autonomy in controlling external sources of dignity.[2-4,8,12,14,21,23-25] In an attempt to explore the questions raised by these dichotomies, the authors begin with an overview of the Oregon Death with Dignity Act. From there the concept of the "good patient," as found in the literature, is presented. Subsequently, the notion of the "good death" is explored including the contrasting perspectives of physicians and nurses, as elucidated by recent research studies. The authors conclude with suggestions for future research that may aid us in our continued efforts to

---

*Kathryn Proulx, RN, MS, CS, University of Massachusetts, Amherst, Massachusetts.*

*Cynthia Jacelon, PhD, RN, CRRN-A, University of Massachusetts, Amherst, Massachusetts.*

understand the biological, psychological, sociological, and philosophical/spiritual aspects of this complex human phenomenon.

## Methods

This review of the literature on dying with dignity was part of the theoretical phase of a concept analysis of dignity. The selected 26 articles spanned the years between 1985 to 2002 and were reviewed using a matrix method.[1] All of the articles were chronologically evaluated on a structured spreadsheet (matrix) that included 14 topics: author, title of article, journal identification, year of publication, purpose, source and type of evidence, theoretical framework, methodological design, definition of dignity, defining attributes, antecedents, consequences, empirical referents, and miscellaneous notes. Following this abstracting process and using the created matrix as a reference, a synthesis and critical analysis of the articles was undertaken. The search included the electronic databases of OVID, MEDLINE, PubMed, CINAHL, and PsychINFO. Research and theoretical articles originated from the disciplines of nursing, medicine, sociology, law, ethics, and psychology.

## Oregon Death with Dignity Act

The Oregon Death with Dignity Act can be viewed from two dichotomous perspectives. On one hand, it opens up choice to dying patients who might preserve their dignity by arranging the timing of death before they become totally incapacitated.[18-20] On the other hand, it risks capitulation to societal pressures to create "good patients," who seek not to burden others nor to drain economic and medical resources that could be put to better use in the service of individuals who are economically productive.[15,16,20,21]

The law arose from a citizen-initiated ballot that asked the question: "Shall law allow terminally ill, adult, Oregon patients voluntary informed choice to obtain a physician's prescription for drugs to end life?" The referendum originally passed by a 2 percent margin in 1994, but was delayed by legal injunction until 1997.[20] Under the Oregon Death With Dignity Act, a competent adult citizen of the state of Oregon, diagnosed with a terminal illness that is expected to result in death within six months, may obtain and self-administer a lethal dose of medication expressly prescribed by a physician for the purpose of ending that person's life.[15,20,21]

This law provides dying patients with full autonomy to choose to die while still in full control of cognitive and bodily functions and before they become a burden to others, thus preventing possibly unbearable pain and financial hardship. To some, death is a natural part of existence, and the proper time to die with dignity is when one's quality of life shifts from positive to negative.[16] Loss of dignity may be one aspect of a common pathway leading some dying patients to lose their will to live.[10,11] One of the primary reasons given by dying patients seeking hastened death was hopelessness and a belief in the pointlessness of living longer.[10,11,15,19,20] For those patients whose dignity is primarily experienced through independence and autonomy, euthanasia may be a welcome option. Therefore, in response to the American healthcare system's inability to find ways to uphold individual patients' dignity during their transition to death, more patients may choose euthanasia.[10,11,22]

Concerns regarding implementation of laws such as the Oregon Death with Dignity Act include the fear that societal pressures against wasting limited resources on the dying will result in unethical increases in the numbers of assisted suicide.[15,20,21] In a theoretical examination of the proper time to die,[16] it was discovered that, at a societal level, prolonging the negative quality of life of some people can only be possible by consuming the positive life of other productive members of society. Given this perspective, it is possible that the already vulnerable and frail may have to justify their existence and may feel a duty to die so as not to burden society.[15] This situation would constitute a loss of the inalienable right to life, serving as a form of discrimination against persons with life-threatening illness and wielding a blow to a central value of human dignity in America's current legal system.[15,21]

