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Making the Case for Talking to Patients about the Costs of End-of-Life Care

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The cost of health care at the end of life accounts for a high proportion of total health care costs in the United States. The percentage of Medicare payments attributable to patients in their last year of life was 28.3% in 1978 and has remained substantially the same at 25.1% in 2006. This indicates how little progress has been made in containing these costs, though doing so will be important to promote a financially sustainable health care system.¹ These expenditures also highlight the prospect that efforts to reduce health care costs overall are likely to disproportionately affect the care patients receive at the end of life.

In this paper, we argue that in order to contain end-of-life costs, it will be appropriate for clinicians to explicitly discuss the topic of end-of-life health care costs with their patients. There are two aspects of the cost of care that might be discussed: (1) the shared costs of health care that are borne collectively as insurance premiums and taxes, and (2) the costs that individuals incur personally at the time of illness. Addressing both aspects may be warranted, although the justification for, and approach to, these discussions differ. We suggest that it is possible to have these clinical discussions in a respectful manner that promotes fairness, respect for patient autonomy, and sensitivity to the needs of the patient. We recommend two approaches to familiarize patients with such discussions: (1) discussion of health care costs from the outset of chronic or terminal illness and (2) the incorporation of financial considerations in advance care planning. By having these anticipatory conversations throughout a patient's illness trajectory, doctors can allow patients important time to contemplate their end-of-life preferences and allow them to prepare for the difficult trade-offs that they may have to make at a later point.

Though the reasoning we develop in this paper focuses on discussion of end-of-life costs, we believe it is appropriate for clinicians to engage with patients in discussion of the costs of illness and medical care in general; we concentrate on the justification for addressing end-of-life costs in keeping with the theme of this issue of *JLME* and because some might consider end-of-life costs an exception to this general view. We conclude the paper by offering some notes of caution.

Societal and Personal Healthcare Costs at the End of Life

The burden of rising health care costs has been well documented. In an examination of the long term outlook for health care spending, the Congressional Budget Office estimated, prior to 2010 health care reform, that total U.S. spending on health care would reach 25% of the gross domestic product (GDP) in 2025, 37% in 2050, and 49% in 2082. Such a rapid rise

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in expenditures has ramifications at the individual and societal level. In 2005, 46% of these funds came from public programs such as Medicare, Medicaid, and SCHIP; 41% stemmed from private sources, such as private health insurance plans; and 13% was paid directly by patients through out-of-pocket costs. Federal spending on Medicare and Medicaid alone was projected to rise from 4% of GDP in 2007, to 7% in 2025, to 12% in 2050, and to 19% in 2082.² A significant amount of this spending comes from the disproportionately high cost for end-of-life care. As we have already noted, a quarter of Medicare expenditures have persisted in going to those beneficiaries who die annually despite changes in the delivery system.³

The personal implications of medical costs that individuals experience in the form of out-of-pocket expenses along with the income loss and other financial burdens of illness are a pressing problem that is often insufficiently appreciated. Several studies have underscored the burden that health care costs place on individuals – in 2009, 21% of Americans reported having difficulty paying for necessary health care.⁴ A study conducted in 2006 found that of people with chronic illness, or with family members who had a chronic illness, 30% had problems paying medical bills; 16% used up all or most of their personal savings; 12% were unable to pay for basic necessities; and 5% declared bankruptcy.⁵ Of people with cancer in the same study; 19% had used up all or most of their personal savings; 21% were unable to pay for their basic necessities; and 9% had declared bankruptcy. A more recent study found that one out of every six patients living with cancer went without a cancer treatment due to costs.⁶ In a study of patients specifically identified as terminally ill, 17–28% reported spending 10% or more of their income on health care costs outside of insurance premiums.⁷

The economic burden for caregivers of the terminally ill is also substantial.⁸ One study noted that 10–16% of terminally ill patients and/or their families had to take out a loan or mortgage, spend their savings, or obtain an additional job to cover medical care costs.⁹ A separate study found that 31% of families with seriously ill patients used up all or most of their personal savings.¹⁰ Maintaining employment was another issue: 77% of caregivers for terminal cancer patients reported missing work due to their care giving responsibilities.¹¹ Though families ought to be – and often are – very supportive and understanding throughout a relative's terminal illness, dying patients can experience an added stress and helplessness due to costs that their caregiver's incur. Part of the anxiety relates to the financial consequences they anticipate for their family members and others after their lives have ended.

