

Advanced Care Planning and Advanced Directives

Effects on Autonomy and Spending

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I. Introduction

End of life care is a difficult yet important subject that few individuals truly wish to think about. The rates of chronic illnesses and cancer are growing, and technological advances can prolong life at advanced stages of illness. Cancer is the second leading cause of death in the United States, second only to heart disease. About 610,000 people die of heart disease in the United States every year—that's 1 in every 4 deaths according to the Center for Disease control and prevention (CDC, 2018). According to the National Cancer Institute (NCI), in 2018, an estimated 1,735,350 new cases of cancer will be diagnosed in the United States and 609,640 people will die from the disease. Current cancer mortality is 163.5 per 100,000 men and women per year, based on 2011–2015 deaths (NCI, 2018). Care for patients at the end of life is known as palliative care. Palliative care can occur in a hospital, skilled nursing facility, in hospice centers, or at home. According to an article by the Stanford School of Medicine, “Studies have shown that approximately 80% of Americans would prefer to die at home, if possible. Despite this, 60% of Americans die in acute care hospitals, 20% in nursing homes and only 20% at home. A minority of dying patients use hospice care and even those patients are often referred to hospice only in the last 3-4 weeks of life” (2017, p. 1).

Some evidence suggests that there are instances where procedures and medications are offered by physicians in a futile attempt to prolong life at any cost, despite the low probability of improving the quality of life or improving the health outcome. For example: costly chemotherapy drugs for advanced terminal cancer that will unlikely change the outcome of or the burden of disease and have serious side effect profiles. A study by the BMJ showed that out of 386 terminally ill cancer patients, 56% were receiving palliative chemotherapy, which is chemotherapy that is not used for purposes of curing the disease. The conclusion was “the use of

chemotherapy in terminally ill cancer patients in the last months of life was associated with an increased risk of undergoing cardiopulmonary resuscitation, mechanical ventilation or both and of dying in an intensive care unit (2014, p. -2). The study also indicated that hospital administered palliative chemotherapy was perceived to be most distressing. Regression analysis indicated that anxiety and depression accounted for most of the variance in quality of life. The use of chemotherapy has high levels of side effects such as fatigue, nausea, vomiting, migraines, hair loss, weakened immune system, etc.

In many end-of-life care scenarios, there is usage of feeding tubes, respirators, and other means that sustain life, even with little chance of improving morbidity or mortality. These procedures can maintain the respiratory, and cardiovascular systems of the patient. In many instances, treatments and interventions in late stage disease do not yield benefit equal to the cost and according to Fuchs, in those situations' treatments "constitute economic overutilization, even if it is not detrimental to health". (2011, p. 19).

A hypothetical example may help solidify this point in the reader's mind. Jane, a Medicare Beneficiary, is 79 years old and has been diagnosed with end stage congestive heart failure, comes into the emergency room having coded (no detectable heart beat) and a heart rate is brought back by Emergency personnel. She is in a coma, on a ventilator, with a feeding tube and has been given 3 different CT and PET scans to see if there are changes to her heart and brain activity. Her family is asked to make a difficult decision and decide to continue interventions and treatment. She spends 3 weeks in intensive care unit (average length of stay varies widely across demographics, illnesses, and severity of condition), after which she dies from complications. This is a very common example of a patient who did not have an advanced directive, leaving it up to family members to make decisions. If she had an Advanced Directive,

stating her preferences, she may not have been given life extenuating treatments, if those treatments did not align with her values and goals for her care.

According to the American Association for the Surgery of Trauma, “Mechanical ventilation is one of the most common interventions implemented in the intensive care unit. More than half of the patients in the ICU are ventilated the first 24 hours after ICU admission; comprised of individuals who have acute respiratory failure, compromised lung function, difficulty in breathing, or failure to protect their airway. Although lifesaving, mechanical ventilation can be associated with life threatening complications, including air leaks and pneumonia. 790,257 hospitalizations involving mechanical ventilation in 2005, representing 2.7 episodes of mechanical ventilation per 1000 population; estimated national costs were 27 billion representing 12% of all hospital costs” (Kirkton, 2011, p. 1).

