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How Should Cost-Informed Goals of Care Decisions Be Facilitated at Life's End?

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Abstract

Interventions near patients' deaths in the United States are often expensive, burdensome, and inconsistent with patients' goals and preferences. For patients and their loved ones to make informed care decisions, physicians must share adequate information about prognoses, prospective benefits and harms of specific interventions, and costs. This commentary on a case discusses strategies for sharing such information and suggests that properly designed advance care planning incentives can help improve communication and decision sharing.

Editor's Note

The case to which this commentary is a response was developed by the editorial staff.

Case

DD is the designated durable power of attorney for health care, who has served well in this capacity by prioritizing her mother's previously expressed wishes to the best of her ability. DD has also, to this point, represented all DD's siblings as they discuss with care teams the care of their elderly parent in hospital and nearing death. DD and the health care team have discussed initiation of life-sustaining interventions (eg, mechanical ventilation,

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The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. This article is the sole responsibility of the author(s) and does not necessarily represent the views of the National Institutes of Health or the US government. The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

intubation, artificial nutrition and hydration), as well as a hospice care referral, given the patient's diagnosis and impending death.

DD explains to the health care team that her mother had previously indicated she wanted all lifesaving therapies but that she values quality of life over extended life. The patient had also expressed a desire not to become a family burden. While sharing this sentiment, DD expresses, "For long hospital stays, no one needs to know the price of services to know it's expensive and that it will leave us bankrupt—\$100 a day, \$1000 a day out of our pockets. That is too much for most American families and it's too much for us. Our kids won't be able to go to college, and we won't have enough to pay for my father's medicines.

Commentary

Health care in the United States, especially near the end of life (EoL), is extremely expensive. Medicare is the primary payer for health services rendered to patients over age 65 in the United States, and an estimated one-quarter of total Medicare spending is on about 5% of Medicare beneficiaries in their last year of life.^{1,2} These statistics are retrospective, however—the fact that much has been spent on patients in the last year of life *ex post* does not necessarily mean that the spending was futile *ex ante*,² as these care decisions were made when patients were still alive, often with the hope that the (expensive) care could rescue them from imminent death or at least prolong their lives for an extended period of time. While cost is important for care decisions across the lifespan, it takes on special significance and meaning in the context of EoL care, which we define as care received for either life-prolonging or palliative purposes by patients with a high likelihood of dying, such as those with advanced-stage cancer or heart disease. In this context, as recovery to full health is not realistic, cost-informed goals of care should mean goals of care informed by broader definitions of cost and benefit, including not only clinical benefits and harms but also out-of-pocket monetary costs and their financial implications for patients and families, taking into account patients' prognosis and preferences.

Cost-informed goals-of-care decisions are especially important, as concordance between patient preferences and care received is widely recognized as the hallmark of high-quality EoL care.³ Moreover, these decisions are made against a backdrop of a fragmented health care system that often promotes aggressive care, especially for patients near death, which is costly for several reasons.^{4,5} Despite recent reforms emphasizing paying health care practitioners for performance,⁶ much of the US health care system (including Medicare) is still dominated by fee-for-service incentives, wherein a higher volume of services is financially rewarded.^{7,8} The relatively rapid adoption of health care innovations, including new or experimental treatments (such as the recent approval of a new drug for treating Alzheimer's^{9,10}), and the high prices paid for them also distinguish the United States from many other developed countries.^{11,12}

In this commentary, we discuss the opportunities and challenges for individual physicians (both generalists and specialists) in providing patients near the EoL and their families and caregivers with sufficient information regarding prognosis, potential benefits and risks, and out-of-pocket costs to make cost-informed goals-of-care decisions. We also discuss

the role of advance care planning (ACP)—the ongoing process in which the patient, their family, and health care practitioners reflect on the patient’s goals and values (eg, extending life vs improving quality of life) and discuss how these should inform the patient’s current and future medical care¹³—in facilitating cost-informed goals-of-care decisions. Improved decision-making processes regarding EoL care is particularly important for socially disadvantaged patients, who often lack both adequate information and the financial resources needed to receive quality health care concordant with own preferences.

