Insight

A Better Approach for End of Life Planning

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Executive Summary

The U.S. medical system is expensive, with many observers focusing on the high cost of end-of-life care. Yet, 98 percent of patients near the end of their life want some level of care short of the medical default of "all possible care." Conservative health-care principles respect individual freedoms and would permit patients to control their care.

In addition, nearly 70 percent of ailing seniors will eventually become unable to communicate their care preferences. The resulting gap between what patients want, and what they receive is usually the result of fear, lack of information or misinformation, and poorly aligned incentives. End of life care planning can help fill this gap, put Americans in control of their own care, and make patients' final stages of life more comfortable and dignified.

Introduction

Americans today are unique in world history for the level of medical science and their relatively unrestricted access to health care interventions with the potential to save and extend life. The impact of modern medicine on our collective understanding of death has shifted away from recognizing death as an unavoidable part of life, towards viewing death as something that can be fought and defeated.[1] As a result of this mentality, end of life care is often aggressive, expensive, and misaligned with patients' preferences.

Given the choice, most people would prefer to spend their last days in their own homes, rather than in hospitals or other institutions.[2] Yet over half of Americans 65 and older pass away in acute care hospitals or nursing homes.[3]

The need to ensure that individual autonomy is considered and respected near the end of life is rapidly increasing. Every single day, over 10,000 baby boomers turn 65 years old and gain Medicare eligibility.[4] Between 2010 and 2050 the number of Americans on Medicare will double to 84 million, octogenarians will quadruple to 8 million,[5] and the ratio of potential caregivers to Americans over 80 years old will dive from 7-to-1 in 2010, to 4-to-1 in 2030.[6] Though we are fortunate that medical science has been able to extend the number of years a Medicare beneficiary is expected to live by about 300 percent,[7] Americans have not changed how they talk about and plan the final stages of life.[8]

This paper seeks to illuminate what seniors—Medicare beneficiaries specifically—desire near the end of their life, the gap between those desires and their experience, what doctors experience as health care providers treating patients in the final stages of life, and how advance health care planning can improve the experience for everyone involved.

Living Well at the End of Life

HOW DYING PEOPLE WANT TO BE TREATED

In recent years, studies have investigated what is important to Americans as they approach their last years and months. Unsurprisingly, patients are primarily concerned with their physical comfort, mental alertness, and the well-being of their families.[9] Yet the care they receive is often at odds with these preferences.

Among those seniors who have taken the time to spell out for their physicians how they envision their final days, only two percent of respondents requested "all possible care."[10] A study of patients who understood themselves to be terminally ill with advanced cancers found that only 17 percent of respondents expressed interest in "life extending treatment."[11] Instead, most patients valued quality of life over extending it.

Physical comfort comes primarily from palliative care, which is provided without the intent to prolong the patient's life or battle any diseases.[12] Instead, palliative care primarily focuses on managing pain, enabling comfortable sleeping and eating, and keeping the patient clean.

Mental and spiritual comfort are ranked nearly as highly as physical comfort when it comes to the end of life. Remaining mentally present ranks as a top priority, and may even take precedence over pain management for some. Near the end, confusion, dementia, anxiety, and depression are common experiences which may be exacerbated by medications prescribed for pain.[13] Many would prefer to spend their last days at home, but deaths occurring in institutional settings have become more common.

HOW PATIENTS WANT THOSE THEY CARE ABOUT TO BE TREATED

American seniors have reported that the well-being of their loved ones – emotionally, financially, and otherwise—was one of their top priorities when facing the end of their life. [14] Though it is not often discussed openly, end of life care can be devastatingly expensive for families, especially when a patient has not made clear a desire to avoid expensive life-extending treatments. In addition, the days immediately before and after the death of a loved one can be emotionally taxing. Most people recover from the death of a loved one enough to continue living their lives within a few weeks or months, but some experience complicated grief, which may persist for months or even years following the death.[15] Complicated grief often requires professional interventions, which can become economically draining or even threaten the sufferer's employment and relationships.

Complicated grief is more likely to be found in families where members were not expecting the patient to pass away, where the family members continued to hold an unrealistic expectation of recovery, where the patient left no clear guidance about treatment decisions which were then placed on the family, and where family members disagree with treatment decisions made by the patient or another family member.[16] According to a 2012 study of patients in California, among adults who have not had end of life care planning discussions with their loved ones, only 13 percent said it was because their loved ones did not want to discuss it; often the patient avoids the discussion for fear of upsetting family members, even though it may help those same family members cope in the long run.[17]

HOW DYING AMERICANS ARE CURRENTLY TREATED

Despite overwhelming conformity when it comes to what Americans claim is important to them at the end of their life, patients do not always receive the level of care they desire. This happens when patients fail to plan

ahead or their wishes are not followed, and the default standard of care is "all necessary care." This standard of heightened levels of care contributes to the estimated $810 billion in unnecessary, unbeneficial, or wasteful care provided to Medicare beneficiaries who spend most of their Medicare dollars in the last year of life.[18]