## The good patient

If the good patient is one who is passively compliant with societal norms, family wishes, or health providers' recommendations, then it is likely that the good patient may lose the opportunity for the experience of dying with dignity. Philosophically, Frankl[7] speaks of dignity as the unconditional value inherent within each and every human being. Several authors assert that dying with dignity rests on the fundamental knowledge that intimates, caregivers, and strangers perceive the dying person to be as fully human as they are.[5,7,8-13,22] Frankl[7] further believes that life has the potential to be meaningful under all conditions: work, creativity, joy, suffering, and death. "Morally and spiritually this insistent claim to dignity points to something in humans that is genuinely transcendent, something that reflects our freedom to call into question all social roles, to say out loud that we are more than our frailty, role performance, or buying power."[9]

As healthcare providers in the American culture, we may have some general beliefs about what dying with dignity might entail, but we cannot know what it means for any given individual unless we take the time to ask, listen, and understand. In order to experience meaning and dignity in death, dying patients must have a voice to choose the circumstances of their death according to what matters most to them. If dying patients are to feel comfortable voicing their needs and preferences, our culture and healthcare system must value the reality of dignity and meaning inherent in the process of dying, thereby assuring all dying patients of their goodness and worth.

## The good death

The notion of a "good death" in modern American culture includes such concepts as "death with dignity," peacefulness, physical comfort, autonomy, preparedness, connectedness with loved ones, awareness, discretion, meaning, and acceptance.[5,6,8-11,22,23] Moreover, the good death ideology is based on values experienced as societal pressures derived from current social conditions and interests.[23] Thirty years ago, cultural expectations for healthcare professionals and family in caring for the dying entailed waiting for death.[3] In contrast to this not so distant past, currently, when an old and frail person is in distress, the immediate cultural understanding of the situation is through a medical lens that aims to cure and sustain life.[3] The transitional process between life and death is not well served by medical technology in the US.[4] Because of the availability and reverence for medical technology in American healthcare, not knowing when dying begins and when death is likely to occur commonly results in the prescribing of active, life-prolonging treatments right up until death.[4] As a result of this uncertainty about the timing of death, both families and healthcare professionals are faced with many more active moral conflicts and decisions. Despite agreement that autonomy,[3,4,10-12,18,24] self-control,[10-12,18,22,25] comfort,[3-6,10-12,22] privacy,[5,10-12,22] and honest communication[5,10-13,20] are essential components of a dignified and good death, the physician may recommend continued curative treatment of a dying patient to avoid criticism by colleagues, and the family may agree to another round of treatment to avoid blame or guilt.[8] Although advanced directives were developed to reduce uncertainty in end-of-life care, African Americans prefer to discuss end-of-life issues face-to-face with family members, rather than relying on a written legal document.[25] Sensitivity to cultural differences in values towards sustaining dignity in end-of-life care is essential.

Despite these realities, there is growing support for the idea that human dignity is largely lost when the life of a terminally ill person is prolonged by technology.[2-4,6,12,13,16,24] These authors suggest that, increasingly, hospitals and healthcare providers are urged to allow dying patients to maintain a sense of autonomy and control over their lives, with the freedom to choose a style of dying. In exploring the meaning of dignity in palliative care, Gamlin[12] concluded that the experience of dignity might change across different stages of illness, making effective communication between patients, family, and healthcare providers essential. Many patients are preferring to die in their own homes, surrounded by family, with a spiritual rather than a curative focus.[5,8,14,16,22] Dying with dignity, or the "good death," involves having one's human value and worth acknowledged,[7-9,22] being cared for with respect and empathy,[5,8-11,13,20,22] having a voice regarding one's process of dying,[3,4,8,10-14,20,23,24,25] minimizing physical and emotional suffering,[3-6,10-13,17,20] safeguarding one's privacy,[10-13] emotionally connecting with others,[8,9,22] resolving personal affairs,[5,10,11,22] and having access to spiritually resonant sources of support.[5,10,11,14,16,22] Since dying persons deprived of their dignity are more apt to lose their will to live and thereby seek out the option of assisted suicide, several authors emphasized the necessity of honoring the dignity of individuals in the process of dying.[10,11,19,20,26]