Terminally ill patients do consider the financial burden that their illness can place on themselves, their family members, and significant others. *USA Today* reported on cancer patient, Frank Beck, whose care was so expensive that he felt guilty for the financial strain that treating his illness was placing on his family: “You add all these things up and you say, ‘How can I justify that? Am I taking money away from everybody else just so I can be around a little bit longer?’”¹²

The Varied Nature of End-of-Life Experiences

Any argument for encouraging physicians to talk with patients about the ramifications of end-of-life treatment decisions, be it financial or otherwise, needs to take into account how varied the end-of-life experience may be. Deaths occur more and less prematurely, and can be more or less sudden. Under these varied circumstances, patients and their families may be more or less prepared for death. While we assume that all patients who are terminally ill, if they are at all conscious, are likely to be inwardly focused and preoccupied with only the most essential of personal concerns, some fortunate patients who have lived long and full lives may feel that they have already had their fair share of health care resources. There will

also be patients who will, for reasons unassociated with cost – for instance, quality of life – opt for a less expensive, palliative care approach. At the other end of the spectrum, younger patients or patients who have not had adequate time to accept the terminal nature of their condition are likely to be far less accepting of death. Also pertinent to our analysis of clinical discussions of the cost of care is the reality that patients may vary with regard to their financial and social resources. These differences will matter in our considerations about the ethics of discussing costs with patients.

Ethical Justifications for Discussing Cost in the Clinical Encounter

Assumptions

Before offering any justification for discussing costs with patients, we acknowledge some assumptions we make about the role of physicians in determining the costs of medical care. While we will not focus on the justification of that responsibility here, we rely on reasoning offered elsewhere about the legitimate role of physicians in stewarding health care resources.¹³ Physicians strongly influence the kind of care patients receive. In selecting diagnostic and therapeutic interventions, they are in an inescapable position to determine how health care resources are used. Consequently, they are able play a role in determining whether or not they are distributed fairly.¹⁴ Numerous strategies, including practice guidelines, triage policies, waiting lists, and cost-effectiveness data, are increasingly available to help physicians and other clinicians use health care resources efficiently and fairly on behalf of patients. Physicians, in turn, make decisions about the use of resources at the bedside by three mechanisms: (1) on the basis of resource constraints such as short supplies or institutional allocation decisions that are imposed upon them; (2) by following rules of medical practice such as guidelines or triage policies; or (3) by exercising clinical judgment where the first two mechanisms do not apply.¹⁵ Given the influential role of physicians in health care expenditures and resource distribution, we hold the view that it is within the purview for physicians to communicate with patients about the cost of various treatments and the financial basis of some of the treatment decisions and recommendations they make.

There are two alternatives to our recommendation about explicit clinical communication regarding resource limitations and the cost of care. One is that physicians will pay attention to costs in medical decisions and try to contain them without clinical discussion with patients. That is practice bedside rationing without informing patients. The other is that physicians will ignore cost in medical decision-making, opting simply for the most effective treatment (which is often the most expensive) regardless of the cost. We argue that neither of these alternatives is ideal – the former lacks the procedural fairness necessary for fair distribution of resources; the latter contributes to soaring health care costs and the lack of sustainability in the U.S. health care system. Given the consequences of these options, it is reasonable to explore the justification for discussion of costs, which we do below.

Costs associated with illness and medical care are partly shouldered by financing mechanisms that involve socially shared responsibility and are partly borne by individuals and those close to them. By socially shared responsibility, we mean the insurance premiums and taxes that are collected and pooled to share the burden of health care costs. By personal costs, we are referring to the costs of care incurred by patients at the time of illness. The ethical rationale and approach for discussing and weighing societal and personal costs in clinical decisions differ and we therefore address them separately.