Prognosis

Prognosis is crucial to informing patients’ or their health care proxies’ evaluation of care options. Studies on patients with advanced cancer have found that the majority of patients are unaware of their prognosis,¹⁴ despite having a desire to discuss it with their physicians,^{15,16} likely because many physicians do not explicitly discuss prognosis or life expectancy with their patients at EoL.¹⁶ Studies show that terminally ill patients who have a clear understanding of their prognosis (that they likely have months, not years, to live) are more likely to (a) engage in ACP¹⁷ and to (b) receive less burdensome, aggressive, and unbeneficial care^{16,17,18,19} and (c) more value-consistent care.¹⁸ Knowledge of prognosis also better equips patients to navigate the complexity of Medicare benefits and eligibility for certain types of care, such as hospice care, which requires that the patient be certified by 2 independent physicians as having less than 6 months to live.²⁰

Prospective Benefits and Harms

It is well documented that aggressive and burdensome treatments with few proven benefits are frequently used at EoL, such as intubation of patients with advanced dementia^{21,22} and chemotherapy for patients with metastatic cancer.²³ Research shows that physician beliefs and preferences regarding aggressiveness of treatments strongly predict variation in EoL spending across regions in the United States, whereas patient preferences for treatment at EoL (eg, comfort care vs aggressive care) have very little relation to EoL spending.²⁴ This finding is likely attributable to patients either not being actively involved in the care decision process or not understanding the pain and suffering they would need to endure merely to be kept alive in a seriously debilitated state, not to mention their not understanding the ambiguous survival benefits (or lack thereof).²⁵ In fact, a large body of literature has documented the significant barriers to effective physician-patient communication in the context of EoL, such as physicians’ lack of communication training and skills and the exclusive focus on clinical parameters.^{25,26,27}

For most patients near the EoL, as in the case of DD’s elderly parent, a decreased quality of life is part of the broader definition of patient “cost” that needs to be taken into account. We thus advocate for adequate focus on the impact of treatments on quality of life, such as on acceptable health states and valued life activities²⁶ (in addition to survival), as an integral part of medical decision making and physician-patient communication at EoL. For patients or their health care proxies with sufficient numeracy, quality-adjusted life years could be used as a guide to compare treatments, as the measure explicitly incorporates both quality of life and length of survival. Furthermore, clinicians should promote a deeper understanding of side effects (eg, specific toxicities or common side effects such as nausea,

vomiting, headache) associated with each treatment among all patients or their health care proxies. We acknowledge, however, that health care system-wide reforms, including better communication education and palliative care guidelines, are essential to improve the shared decision-making process regarding EoL care.²⁷

Financial Burden

Physicians might feel that they should promote the most effective care regardless of cost. However, in the US health care system, out-of-pocket cost is a consideration for most patients, and discussing it better equips them to make informed decisions.²⁸ Even with Medicare coverage, patients are still responsible for 20% of copayment for physician services (unless they have supplemental coverage, which many do not), which can be substantial. For instance, for chemotherapy infusions, the copay could approach \$10 000 for certain brand-name cancer drugs.²⁹ Riggs and Ubel suggest that “a useful rule of thumb is to consider a trade-off related to the cost of care reasonable if the physician would endorse the same trade-off in response to a strong patient preference that was not related to out-of-pocket costs.”³⁰ In the context of EoL, since treatment “effectiveness” in terms of curing the condition is no longer a realistic goal, the emphasis in goals-of-care discussions should be put on weighing the goals of prolonging life, quality of life, and cost concerns in a way consistent with patient preferences, if such preferences are documented or can be elicited. Extending life by days or weeks should not be assumed to be the only or even the most important criterion for decision making.

