



Editorial

When It's Your Time, Will It Be Your Way?

The Institute of Medicine's critical report *Dying in America*¹ highlighted the critical needs related to that issue via its subtitle: *Improving Quality and Honoring Individual Preferences Near the End of Life*. The first recommendation in that report defines comprehensive care for individuals nearing the end of life (EOL) and, in part, characterizes that care as "... patient-centered . . . and consistent with individuals' values, goals, and informed preferences."^{2(p3)} For both our patients and ourselves, it is important that we make time to document our preferences for EOL care so our wishes can be shared with those who will be caring for us and making decisions on our behalf.

Our preferences for EOL care are typically documented in an *advance directive*, a legal document consisting of a *living will*, that specifies the types of care and treatments that one does and does not wish to receive under certain conditions (eg, if you were permanently unconscious or had a terminal illness), and a durable power of attorney for health care (ie, health care proxy, medical power of attorney), which identifies who would serve as your surrogate decision maker(s) for health care decisions if you were unable to make those decisions.³ Some states combine the living will and health care power of attorney into a single document, whereas others require these to be separate documents. Some states detailed these preferences in a set of Physician Orders for Life-Sustaining Treatment (POLST) or Medical Orders for Life-Sustaining Treatment (MOLST) documents⁴ intended to cross all care settings with the patient.

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Two major obstacles that can thwart the potential effectiveness of an advance directive for improving the quality of EOL care are failure to prepare an advance directive and disregard of an existing advance directive.

Failure to Prepare an Advance Directive

I don't know the degree to which critical care nurses are complicit in failing to prepare these documents, but if we mirror the larger US population, only 25% to 30% of us have completed an advance directive.⁵⁻⁸ Why a substantial portion of the adult population in the United States has not yet identified their personal preferences for care if they faced a life-ending condition is not known with certainty, though a recent study found that the most frequently cited reasons were not knowing what advance directives are and family already knowing their wishes.⁸ Other plausible explanations include not perceiving its necessity due to youth, current good health, or unease in pondering one's mortality and unintended legal and procedural consequences that may pose barriers to understanding or completing these documents.⁹

As discomforting as it may be to plan for our own demise, that effort affords us the greatest possibility for ensuring that time is consistent with our deepest wishes. None of us knows when we might need to deal with such unwelcome news, so my suggestion is to thoughtfully consider what would be most important to you at the end of your life and summarize what you want so it can be discussed and shared with those most likely to carry out your wishes.

Inability to Determine Whether an Advance Directive Exists

Even when advance directive documents are prepared, they may not be implemented for any of a number of reasons. For example, the existence of these directives may not be known to health care providers at the time care is needed, patients may be unable to indicate whether these documents exist or to describe their preferences at the time they require care, immediate family members or surrogate decision makers may not be known or available when the patient presents for care, or the documents may be impossible to access due to their physical location or their digital security requiring passwords. In many instances, circumstantial exigencies can make it impossible for health care staff to follow a patient's wishes relative to treatments they do or do not want. Health care staff have no alternative but to follow established protocols of care to meet the patient's needs.

Disregard of a Known Existing Advance Directive

Gallup polls in 1992¹⁰ and 1996¹¹ found that 90% of Americans would prefer to be cared for at home if they were terminally ill (6 months or less to live). A decade later, a Pew report¹² reaffirmed that a vast majority of adult Americans (about 80%) would prefer to die at home rather than in a health care facility. One of the vexing realities in EOL care is that despite more Medicare beneficiaries dying in palliative care or home settings since 2000, the frequency of hospitalizations into acute and critical care units and the frequency of transitions across multiple care sites during the EOL actually increased, reflecting persisting emphasis on provision of aggressive, curative care, only punctuated by brief hospice stays immediately preceding death.¹³ This dissonance was cogently summarized in an editorial by 2 physicians at Yale: "The focus appears to be on providing curative care in the acute hospital regardless of likelihood of benefit or preferences of patients."^{14(p489)} Several studies have attempted to construct an accounting for this disparity between what patients want and what many physicians administer by examining physician attitudes toward EOL and advance directives.