Shared Societal Costs

The argument for discussing and attempting to reduce pooled costs in the course of the clinical encounter relates to the need to collectively share responsibility for wisely using

medical resources. This argument pertains across the spectrum of medical need, ranging from health promotion to end-of-life care. Opting for less expensive medical care is in the long-term financial interests of all who contribute financially since choosing such options will ultimately help constrain taxes and insurance costs. Individuals should be encouraged to forgo some benefits for the sake of society as a whole in an effort to avoid a tragedy of the commons – the tendency of each of us to spend unstintingly with the net effect being that our society accrues unsustainable aggregate costs. Were we to avoid this tendency, there is the prospect that each individual will ultimately personally benefit.

However, using this logic to argue that physicians should discuss societal costs with their dying patients is unlikely to hold water. Such an argument would be particularly unpersuasive to a person at the end of their life whose personal prospect for the future is painfully limited and is therefore less likely to be concerned by the long-term financial interests shared by everyone. Given those circumstances, the most compelling justification for discussing the societal costs of terminal illness is likely to be predominantly related to procedural justice – the idea that fairness to all patients requires explicit procedures that are even-handed and transparent. If any care is withheld, informing patients of this provides them with the opportunity to ask questions, seek help elsewhere, or challenge the legitimacy of their decisions. The need for openness and accountability pertains to all patients, including patients at the end of their lives, and we project that the need to establish transparent procedures to grow in the near future.

While the Patient Protection and Affordable Care Act enacted in 2010 takes effect, clinicians and insurers will face pressures to constrain costs. The legislation includes strategies aimed at controlling health care spending by expecting insurers, hospitals, and clinicians to reduce costs.¹⁶ The strategies will include incentives that promote care that is less expensive, taxing expensive health insurance plans, and holding down Medicare costs, all of which will require doctors to pursue more cost-effective care.

If physicians face increasing pressures to deliver cost-effective care to their patients, doing so consistently and honestly, rather than surreptitiously, in a way that allows patients to understand the need for value-driven treatment decisions, will allow them to question the choices of insurers, hospitals, and doctors. This is likely to serve as a check that guarantees even-handedness in the application of limits.¹⁷ Without notifying and explaining to patients that considerations regarding the relative benefits and costs of various treatment options were a part of the rationale in selecting certain types of care, they will have no opportunity to fully understand, participate in, and possibly appeal the decisions. While critics of this legislation might not endorse the strategies it utilizes to contain costs, they still face the inescapability of rising costs and the need to offer alternative cost containment strategies that will likely require similar notification.

We should clarify that we are not suggesting that such explicit discussion and due process is exclusively warranted for end-of-life care costs. We are saying that due process may be more heavily relied upon for justifying discussion of end-of-life costs than the costs of care earlier in the life cycle because the shared benefits of cost containment are less germane for patients approaching the end of life.

Personal Costs

Discussing the personal costs of end-of-life care in the clinical encounter can contribute in important ways to a patient's autonomy and best interests. It can do so by allowing a patient's financial concerns to be incorporated into the planning of care to the extent, and in the manner, that the patient desires. As such, dying patients are more likely to be comfortable with having this aspect of cost incorporated into clinical conversations. Though

the options for care of a terminally ill patient may range in cost and have varying personal and financial ramifications, the financial aspects of care are all too often not explicitly addressed with patients.¹⁸ This is despite the fact that 63% of patients in one study wanted to discuss such costs, and 80% of physicians believed that patients want to discuss these costs.¹⁹

When costs are not openly addressed, patients have no opportunity to be involved in the financial dimension of decision-making regarding their care. Furthermore, they are unaccustomed to making important tradeoffs regarding expected benefit and cost.²⁰ This can have adverse effects on a patient's health – particularly when a patient cannot adhere to a recommended treatments due to cost and is not advised that a less expensive option may be available.²¹ By discussing personal costs in the clinical encounter clinicians can explore with a patient the more affordable options to which he or she can more readily adhere. Discussion of medication costs has been more fully explored in the literature.²²