Despite the fact that only 18 to 36 percent of Americans have planned ahead, roughly half of Medicare beneficiaries are mentally or physically unable to participate in decision making in the last month of life, and about 70 percent were unable to participate in their last few days.[19]

OBSTACLES TO OBTAINING PREFERRED CARE

The first major obstacle for terminal patients is not fully understanding their prognosis. It is common for physicians to explain a diagnosis without making sure the patient understands the prognosis. Focus on minute possibilities for recovery may leave patients with overly optimistic expectations of recovery, and by the time they understand the situation fully, it may be too late.[20] Furthermore, physicians receive an average of only 17 hours of training in palliative care in medical school, and little or no training on how to communicate with patients about the full spectrum of end of life care options.[21] As a result, physicians may lack the information and skills necessary to navigate the breadth of care available at the end of life.

Another contributing factor to Americans foregoing advance care planning is a misunderstanding of the legal importance of having a plan in advance.[22] Surveys show members of low income and minority communities in particular may not be informed that providers need the patient's consent in order to provide or withdraw any course of treatment, and a pervasive fear exists that a request for anything less than "all necessary care" will give physicians carte blanche to refuse to provide treatments the patient does want.[23]

As problematic as the patients' failures to participate in advanced planning is, even when there has been some level of planning, patients' wishes are not always followed. One major reason for this is that the advance planning conversation is not documented. One study found that 83 percent of patients over 60 years old who had discussed their preferences for care had no record of the conversation or those preferences anywhere in their medical record.[24] Patients under 75 years old who had indicated to their physician who should serve as their health care agent or medical proxy should they become incapacitated had this information in their health records *zero* percent of the time; only 16 percent of those over 75 saw this information recorded. Even if a provider did record this information, studies show that the odds of it being shared with any of the patient's other health care providers are no better than 50/50. [25]

Advance directives, also known as living wills, are the most common type of formal advanced care planning beyond simply appointing a health care agent. Advance directives are tools through which patients may express preferences for how they would like to be treated under any given circumstance.[26] Unfortunately, these legal documents cannot predict or account for every possible outcome, so they are vulnerable to being incomplete or used incorrectly.

Numerous studies have found that as many as 40 percent of physicians do not fully understand how and when advance directives should be applied.[27] Confusion is especially common when the patient is experiencing an acute episode that is not directly linked to the chronic or terminal illness contemplated by the directive. Any perceived vagueness in the directive could also cause confusion, leading to the directive being put aside and a default standard of "all necessary care" being applied.[28]

Friends and family members are notoriously unable to accurately predict what level of care the patient would prefer, consistently allowing more medical interventions than the patient or even they themselves would want. [29]

Disputes within a family over end of life care may end up leaving provision of care at the default "all necessary care" setting, which could lead to interventions such as ventilators or feeding tubes when these would in fact be medically futile. Though the Supreme Court has held that removing life support is a protected right equivalent to the right to refuse these interventions in the first place, some families may find removing life support to be more difficult than declining it – especially if it was not explicitly discussed by the patient.[30]

Stereotypes and assumptions relied upon by medical proxies based on factors other than direct instructions from the patient also contribute to an excess of medical interventions. Studies have shown that Hispanics, Catholics, and African American Protestants—the demographics widely considered the most likely to request "all necessary care"—in fact often request levels of care below "all necessary care."[31] It has also been found that stories of negative experiences surrounding the death of a loved one, and related fear about one's own death, are pervasive throughout our society, and are shared among all racial, ethnic, religious, social, political, educational, and occupational groups; when it comes to dying, stereotypes based on religious, racial, and ethnic backgrounds fail to hold up.[32]

Medicine at the End of Life

Seniors and terminally ill patients are not the only ones facing confusion at the end of life. Doctors and health care providers generally have to walk a fine line between their role as healers and their role as agent for a person who is unlikely to ever heal. Serving as an agent for a dying person can be a distressing experience that may induce feelings of ineptitude or helplessness.

With these facts in mind, it is unsurprising that physicians are unlikely to take the initiative to begin a conversation about care at the end of life – in fact 90 percent of seniors in one survey claimed that their doctor had never mentioned end of life planning to them.[33] It is also unsurprising that many physicians attribute their failure to instigate these conversations to a fear that discussing death will cause their patients to lose hope.[34] This fear is unfounded, as studies have shown that seriously ill patients who have engaged in end of life care planning actually demonstrated statistically *better* health outcomes than those who did not participate in any advance planning.[35]

Another less flattering, though potentially important, explanation for the silence from physicians is that there is nearly no mechanism through which they can receive compensation for time spent on these conversations.[36] Most Medicare services are provided on a fee-for-service basis, where each screening, diagnosis, and treatment is coded and billed for separately. But there is no code for talking to a terminal patient, no way to bill for the extensive amount of time and resources it would require for a doctor to become informed about all available courses of action, and then sit down and explain them to the patient.[37] Today, these conversations are largely at the doctor's expense during time that could be spent on reimbursable activities with another patient.