## Physician perspective

Interestingly, several differences in philosophy and approach regarding promoting the good death by physicians[3,4,6,17,21,27] and nurses[2,6,12-14,20,25] were identified in the articles reviewed. In 1993, Miyaji[27] interviewed 32 Harvard physicians about truth-telling in the care of dying patients. Using the methods of Glaser and Strauss, Miyaji analyzed and categorized the interview data into a professional discursive framework. The analysis revealed that how doctors control information is closely related to how they handle other aspects of clinical practice, such as their own emotional coping, institutional and legal concerns, and power relationships among patients, doctors, and other caregivers.

The controversy over truth-telling in medical practice has been historically framed in terms of the dichotomy between the physician's paternalism and the patient's autonomy. In other words, is the physician's role one of acting for the patient's "benefit" (knowing what is best), or is it a contractual agreement between two equals? Although a shift in patients' rights occurred in the 1970s, physicians today still believe that knowledge is power.[27] If patients have more information, they have more control over their body and life, and thus are more autonomous. The physician's perception of what the patient needs to know is often influenced by his or her need to maintain trust and avoid legal problems. A physician is more likely to be active in patient communications regarding treatment than prognosis. If a patient doesn't ask, the physician will often assume the patient doesn't want to know.[27] Such factors as patient age, gender, education, and occupation can influence the amount of information a physician will provide. When a physician withholds information to sustain patient hope, this hope is largely related to the physician's own philosophy about life, views of his role as a physician, and his own hopes.[27] Frequently, the behavior a physician might perceive to be altruistic has paternalistic qualities.

In another study of physicians, Ganzini et al.[17] used a self-administered questionnaire to examine Oregon physicians' attitudes toward and practices regarding care of dying patients following the implementation of the Oregon Death with Dignity Act. Of the 2,641 Oregon physicians who completed questionnaires, 38 percent reported that they found caring for dying patients emotionally unsatisfying, while 46 percent reported that they found caring for the dying intellectually unsatisfying. These responses suggest that some aspects of caring for dying patients may be uncomfortable for many physicians.

## Nursing perspective

In contrast with the physician role in caring for dying patients described above, Martocchio[13] proposes that the role of nursing in end-of-life care is one of listening to what matters to the dying patient, thus honoring the individual's dignity. Martocchio claims that sources of dignity for the dying vary, but commonly include a sense of autonomy, connectedness with loved ones and caregivers, aesthetics, and spirituality. Furthermore, she believes that fitting the patient's agenda for dying with dignity with the reality of life from the dying person's perspective is paramount to creating an environment for personal achievement and the conviction that life has meaning even during the last days or hours.

Similarly, Jansson, Norberg, Sandman, and Astrom[2] found that nurses try to respect and promote autonomy in dying patients. In this phenomenological study, the researchers found that experienced oncology and geriatric nurse participants (n = 40) listened, respected patient wishes, and gathered relevant information from family, friends, and physicians in order to help patients make informed decisions. In this study nurses spoke of their aims "to put themselves in their patients' shoes."[2] From that vantage point, they frequently strove to advocate, support, protect, and defend patients from an "adversary," which was sometimes identified as a paternalistic physician or a rigid ward routine. Patients with dementia posed a particular concern for the geriatric nurses in this study. The nurses expressed fear of projecting their own wishes onto the demented patients in a paternalistic manner. In contrast to physicians' comfort with paternalism,[27] nurses experienced fear and guilt.[2]

It is important to note that in the study by Jansson and colleagues,[2] the majority of cancer nurses did not support euthanasia and would not participate if it were against their ethics. Since the American Nurses Association does not support euthanasia,[6,20] unlike physicians, nurses are protected from having to take an active role in this process in Oregon.[8,15,18-20,23] Tuten[20] observes that nurses providing end-of-life care generally appear comfortable with the widespread practices of passive euthanasia, such as withholding food or water or discontinuing a ventilator to avoid prolonging suffering. She also suggests that the practice of prescribing pain medications to relieve suffering at doses sufficient to end a patient's life is more acceptable to many nurses than the prescribing of drugs to directly precipitate death. However, the issues surrounding euthanasia and dying with dignity are not black and white. If nurses are going to fulfill their notions of the nurse-patient relationship and truly walk in their dying patients shoes, deeper professional exploration and personal soul-searching becomes crucial.