Informing patients about treatments that range in expense will offer them the possibility of reduced personal costs, such as out-of-pocket expenses and co-pays, and free up financial assets that could be spent on other worthwhile pursuits. It may be particularly important to engage patients in decisions about the range of care options at the end of life because the preferences of dying patients are likely to be hard for clinicians to predict without explicit discussion. This is particularly so as patients approach the end of life and the value that they place on the short amount of time they have left to live quite likely increases. Patients and those close to them may be willing to spend much more, or much less, on medical care than they might at other times. This point only highlights the need for discussion since patients face heightened tensions between competing concerns as they face the end of life.

The prevailing tendency to avoid discussing the financial ramifications of illness and medical care is not necessarily the preferable approach; it diminishes the patient's chances of shaping the end of life in a way that is most compatible with their values and life plans. In this way it undermines their autonomy and leaves to the clinician the role of suggesting treatment options without awareness of the consequences for the patient.

Alternatively, when financial matters are not discussed, the clinician could be aware of the financial ramifications but be unaware of, or be indifferent to, the patient's preferences. When given a choice, patients might prefer to spend their money on a last vacation, save it for their spouse's living expenses, or set it aside for their grandchild's future education, as opposed to using it for a last-chance cancer treatment that has a high cost and low chance of benefit. End-of-life choices are often very complex, involving various unpredictable value judgments, including the following: (1) a patient's opinion on quality of life vs. length of life; (2) their conception of a "good" dying experience; (3) religious beliefs; and (4) personal circumstances (for instance, family pressures and/or financial status). Neglecting any part of the equation, including finances, makes it less likely that the clinician and patient will make the best choice, all things considered.

One might counter that both clinicians and patients are too inadequately informed about the costs of illness to be able to have a useful discussion about it. We would argue that while they may lack information, the preferable approach is to seek out data and the support of financial counselors in the clinic rather than discouraging the conversation. Moreover, we project that this concern will be less applicable as more information is available through comparative and cost-effectiveness research.

In exploring the reasons for encouraging discussion of finances between clinicians and patients for the sake of autonomy, we would also point out that there is justification for endorsing clinical discussion of financial concerns based on the important personal

opportunity costs posed by medical care. Social epidemiology points out how crucial factors other than medical care are to health status.²³ Patients in lower socio-economic strata – i.e., those with lower incomes and less education – are likely to have a shorter life expectancy than patients in higher socio-economic strata. At the end of life, patients in lower socio-economic strata are less likely to have pensions and other accumulated assets, and are less likely to be able to afford adequate housing conditions, adequate nutrition, and safe, peaceful neighborhoods – all of which may be just as important to the quality of a dying patient's end-of-life experience as their medical care.

To the extent that these factors matter in a terminal patient's life, it is helpful for clinicians to take a comprehensive approach in their medical consultations. This involves shifting towards a more nuanced view of the clinical relationship that takes into account the reality that medical interventions alone will not suffice to promote a good dying experience. For this reason, clinicians are well advised to recognize that costs incurred by patients through end-of-life medical care may potentially undermine other factors that contribute to their health status and other important aspects of their well-being.²⁴

Clinicians thus have good reason to discuss personal finances, and more broadly, various socio-economic factors, with their patients. In so doing, clinicians will be more attuned to their patients' circumstances and needs. As a result, clinicians will be better prepared to collaborate with patients to shape decisions in a way that best achieves the patient's end-of-life goals within the constraints of the patient's life circumstances.

The Connection between Personal Costs and Societal Costs

Though the justifications for clinical conversations about the societal and personal cost of care differ, it is important to note how tightly linked societal costs are to personal costs. The cost of any particular treatment that a patient receives is quite likely to be paid for both by the patient's insurer and by the patient personally. When a drug is expensive for society, the out-of-pocket costs also tend to be high. One prime example of this is cancer drugs. Once the cost of a drug reaches a certain cost threshold for society, they form a new tier of drugs (tier four) where out-of-pocket costs rise dramatically.²⁵ Because of this, strategies to reduce personal costs are likely to have the additional benefit of reducing societal costs, and vice versa. Hence while there are important reasons to approach the discussion of personal and societal costs differently, the costs themselves tend to vary in relation to one another.