When it comes to end of life care, some individuals prioritize comfort, others prioritize cost, while others desire the greatest amount of care possible. Opinions and preferences vary widely across cultures, religions, and personal values. One thing that is agreed upon is the individual autonomy to choose what constitutes quality of life for oneself and to make choices accordingly.

The cost of end of life care is becoming increasingly more relevant as 7,500 baby boomers are aging into the Medicare system every day. The use of taxpayer dollars on quality services that meet individual demand, protect personal autonomy, while containing cost, is a top priority for health economists and lawmakers.

An Advanced Directive and a Care Plan Conversation, also known as Advanced Care Planning, are two processes that promote cost savings and increase in personal autonomy. This paper argues that all Medicare applicants should be required to accept or deny the opportunity to

participate in an Advanced Care Planning discussion and sign an Advanced Directive. Making an adjustment to the current default will increase patient autonomy, allow hospitals to provide the best quality medical care, and can alleviate high costs associated with end of life care. The following is a proposal that would involve inserting the question of Advanced Care Planning in the Social Security Medicare Application in the 3rd section that asks about employment and other health insurance coverage. The verbiage would be in a two-question format: 1) Do you currently have an Advanced Care Directive? If no, 2) Are you willing to participate in an Advanced Care Facilitated Conversation within 6 months of your application and complete an Advanced Directive? This is not an exact suggestion of a policy, but simply a representation of how the proposal could be implemented in the application process. This policy would be a change from default to an “active choice policy”.

II. Literature Review

The results of a literature review regarding the prevalence and effectiveness of the Advanced Care Planning process and Advanced Directives in healthcare, revealed a wide range of important considerations. In a report from Palliative Medicine on the effects of advance care planning on end-of-life care, 113 relevant studies were reviewed that concluded that Advance Care planning was found to decrease life-sustaining treatment, increase use of hospice and palliative care and prevent hospitalizations. The overall results of the studies reviewed concluded that having a complex advance care planning intervention documented, increased compliance with the patient’s end-of-life wishes to forego extraordinary measures. (Brinkman-Stoppelenburg, Rietjens, & Van der Heide, 2014). Most of the studies were observational (95%) originating in the United States (81%) and were performed in hospitals (49%) or nursing homes (32%). A few examples of the literature included articles in *The Journal of Clinical Oncology*,

the Journal of Critical Care Medicine, the Annals of Internal Medicine and Archives of Internal Medicine.

The Journal of Clinical Oncology writes, in a study they conducted on the attitudes towards care in individuals with advanced illness, that at the time of inclusion, 20% of all patients had discussed their wishes concerning medical treatment at end of life with a primary care physician, and 39% had expressed attitudes to their relatives. Wishes discussed during ACP process concerned pain management, place of death, euthanasia, and conditions of foregoing treatment. The study found that patients that discussed wishes were less inclined to strive for length of life and were more inclined to strive for quality of life. At the time of inclusion only 10 of the patients had an AD, and results showed that they were less inclined to strive for life prolongation, and were more likely to refuse life-prolonging treatment options (2016, pp. 1-4).

The Annals of Internal Medicine reviewed the effects of advance directives on medical treatment in a randomized, controlled trial, and reported that most surveys conducted suggested that patients “are calling for less, not more, of the expensive, high-technology treatment often used in terminal phases of illness” (2012, p. 1-3). Interestingly, the study found that having only a written Advance Directive (AD), without an ACP process in place, had no significant positive or negative effect on the care the patient received or the medical treatment charges.

An additional study conducted by Singer, et al., interviewed patients about the ACP process, and found that patients were more interested in the social process of ACP, and not only on completing the written AD. According to the report, patients had the “underlying goal of exercising control of their own care “(1998, p.879).

The findings of Thomas J. Prendergast MD. conclude that preferences for care are not fixed, but emerge from a process of communication, discussion, and feedback. He emphasizes

that an approach based on this type of communication will have positive results and can foresee this as a hopeful model for physicians working in intensive care units (2001, p. 1).

These series of articles led Brinkman-Stoppelenburg, et.al., to the coherent conclusion that communication-based approaches using (ACP) are effective and not only reduce the amount of life-prolonging care but are also working to promote better quality of care and greater satisfaction for patients and families, “to increase compliance with patients end of life wishes” (2014, p. 2).