Attitude Toward and Disregard of Advance Directives by Physicians

A survey of 765 physicians who graduated from Johns Hopkins School of Medicine between 1948 and

1964 found that 64% had an advance directive that they had discussed with their spouse or immediate family, although 70% had not discussed it with their personal physician. In addition, more than 80% of these physicians indicated that the EOL care they would select was to receive pain medication, but refuse life-sustaining medical treatments.¹⁵

In a 2011 essay titled "How Doctors Die," a retired family practice physician described why physicians administer so much care to patients at the end of their lives that they would not want for themselves.¹⁶ His explanations for their aggressive EOL treatment included patients who have not made their wishes known, overwhelmed families who request that everything be done, expectations of outcomes that may be misguided or unrealistic, physicians attempting to address patient or family wishes or to minimize potential for litigation, as well as possible exploitation to earn higher fees. I would summarize his explanations for why "doctors don't die like the rest of us"^{16(p1)} as "they know better," that is, despite understanding and having access to all possible options for the latest medical therapies, they have also witnessed numerous instances of care they considered futile and recognize the limitations and tradeoffs of what even the best medical care can provide. As a result, when physicians approach their life's horizon, they prefer to go gently home rather than fight in a hospital.

The question of why physicians choose to forego highly aggressive medical treatments for themselves at EOL, yet administer that care to their terminally ill patients was revisited in a 2014 Stanford University study.¹⁷ In contrast to the Johns Hopkins survey, the Stanford study employed a larger, younger and more demographically diverse sample from 2 academic medical centers, yet found that physician attitudes toward advance directives had not substantially changed and that more than 88% of physicians opted to forgo resuscitation and aggressive treatment if they had a terminal illness. Allowing for the possibility that terminally ill patients might request aggressive care, the study found no data to support that contention, instead citing that the local health system culture and physicians' personal practice styles were the primary contributors associated with providing intensive treatments to the terminally ill. Because patients receiving such care in the last 6 months of life do not have lower mortality rates compared to those who receive less aggressive care, this begs the question of what biases or incentives may underlie

“the prevalent national practice pattern of subjecting dying patients to ineffective, burdensome high-intensity treatments” while doctors choose low-intensity EOL treatments for themselves.^{17(p7)}

As if disrespecting a terminal patient’s expressed wishes for care were not sufficiently troublesome, there have also been reports of corrosive interactions and verbal sparring between physicians providing aggressive treatment and those attempting to provide palliative care.¹⁸ In a 2012 survey of physician members of a national hospice and palliative medicine society, more than half reported instances when palliative care had been characterized as murder, killing, or euthanasia by a patient’s family member or other health care professionals, including other physicians.¹⁹

Attitude Toward and Disregard of Advance Directives by Nurses

Nurses should not erroneously conclude that concerns related to health care professionals disregarding patients’ expressed wishes for EOL care can be leveled only at physicians. Although most of the research in this area has concentrated on physicians, a growing number of studies suggest that nurses in many countries around the world exhibit a comparable dichotomy of assigning more aggressive care for terminally ill patients than patients wish to receive and more aggressive than the nurses want for themselves. Studies have included registered nurses from Scotland, Wales, Canada, and Sweden²⁰; Sweden and Germany²¹; Korea²²; and nearly 1100 nurses from Hong Kong, Ireland, Israel, Italy, and the United States.²³ In this study, although patient preferences for care were not known, in each country, nurses chose more aggressive options of EOL care for patients than they would chose for themselves or for their own parent.

Closing

Despite the many obstacles that may arise in living our life as we would like, few are as open to improvement as having it end as we wish. To the extent that we can control our location and ministrations at that point, the least we can do is to identify what we want and do not want, where we would or would not like to be located, and any other aspects that may be important to us. Both nurses and physicians have challenges ahead in getting some of our colleagues to honor and respect patient preferences about their EOL care, but we can take personal responsibility to ensure our own advance directive is updated and distributed.

As critical care nurses, we can also make every effort to encourage patients and families to prepare these documents. Advocating on behalf of patients to ensure their wishes are followed needs handling via institutional policies and procedures rather than verbal battles at the bedside. Encouraging and supporting respect of a patient’s wishes is something we can do right now to improve EOL care. **CCN**



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Survey

Help *CCN* document critical care nurses’ opinions and status on this issue by e-mailing your replies to the following 2 questions to GrifCCN@comcast.net:

1. If you had a terminal condition with death anticipated within 6 months, which of these end-of-life care options would you prefer for yourself?
 - a. Go home with comfort measures or hospice, as necessary, but no cardiopulmonary resuscitation or extraordinary measures
 - b. Remain in whichever health care facility is necessary to receive all available medical therapies that could possibly extend my life
2. Do you have an advance directive that identifies your end-of-life preferences?
 - a. Yes
 - b. No