The Nature of the Discussion

The nature of clinical discussions of cost should reflect the need for fairness and concern for the patient's health and other interests. Though discussions of *societal* costs are important and ought to be pursued, beginning clinical conversations by referencing group costs is unlikely to be the most sensitive or effective approach unless doing so is important for maintaining honest communication. Over time, if hospitals and insurers encourage more cost-effective care, societal costs will need to be increasingly incorporated into clinical discussions. For the moment, however, broaching the topic of societal costs is unlikely to be appropriate or well received at the end-of-life unless required for transparency.

On the other hand, research indicates that patients are likely to be receptive to discussions of *personal* costs in the clinical encounter. A qualitative study done in California, for instance, revealed that patients generally find it appropriate for doctors to broach the concept of personal expenses.²⁶ However, when physicians make medical decisions that are influenced by cost, patients have indicated a desire to be reassured that cost was not the only or the main consideration.²⁷ For this reason, it will be important for cost conversations to be secondary to clinical conversations regarding the health of the patient.

When costs are broached, the conversation will need to use empathetic communication strategies, during which physicians ought to foster joint decision making with their patients.²⁸ Without reaching a decision together, patients will feel that important care was taken away from them. One member of a focus group said, “When they don’t let you [receive a certain treatment], there is always a thought in the back of your mind, ‘they should have given me that, I could have been better.’”²⁹ Patients have reported feeling that conversations regarding cost were most helpful when the physician expressed sympathy for their financial constraints, informed them about the least important medications to take, referred them to drug payment programs, asked if they could afford prescriptions, and passed along information on where to get less expensive medications.³⁰ In the same way that doctors commonly encourage dying patients to consider how they want quality of life to enter into their decision-making regarding end-of-life treatment, they should similarly encourage the patient to deliberate about how they want the cost of end-of-life treatments to affect their end-of-life choices.

Physicians will need to be caring, sensitive, open and non-directive when engaging in these conversations. A doctor might introduce the concept of personal costs to a patient for the first time in the following way:

As we consider what treatment is best for you, I will mention a number of treatments. The treatments vary in how effective they are, how many medical side effects they have, and in how expensive they are. We will aim to find a treatment plan that best suits you. I generally try to take this approach with all my patients. If you have any personal concerns that are important to think about while we are making these decisions, please let me know about them. I know, for example, that a person’s financial situation might be affected by the cost of medical care. If you would like, we can talk about how we can best manage your treatment in a way that is sensitive to your financial concerns.

The physician is attempting to be open about the realities of his or her practice, while focusing on the personal financial needs of the patient. In so doing, the physician is allowing the patient to control the role that they want costs to play in their clinical discussions.

During the conversation, it is reasonable for the clinician to provide a range of therapeutic options that vary in cost along with the probability of success, convenience or expected duration of survival at the point of terminal illness. Data suggests that patients would find this appealing. For example, one study (n=5085) revealed that two-thirds of patients would consider drugs that had lower effectiveness, higher chance of side-effects, or higher dosing frequency if they were less expensive.³¹

The most robust conversations are likely to allow patients to choose from a set of options for more or less intensive care with stopping points that are dictated by prognosis, functional status, and quality of life. Certain markers such as failure to respond to a first or second line of standard treatment regimens and severely limited functional status could trigger a shift to the mode of comfort care. This approach requires acknowledgement that the ability to accurately predict when the end of life will come can be limited.³² If the patient indicates a desire to have cost incorporated into the decision-making process, the conversation should minimally include a set of treatment options that ranges in cost-effectiveness, education regarding the most (and least) important medications to take, and referrals to drug-payment programs.³³