While it is unrealistic to ask physicians to be well-informed about patient-specific cost information, there are a few things physicians could do to improve communication with patients about costs. These include (1) initiating the conversation about costs by discussing general “expensiveness” of treatments, since physicians usually have some idea about which treatment option may be most expensive; (2) asking about patients’ or families’ financial circumstances or hardship and insurance coverage; and (3) directing patients or health care proxies to financial assistance programs if appropriate and to price transparency platforms (if available).³⁰ Additionally, social workers and case managers can play an important role in helping patients understand the financial consequences of treatments and direct them to resources as needed. It is important to note that while federal legislation mandating hospital price transparency is in place,³¹ existing evidence suggests that price transparency tools have had little effect on reducing patient out-of-pocket costs.^{32,33} They are thus unlikely to be effectively utilized by patients without proper guidance from clinicians and case managers.

Patients from vulnerable groups, who lack the financial resources to pay higher health care costs, may especially benefit from cost discussions.^{34,35} Other families like DD’s might still benefit from cost-saving strategies, such as switching to lower-cost alternative treatments. Although fear of harm to the patient-physician relationship has been cited as a barrier to conversations about cost of care,³⁶ recent research shows that patients prefer physicians who discuss cost over those who do not,³⁷ and inclusion of cost information has been shown to inform patients’ hypothetical decisions regarding treatments without changing their attitude toward physicians.³⁷

Planning

As discussed above, comprehensive information on prognosis, clinical benefits and harms of treatments, and treatment costs are all indispensable components of ACP, which gives patients the opportunity to put in place advance directives that document their wishes regarding medical treatment and to appoint a surrogate decision maker (ie, health care proxy).^{38,39} Simply having an ACP conversation or intervention without adequately communicating all of the above aspects of care can limit its effectiveness. Communication failures may explain the mixed findings regarding the effect of ACP interventions on care quality and patient satisfaction.⁴⁰ Adequate communication between patients and their proxies is just as important as the communication between patients and their physicians to ensure that the proxies properly understand patient preferences and to resolve any potential conflicts of interest (especially if family asset reallocation is involved in paying for medical treatments).⁴¹ In the case of DD's family, for example, early ACP discussions could potentially facilitate agreement among DD's parent, DD, and DD's siblings regarding the optimal treatment.

None of the aforementioned components of ACP would be realistic if clinicians did not have sufficient time or incentives to have these discussions with patients. To overcome these barriers, on January 1, 2016, Medicare began reimbursing clinicians (both physicians and nonphysicians) for having ACP discussions with patients.⁴² Early evidence suggests that ACP billing was associated with significantly less intensive EoL care (eg, hospitalizations, emergency department visits, intensive care unit stays).⁴³ However, the uptake of ACP billing codes remains low among providers.^{42,44,45} Recent research identifies a number of barriers to ACP billing,⁴⁴ including low reimbursement (\$80 to \$86 for the first 30 minutes and \$75 for each 30 minutes thereafter, although ACP codes could be billed as often as needed)^{46,47} and disruption to clinical workflow.⁴⁴ While explicitly incentivizing clinicians to have ACP conversations is a necessary first step to improving clinician-patient communication, it is clear that further reforms are needed, such as revising the ACP reimbursement structure and incorporating ACP in existing quality payment programs to allow for a more streamlined billing process and improved incentives. The latter could be accomplished by extending the Medicare reimbursement scheme for care planning for patients with cognitive impairment, which requires a written care plan for billing, to ACP.⁴⁷ Potential benefits of ACP reform include incentivizing utilization of advance directives for both clinicians and patients, ensuring that patient preferences are properly documented, and promoting annual updates of advance directives documents during annual wellness visits, for example.

Conclusion

Meaningful shared decision making among patients, family members, and clinicians requires improved communication about patient prognosis, clinical benefits and harms of treatment options, and treatment costs. Knowledge of all these aspects of care would help patients at the EoL express their preferences or help their health care proxies, such as DD and her family, better express patient preferences and make informed care decisions. Shared decision making is especially critical for patients who are socially disadvantaged or cognitively impaired. Incentives for ACP, if properly designed, hold the promise of

facilitating the shared decision-making process and improving quality of care and quality of life for patients at the EoL.

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