In recent years, legislators have tried to address this misalignment of interests. The Patient Self Determination Act of 1990 requires most health care institutions to inform patients in writing that they have a right to create an advance directive.[38] This law is a good idea, but in practice usually manifests itself as one of many forms patients are asked to sign at check-in. This law also does not extend to individual physicians, so the topic of advance directives is only required to be raised when a patient is already experiencing an acute episode.[39]

Another more comprehensive attempt to end the institutional silence around advance care planning originated as §1233 of America's Affordable Health Choices Act, a predecessor of the Affordable Care Act (ACA).[40] This provision outlined a method of payment for physicians who spent time engaging in end of life care planning with their patients. Despite having the potential to improve individuals' experience at the end of their life while

managing costs, the provision was ultimately cut from the final bill, passed in 2010.

In the recent past there have been multiple attempts to reform how Medicare pays for end of life counseling, but have so far fallen short of passing through Congress.[41] A bi-partisan bill to reimburse doctors for end of life planning was introduced in June by Senators Mark Warner (D-VA) and Jonny Isakson (R-GA) with the support of various stakeholders.[42]

Finding Solutions

Because death is such a uniquely personal experience and each individual's fears and ideals about it are so specific, it would be impossible to create a one-size-fits-all answer to how care should be provided. Creating an advance directive has benefits, but they are misunderstood, inconsistently applied, and their usefulness is limited in scope. Appointing a health care proxy is an efficient means of easing the transition of decision-making power between the patient and his or her agent, but as is described above, does not always result in the patient receiving the care he or she would want. A better approach to planning for the end of life is needed.

BENEFITS OF END OF LIFE CARE COUNSELING

Health care planning, or end of life care counseling, is an alternative that holds the most promise for meeting the needs and desires of physicians, patients, and their loved ones. End of life care counseling would ideally be a collaborative effort between a patient, a health care proxy, the primary care physician, home health providers (if relevant), specialists, nutritionists, pharmacists, and any other parties the patient feels should be involved, such as a religious minister or social worker, and these people would be compensated for the time spent planning.[43]

By including all interested parties in the planning process, the patient may be assured that most eventualities will be discussed and accounted for. This will also guarantee that all treating physicians are aware of and have a record of the patient's preferences and plans, and that there is an opportunity to discuss the patient's choices so that the group is informed about the patient's reasoning in addition to their decision, and may therefore be more able to adapt to slight variations of the likely scenarios. A German study found that advance care planning of this type is more efficient than simply relying on an advance directive because it takes family and cultural relationships into consideration and allows the patient the opportunity to elaborate on what they want and why they want it;[44] this less rigid approach helps to "specify the process rather than the outcome."[45]

When asked, 75 percent of respondents in a 2012 study said they would "probably" or "definitely" be interested in having a discussion about their end of life treatment choices if they were seriously ill. This study also found that 81 percent of respondents believed compensating physicians or other health care providers for this time would be a "very good idea".[46]

If the care counseling team succeeds in creating a plan, the fact that they are all privy to it will likely increase the patient's chances of receiving the level of care he or she would prefer – whether it's home-based palliative care, all possible care in a hospital, or something in between. Several studies of the effects of advance care planning have found that planning that includes some limitations on treatment (about 98 percent) does in fact increase the chances of the patient dying in his or her own home.[47] The corresponding financial benefits of this were nearly exclusively seen in high spending areas of the country, where end of life care planning was associated with a drastic reduction in the utilization of life-sustaining treatment and hospitals, and an increase in the use of hospice care, contributing to up to $5,000 per patient in total savings.[48] Another study found, on average, the medical costs during the last week of life were about 36 percent lower for individuals who had participated in end of life counseling, which resulted in about $1,041 savings in the final week alone.[49]

In addition to the financial savings associated with end of life care is the effect on interpersonal relationships. Successful advanced care planning can contribute to a more trusting relationship between a patient and his or her health care provider, as well as relieving friends and family of some of the additional stress of making difficult care decisions.[50]

Conclusion

Despite the consensus that most Americans would prefer some level of care other than what they actually receive at the end of life, and despite the fact that most people would prefer less—and less costly—care, the largest health insurance payer in the country—Medicare—still has no mechanism for helping terminally ill patients effectively plan for end of life care. The physical, emotional, spiritual, and interpersonal effects of receiving care other than what is desired can be profound and long lasting. The graying of America's population will only exacerbate the impact of this disconnect between what patients near the end of life want and what they actually receive.

End of life care planning will be an important first step towards filling these gaps, and generating educational, financial, and societal support for this planning will be the key to making meaningful improvements to the way we provide care to patients at the end of their life.

[1] Committee on Approaching Death, Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life, 445 Institute of Medicine (2015); http://www.pallimed.org/2014/09/new-iom-report-dying-in-america.html.