The Timing of the Discussion

We suggest two strategies that clinicians might use to foster effective and sensitive discussion of end-of-life costs with their patients. The first is to encourage discussions of the financial ramifications of illness throughout the illness trajectory so that attention to costs becomes routine. A few examples illustrate how such an approach might be useful to patients and might set the stage for such discussions at the end of life. For example, patients with chronic diseases are likely to be very appreciative of doctors who discuss the comparative convenience, effectiveness, and price of any aspect of their medical regime that requires chronic or even life-long administration. If a patient with a chronic illness has any sense of urgency about finding affordable, long-term care, be it medications, medical supplies, physician visits, or allied health services, a physician's recommendations will be very helpful.

Consider another example, involving choices that go outside of the sphere of medical care alone. A cancer patient may be considering whether to be treated at a hospital near home or at a distant cancer center. While the distant cancer center may offer some advantages related to coordination and expertise of care, treatment closer to home may allow the patient to continue working on a more regular basis through much of the long course of combined surgery, radiation, and chemotherapy. The closer option might thus offer the advantage of greater financial security. Such a patient is likely to be valuably helped by the clinician who offers to have an even-handed discussion about these complicated options. One might imagine that the discussion continues as the illness evolves. For example, if it becomes apparent that the patient is developing advanced cancer, discussions about whether extremely expensive cancer treatments offer enough benefit to be worthwhile or whether the disease course is serious enough to warrant retirement may be very helpful to the patient.

Given the evidence regarding the financial burdens faced by chronically ill patients, and by cancer patients in particular, it seems particularly defensible to encourage clinicians to adopt this strategy of inquiring early on of their patients whether they are worried about their finances and whether they would like cost to be incorporated into treatment discussions. Offering patients the opportunity to select less expensive treatment options, addressing the impact of illness on the family's well being, and making referrals to financial counseling may be particularly welcome strategies. In so doing, a primary care provider may set the stage for comfortable discussions of financial worries closer to the end of life.

The second strategy to effectively and sensitively broach the topic of cost before the end is near is encouragement of a financial dimension to be added to advance care planning. Exploration and anticipation of choices before the end of life will offer patients adequate time to consider their goals and choose a strategy appropriate for them.

For example, a patient who is beginning to experience cognitive impairment and learns that she is likely to develop dementia might want to specify in her advance directive that she has financial preferences in relation to her choices for long-term care. In particular she may have commitments to her children and grandchildren's future projects that matter more to her than the length of her life. While it may not be possible to anticipate the specific details of the very end of her life, these preferences may help her clinician and family make decisions about nutrition and hydration, antibiotics, and other acute and long-term care treatment decisions.

Another person with this same diagnosis and similar desire to help her family may nonetheless differ in her religious views. She may want to be sure that she will get nutrition and hydration via a feeding tube when she can no longer feed herself. After her clinician encourages her to have discussions with her family, she might incorporate these wishes into

her advance directive by specifying that she would like to have her grandchildren care for her at home in return for a college fund.

Discussions of cost in advance care planning may be especially important given that the majority of patients lack the capacity to make their own medical decisions by the time they reach the end of life.³⁴ In the absence of a written advance directive or verbal discussion regarding a patient's end-of-life preferences, often the next of kin are responsible for making medical decisions on behalf of the patient without adequately understanding their wishes. This will be particularly problematic if they are asked to evaluate how the costs of treatments ought to weigh into the treatment decisions. The spouse or children of a dying patient are likely to experience one of two conflicts when considering cost in evaluating medical decisions for someone else. Either they will have a conflict of interest regarding their inheritance, which may be negatively affected by the cost of expensive, end-of-life treatments, or they may experience an emotional conflict regarding their obligation to pursue the most aggressive care to avoid feeling (or being perceived by others as) insufficiently caring. In either case, family members may be aided in acting as surrogate decision makers, if the ill family member has explicitly articulated financial concerns and goals during advance care planning.