## Discussion and implications for future research

The intrinsic, philosophical view of dying with dignity reflects unconditional human worth.[7,9] This form of dignity is synonymous with an individual's sense of identity and honors the being of each person. It emanates from the realm of spiritual transcendence[5,7-9,11,13,14,22] and is demonstrated by the capacity for giving and receiving compassion and love,[5,7-9,22] essential elements in the process of dying.

In addition, external sources of dignity may enhance or detract from an individual's inherent sense of dignity. For the dying person, these external sources of dignity tend to include autonomy, control, privacy, freedom from pain, connection with loved ones, spiritual resources, and preparing for death.[5,6,10-13] It is in this realm of external sources of dignity that healthcare professionals can have the greatest impact. Open, honest communication among healthcare professionals, patients, and their families is vital in honoring the dignity of the dying. Listening for what matters to each individual patient while planning a way to create meaning and purpose in each person's last days is fundamental to preserving dying with dignity. There is no standard dignified death. The realm of possibilities is as endless as there are persons. Studies in the literature seem to indicate that the perceived role of nursing is highly congruent with the needs of the dying.[2,12-14,20] This would be an important area for further exploration and study.

Currently, in the United States, euthanasia is legal only in the state of Oregon. However, it seems imperative that, as a nation, we develop a multidisciplinary, impartial method for monitoring the implementation of the Death with Dignity Act in order to assess and improve on the current procedures and to protect the terminally ill from abuse.[21] Oregon's statistics indicate that only a modest number of patients have requested euthanasia.[20,26] Although clearly not suitable for all, in the future, euthanasia may become a choice for increasing numbers of dying patients. Further studies of the impact of the implementation of the Death with Dignity Act in Oregon on both patients and healthcare providers will provide needed data in this area.

As healthcare providers, we find ourselves caught in the middle of many dichotomies in the area of dying with dignity. When we are fully conscious of our personal beliefs and values surrounding the process of dying and death, we can greatly enhance our emotional availability as we care for dying patients. We need to talk about our dilemma of caring for patients in life and through the process of dying, choosing words that reflect and encompass a pluralistic range of understanding, meaning, and dignity. Reciprocally, as we respect the dignity of our dying patients, our own personal dignity will be enhanced, allowing us to continue providing care and comfort to our patients and their loved ones with satisfaction.

Death, being a central existential concern of mankind, raises anxiety of such magnitude that a considerable portion of life energy is consumed by its denial.[28] In a youth-oriented, cure-focused American culture that reveres the wonders of modern, medical technology, death can be perceived as failure. We can easily relegate death as one of those unmentionable life problems. Although hospice and palliative care programs support the dying process, administrators of hospital and long-term care settings continue to struggle with the moral issue of ending technological interventions. Ongoing communication within and between healthcare disciplines is necessary to rationally and compassionately care for the terminally ill. As a culture, Americans must continue to move toward acceptance of the notion that the terminal stages of life are part of a process leading naturally and inevitably to death. If our culture cannot consciously acknowledge the meaning and purpose of life and death, dying patients may continue to be subjected to invasive treatments, which ultimately detract from their dignity and prolong suffering. Openness, honesty, time, and courage are needed to deal with death in a way that honors the dying person's life.