References

1. Institute of Medicine. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. Washington, DC: The National Academies Press; 2014.
2. Institute of Medicine. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life. Key Findings and Recommendations*. Washington, DC: The National Academies Press; 2014.
3. National Library of Medicine. Advance directive. <https://www.nlm.nih.gov/medlineplus/advancedirectives.html>. Accessed November 20, 2015.
4. Physician Orders for Life-Sustaining Treatment (POLST) Paradigm website. <http://www.POLST.org>. Accessed November 20, 2015.
5. American Association of Retired Persons. AARP Bulletin Poll. Getting Ready to Go, Executive Summary, January 2008. http://assets.aarp.org/rgcenter/il/getting_ready.pdf. Accessed November 20, 2015.
6. Pollack KM, Morhaim D, Williams M. The public’s perspectives on advance directives in Maryland: implications for state legislative and regulatory policy. *Health Policy*. 2010;96(1):57-63.
7. American Bar Association. Myths and Facts About Health Care Advance Directives. 2011. http://www.americanbar.org/content/dam/aba/migrated/Commissions/myths_fact_hc_ad.authcheckdam.pdf. Accessed November 20, 2015.
8. Rao JK, Anderson LA, Feng-Chang L, Laux JP. Completion of advance directives among U.S. consumers. *Am J Prevent Med*. 2014;46(1):65-70.
9. Castillo LS, Williams BA, Hooper SM, Sabatino CP, Weithorn LA, Sudore RL. Lost in translation: the unintended consequences of advance directive law on clinical care. *Ann Intern Med*. 2011;154(2):121-128.

10. Seidnitz L, Duberstein PR, Cox C, Conwell Y. Attitudes of older people toward suicide and assisted suicide: an analysis of gallup poll findings. *J Am Geri Soc.* 1995;43(9):993-998.
11. National Hospice Organization. NHO Press Release: New Findings Address Escalating End-of-Life Debate. Arlington, Virginia: NHO, October 3, 1996.
12. Pew Research Center for the People & the Press. Strong Public Support for Right to Die: More Americans Discussing—and Planning—End-of-Life Treatment. January 2006. <http://people-press.org/report/266/strong-public-support-for-right-to-die>. Accessed November 20, 2015.
13. Teno JM, Gozalo PL, Bynum JPW, et al. Change in end-of-life care for Medicare beneficiaries: site of death, place of care, and health care transitions in 2000, 2005, and 2009. *JAMA.* 2013;309(5):470-477.
14. Jenq G, Tinetti ME. Changes in end-of-life care over the past decade: more not better. *JAMA.* 2013;309(5):489-490.
15. Gallo JJ, Straton JB, Klag MJ, et al. Life-sustaining treatments: what do physicians want and do they express their wishes to others? *J Am Geriatr Soc.* 2003;51:961-969.
16. Murray K. How doctors die, 2011. <http://www.zocalopublicsquare.org/2011/11/30/how-doctors-die/ideas/nexus/>. Accessed November 20, 2015.
17. Periyakoil VS, Neri E, Fong A, Kraemer H. Do unto others: doctors' personal end-of-life resuscitation preferences and their attitudes toward advance directives. *PLoS One.* 2014;9(5):e98246.
18. The New Old Age blog. Among Doctors, Fierce Reluctance to Let Go. http://newoldage.blogs.nytimes.com/2012/03/29/among-doctors-fierce-reluctance-to-let-go/?_r=0. Accessed November 23, 2015.
19. Goldstein NE, Cohen LM, Arnold RM, Goy E, Arons S, Ganzini L. Prevalence of formal accusations of murder and euthanasia against physicians. *J Palliative Med.* 2012;15(3):334-339.
20. Lever JA, Molloy DW, Eisenmann M, et al. Variability in nurses' decisions about the care of chronically ill elderly patients: an international study. *Humane Medicine Health Care.* 1992;8(2):138-144.
21. Richter J, Eisemann MR, Bauer B, Kreibeck H, Åström S. Decision-making in the treatment of elderly people: a cross-cultural comparison between Swedish and German physicians and nurses. *Scand J Caring Sci.* 2002;16:149-156.
22. Lee J, Kim KH. Perspectives of Korean patients, families, physicians and nurses on advance directives. *Asian Nurs Res.* 2010;4(4):185-193.
23. Coffey A, McCarthy G, Weathers E, et al. Nurses' preferred end-of-life treatment choices in five countries. *Int Nurs Rev.* 2013;60(3):313-319.