In suggesting that financial concerns be explicitly addressed in advance care planning, we would make several points that apply to advance care planning in general. First, patients should be advised to have a discussion with the family along with preparing a written document.³⁵ Anticipatory discussions may help to improve their ability to manage future needs. Indeed published studies indicate that family members who have had an opportunity to have preemptive discussions of treatment preferences with patients feel more comfortable acting as surrogate decision makers.³⁶ A second concern is that patients and physicians will be reluctant to broach the topic of the end-of-life finances just as they have been reluctant to engage in advance care planning as a whole. We contend that when discussed in a manner that is supportive and non-threatening, many patients will welcome the chance to discuss this topic since it is quite likely to be weighing on their minds. Third, patients are not necessarily good at affective forecasting – knowing how they will feel at some time in the future.³⁷ Some will change their minds. Thus, for those patients who remain conscious and able to participate in decisions, the opportunity to revise their previously expressed wishes should be made explicit when death approaches.

Through these strategies, clinicians can avoid abruptly and insensitively introducing financial issues at the conclusion of a person's life when one would prefer to address the painful and important issues of spiritual and existential loss that are appropriately the focus when a person is dying. Furthermore, encouraging patients to discuss the financial consequences of their illness earlier will address the financial burden that they are quite likely facing on an ongoing basis and will allow them to make trade-offs at a time when they can plan for the end of their life in a more controlled fashion.

While we have suggested that it is appropriate to discuss financial concerns about end-of-life care with patients before death is imminent, we recognize that many therapeutic decisions with potentially profound cost implications are often made close to the time of death. At this point, decisions about whether to use or forgo life-sustaining treatments are no longer abstract considerations about the future and are likely to be contingent on many factors that only crystallize as death comes close – including quality of life, probability of benefit from further treatment, and expected gain in survival. Patient and family religious beliefs and inclinations to fend off death or accept it are all likely to influence treatment decisions. These decisions are made all the more difficult while families are likely to be preoccupied and vulnerable and thus hard-pressed to collaborate in making carefully reasoned decisions.

If costs are going to be discussed at this juncture, two points seem most salient. First, the discussion should be handled as gently and supportively as possible. Secondly, as we have suggested above, the introduction of the matter of cost earlier in the illness trajectory may make the discussion of cost at this point more comfortable.

Some Caveats

One concern that must be addressed if the financial aspects of treatment decisions are to be discussed in the clinical encounter is that financially disadvantaged patients may be more likely to forgo expensive care due to personal costs than wealthier Americans, and consequently, they may bear the brunt of the burden in reducing health care costs for all. Without systemic changes, this is likely to be the case. The opportunity costs of pursuing expensive end-of-life treatments will be greater for individuals with few financial assets. Though the wealthy might have reasons to avoid aggressive and expensive treatments at the end of their lives, the financial factors motivating the poor or low-income patient to do so will likely be more salient and immediate. In so far as reductions in cost are for the benefit of all, not for the benefit of the individual patient, it would be unjust to allow the burden to fall more heavily on one particular group, especially given that the financially less-well-off already have worse health outcomes.

Addressing this inequity fully means that public and private insurers must minimize disparities in end-of-life coverage. Primarily, that will entail a determination of what qualifies as a fair and decent minimum of care at the end of life. That minimum ought to be covered for every beneficiary. Ideally, the amount of co-pays and out of pocket expenses ought to be an inverse function of income status, thus minimizing the disparity in the incentives for members of each group as they make end-of-life treatment choices. Certainly efforts to provide nearly universal health insurance move the U.S. toward more equitable financing, and begin to address this concern. We recognize that more fully attending to these disparities is a tall order, one that will likely not be met in the near future. However, conversations that explicitly address the costs of care are advisable nonetheless since they remain likely to mitigate the burden of health care costs at the end of life. As low-income groups are already forced to forgo needed care due to cost, a physician's help in navigating patients to the most effective care they can afford is a reasonable approach even under non-ideal circumstances.