## Acknowledgment

*This study was funded in part by a federal grant administered by the University of Pennsylvania, SNRI. Oral presentation of the manuscript was given at Beta Zeta Chapter Sigma Theta Tau International research day on 4/10/02 in Holyoke, Massachusetts.*

## References

1. Garrard J: *Health Sciences Literature Review Made Easy: The Matrix Method.* Gaithersburg: Aspen Publishers, 1999.
2. Jansson L, Norberg A, Sandman PO: When the severely ill elderly patient refuses food: Ethical reasoning among nurses. *Int J of Nurs Stud.* 1995; 32(1): 68-78.
3. Kaufman S: Intensive care, old age, and the problem of death in America. *Gerontologist.* 1998; 38(6): 715-725.
4. Kaufman S: The clash of meanings: Medical narrative and biographical story at life's end. *Generations.* Winter 1999-2000; 23(4): 77-82.
5. Steinhauser KE, Clipp EC, McNeilly M, et al.: In search of a good death: observations of patients, families, and providers. *Ann Inter Med.* 2000; 132(10): 825-832.
6. Turner K, Chye R, Aggarwal G, et al.: Dignity in dying: a preliminary study of patients in the last three days of life. *J of Palliat Care.* 1996; 12(2): 7-13.
7. Frankl VE: Facing the transitoriness of human existence. *Generations.* 1990; 15(4): 7-10.
8. Holstein M: Reflections on death and dying. *Acad Med.* 1997; 27(10): 848-855.
9. Moody H: Why dignity in old age matters. *J Gerontol Soc Work.* 1998; 29(2/3): 13-38.
10. Chochinov HM: Dignity-conserving care—a new model for palliative care: helping the patient feel valued. *JAMA.* 2002; 287(17): 2253-2260.
11. Chochinov HM, Hack T, McClement S, et al.: Dignity in the terminally ill: a developing empirical model. *Soc Sci Med.* 2002; 54(3): 433-443.
12. Gamlin R: An exploration of the meaning of dignity in palliative care. *Eur J Palliat Care.* 1998; 5(6): 187-190.
13. Martocchio BC: Agendas for quality of life. *Hospice J.* 1986; 2(1): 11-21.
14. Tang ST: Meanings of dying at home for Chinese patients in Taiwan with terminal cancer: a literature review. *Cancer Nurs.* 2000; 23(5): 367-370.
15. Avila D: Assisted suicide and the inalienable right to life. *Issues Law Med.* 2000; 16(2): 111-141.
16. Dimoliatis I: Lord, now you are letting your servant depart in peace: A theoretical model, combining quality of life and years of life, which offers clues for the proper time to die with dignity. *Med Law.* 2000; 19: 635-655.
17. Ganzini L, Nelson H, Lee M, et al.: Oregon physicians' attitudes about and experiences with end-of-life care since passage of the Oregon Death With Dignity Act. *JAMA.* 2001; 285(15): 2363-2369.
18. Kade W: Death with dignity: A case study on being a doctor. *Ann Intern Med.* 2000; 132(6): 504-506.
19. Kissane D, Clark, D: Demoralization syndrome-a relevant psychiatric diagnosis for palliative care. *J Palliat Care.* 2001; 17(1): 12-21.
20. Tuten M: A death with dignity in Oregon. *Oncol Nurs Forum.* 2001; 28(1): 58-65
21. Woolfrey J: What happens now? Oregon and physician-assisted suicide. *Hastings Cent Rep.* 1998; 28(3): 9-17.
22. Block S: Psychological considerations, growth, and transcendence at the end of life: the art of the possible. *JAMA.* 2001; 285(22): 2898-2905.
23. Hart B, Sainsbury P, Short S: Whose dying? A sociological critique of the "good death". *Mortality.* 1988; 3(1): 65-77.
24. Silverberg R: Men confronting death: Management versus self determination. *Clin Soc Work J.* 1985; 13: 157-169.
25. Dupree C: The attitudes of black Americans toward advanced directives.*J Transcultural Nurs.* 2000; 11(1): 12-18.
26. Sullivan AD, Hedberg K, Fleming D: Legalized physician-assisted suicide in Oregon—the second year. *NEJM.* 2000; 342(8): 598-604.
27. Miyaji N: The power of compassion: truth-telling among American doctors in the care of dying patients. *Soc Sci Med.* 1993; 36(3): 249-264.
28. Yalom I: *Existential Psychotherapy.* New York: Basic Books, 1980.