CMS and the Medicare Learning Network offers a comprehensive Advance Care Planning document that guides physicians and informs Medicare patients on their options for receiving Advanced Care planning and assists them to “make important decisions about their care and helps to control the type of care they receive and when they receive it” with a summarized explanation of what a voluntary ACP is. (CMS, Medicare Learning Network, 2018).

Weston explains why Advance Care planning is “one of the biggest challenges for clinicians” (2001, p. 438). He gives a good overview of why physicians struggle with Advance Care Planning. Firstly, many older physicians were taught a paternalistic approach to providing care, having the time to have meaningful discussion is difficult to incorporate into their practice and “finding common ground with patients about management” were other barriers cited. (2001, p. 438).

The BMJ reported results on a research study conducted on 309 legally competent medical inpatients that were followed for six months or until death. The Detering, et al., article reports that the study showed effectiveness of using the Advanced Care Planning process using non-medical advance care planning facilitators to assist in identifying and respecting patient’s

wishes about end-of-life care. Patients were randomized to receive usual care (no advanced directive) or usual care plus facilitated advance care planning. The aim for the randomized advanced care planning group “aimed to assist patients to reflect on their goals, values and beliefs; to consider future medical treatment preferences; to appoint a surrogate; and to document their wishes” (Detering, Hancock, Reade & Silvester, 2010). The primary outcome for the study was whether a patient’s end of life wishes was known and respected. Results were measured and determined by two separate researchers. Other outcomes included patient and family satisfaction with hospital stay, using a five-question survey of patient satisfaction. Levels of stress, anxiety and depression were measured using a 14- item hospital anxiety and depression scale tool that is a validated to measure symptoms of anxiety and depression. Additionally, an eight item, end of life questionnaire was developed and used to assess a family members satisfaction with the quality of a patient’s death, from their own and perceived perspective of the deceased patient. This study extrapolated that “from the perspective of the patient and family, there was a diminished likelihood of stress, anxiety and depression” when an ACP was in place (2010, p. 9).

Explaining how the use of a formal ACP process could improve the patient experience at end-of-life, a group of Advanced Practice Nurses and physicians, found that “only 31% of patients with advanced cancer had participated in a formal ACP conversation (Zhou, Stoltzfus, Houldin, Parks, & Swan, 2010, p. 400). This results in cancer patients dying with unmet needs, “spending their last days of life in physical, psychological, emotional, social and spiritual pain” (Wood, 2002, p. 400). However, the paper reported that when interviewed, 60-70% of American patients are willing to discuss advance care planning if they are asked to do so by clinicians. This suggests that by implementing ACP formally, at the beginning of care, patient wishes could

be identified and respected, while reducing the unnecessary suffering which results in added financial burden as well.

Scott et. al., describes how a public awareness campaign, coupled with implementation of formal ACP programs should be sponsored by hospitals in collaboration with health services, such as Medicare to make “system-wide ACP a reality.” (2013, p. 662). The paper summarized the status of healthcare at end- of- life, stating that up to a quarter of health budgets are spent on inpatient care during the last 18 months of life, without any real evidence that these efforts extend survival or improve quality of life (Zhou et al., 2010, p. 662). The paper describes how to provide strategies for embedding advance care planning into routine care to avoid unwanted, financially burdensome care.

III. Advanced Care Planning and Advanced Directive

The Advanced Directive (AD), is a legal document that coincides with a durable power of attorney, that outlines possible treatments, procedures, medications, tests, and medical equipment, that could be used in the case of injury or illness where the patient cannot speak for themselves. It lists the procedure, medication, test or equipment and then gives a yes or no option to accept or decline the treatment. It is signed by the power of attorney and the patient. The Advanced Directive must be signed with the individual being in a completely coherent state of mind.