By advocating for discussions of cost with patients, we face an additional aspect of the concern regarding inequity. Disadvantaged patients might also be more likely to agree to forgo care to which they are entitled for several reasons. Poor and working class patients are not going to be as educated, empowered, or entitled as richer, middle class patients. Hence they will be less well equipped to argue their case with a doctor. Moreover doctors may be more likely to try to persuade lower income people to forgo care, since it will be easier for them to agree and there are likely to be fewer social consequences than would be the case in having such discussions with their socio-economic peers. It will be very important for clinicians to recognize these hazards and to conduct discussions with sensitivity to, and awareness of, these issues.

Another caveat is that significant time, resources, and information may be required for clinicians to properly discuss financial aspects of care.³⁸ However, it need not be the case that physicians shoulder this role entirely nor do they need to be completely well versed in financial matters. Physicians should understand the need to address financial issues with patients and know to whom to refer patients and where to get financial information. When physicians feel that they are ill equipped to address patients' financial needs, they ought to refer patients to other resources, such as financial counselors or social workers. However,

physicians are still able to contribute, and broaching the subject alone is a worthwhile endeavor for their limited time. We acknowledge the dearth of available information regarding comparative effectiveness. While initiatives such as the Patient Centered Outcomes Research Initiative should help to fill this gap, more information related to the costs of care will be needed before our approach can be most effectively implemented.³⁹

A final caveat relates to the need to determine whether such conversations can be conducted in a way that is helpful to patients rather than overwhelming and confusing. More data are also needed to ensure that clinicians and patients can have such conversations in a way that does not undermine patient trust in the physician's commitment to their overall well-being. It is striking that even in the face of such unanswered questions, an American Society of Clinical Oncology task force issued a Guidance Statement on the Cost of Care advising oncologists to speak about financial issues with their patients.⁴⁰ Clearly there is a perceived need to bring discussions of costs into the clinical encounter.

Will Discussions Contribute to Reduction of Health Care Costs?

While we have proposed that conversations about end-of-life costs in the clinical encounter may contribute to reducing health care costs by encouraging people to consider pursuing less expensive care, this is currently a conjecture. Individuals who are predisposed to choosing a less expensive or palliative approach rather than pursuing life prolonging treatment at all costs, may be likely to do so regardless of whether their physician opens the door to discussing the financial ramifications of treatment choices. However, those patients who are not aware of their options or have not fully considered the full range of consequences of their treatment choices may take these conversations as an opportunity to consider a wider array of treatment options. This could lead to decisions that, in accordance with their interests, it is better to forgo treatments or choose less expensive options than they would have pursued otherwise. Many have proposed that by simply following patient preferences at the end of life and engaging in discussions of advance directives as we currently do, we can reduce health care expenditures.⁴¹ In fact, one study showed that of people with living wills, 93% were more willing to use limited care.⁴² Though patients who prepare advance directives may be a selective group, these data demonstrate the potential for advance care planning to reduce end-of-life health care costs. There have been some legitimate concerns, on the other hand, that the potential savings generated through this mechanism have been overstated.⁴³ Incorporating an explicit discussion of cost in advance care planning may or may not result in more people opting for less expensive care. But we would suggest that reduction of overall costs is not the sole justification for discussing costs with patients. Clinicians will also be helping patients to make the right choice for themselves, which is good in itself.

Conclusion

Finding strategies for discussing end-of-life costs in the clinical encounter will not be straightforward. Patients might be initially averse to discussions regarding the financial aspects of clinical decisions in medical care, and will vary in the extent to which they become comfortable with such discussions. Determining how such discussions might be incorporated into the medical conversations in a manner that will educate and engage patients in an appropriate and non-threatening manner is important. For this reason, clinicians ought to avoid formulating the options as a dichotomous choice of attending to cost at the end of life versus ignoring cost at the end of life. The preferable approach may be to allow patients to determine how they want costs to be involved in their discussions of care. Pursuing such discussions will be easier if the way is paved by more serious national discussions on limit-setting and the need to engage patients generally in the concept of cost-

conscious medical decision making, which will help them grow accustomed to making and reflecting on trade-offs in their personal medical care.

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