The second procedure that should be paired with AD, is the use of Advanced Care Planning (ACP). ACP involves a patient meeting with a certified, trained facilitator that can be either the primary care physician or social worker. The facilitator discusses healthcare treatment preferences that reflect what the person feels is vital to his or her quality of life. The patient

identifies an advocate who also attends the conversation and is usually the individual's power of attorney. The advocate must be willing to accept wishes of the patient in a situation where the patient cannot speak for themselves and will advocate and make decisions for that patient. The facilitator provides education, consultation and written materials that describe each possible intervention in detail and provides enough information to direct the patient's decisions in line with their values for end of life. The conversation ends with an Advanced Directive being drafted and signed at the time of the appointment. The Advanced Directive is then uploaded to a national database that holds health care documents and can be accessed across multiple hospital and healthcare settings. This is imperative for individuals who may travel to other states across the U.S. Physicians and family members will be able to access these documents. Many patients will participate in the Advanced Care Planning process at the time of an appointment with their health care provider. The conversation portion of the ACP is a vital part of the process as it helps the individual understand the interventions in context and is part of the choices the patient ultimately makes about end of life care.

Advanced Care Planning is an effective method of reducing spending and lowering cost. Because there is an increased probability of Medicare patients receiving end of life care ACP is important for those in Medicare whose treatments for end of life care are being paid for with taxpayer dollars. The Medicare Advisory Committee reports that a quarter of the total Medicare budget is spent on beneficiaries in their last year of life, with 40% of that cost exclusively spent on the last 30 days of life. They also found that 22% of terminally ill patients die in the hospital ICU and have hospital bills ranging from \$18,500 to \$40,200. (Aherens & Fowler, 2001, p. 94).

Patients that have an Advanced Directive have shown to have less overall spending on end-of-life care. A study conducted by the University of Michigan research team, analyzed data

on Health and Retirement Study participants who had died between the years of 1998 and 2007. The beneficiary records were linked to Medicare claims and the National Death Index. The study conducted interviews with the next of kin of the respondents after their death. The sample contained 3,302 Medicare Beneficiaries. The conducted study found that there was more spending for individuals that had not participated in ACP, than those that did. It was especially apparent in geographical areas where spending was higher on average. Adjusted spending for those without an ACP was on average \$39,518 and those with and ACP and AD were \$33,933(Langa, Suzman, & Weir, 2011, p. 1-6). An article in The Journal of Palliative Medicine found that “ACP increases documentation and was associated with a reduction in overall costs driven primarily by a reduction in inpatient utilization” (2017, p. 1). The study emphasized increased use in comfort-oriented care, statistically significant reductions in utilization of inpatient care, reduction of days in the ICU and an increase in hospice use with “less risk for in-hospital death (2017, p. 5). The evidence suggests that the default is not a good indicator of preferences. The use of Advanced Care Planning is also effective in reducing the amount of asymmetric information between the patient and physician. If the physician is aware of what the wishes of the patient are, they have greater knowledge of what treatments to prescribe and can lead to greater efficiency and lower costs.

IV. Policy Implications

A policy change, to include the ACP in the application for Medicare, is a beneficial way to lower costs. It would not require any new agency, staff, bureaucracy, or institution. Training for Advanced Care Planning is already integrated into the education of doctors, nursing staff, and hospital social workers, making it a cost-effective solution to possibly reduce over utilization of high cost medical services, and promotes patient centered care. Programs that allow you to

complete Advanced Care Planning online, using in-depth questionnaires, are improving efficiency of the program.

Since the mid 1970's, legislation has been moving in the direction of more patient autonomy in care. In 1976, California was the first state legally to sanction advance directives, in the form of living wills. Since that time, judicial and legislative actions have affirmed patients' rights in decision making at the end of life by standing strongly on the ethical tenets of patients' self-determination and autonomy. According to an article by Alasdair Maclean, "It is now trite to note that competent adults have the legal right to give or withhold consent to medical treatment. However, when the individual lacks the capacity to make a contemporaneous decision, an alternative justification for treatment is required. Medical advances mean patients could be kept alive for prolonged periods of time in minimally cognitive states. Advanced Directives are a way in which an individual can retain decisional authority" (2008, p.1). The 1990 Self-Determination Act mandated health care institutions to inform patients of their rights to refuse or discontinue treatment and required these institutions to ask patients whether they have ADs and to make those documents available (Warner-Stevensen & O'Donnell, 2015). This direction of greater patient centered care has led to the development of Advanced Care Planning. Recently, the centers for Medicaid and Medicare services is proposing to add a separate set of payment codes and a payment rate schedule for ACP between beneficiaries and healthcare professionals and physicians paid under the Medicare Physician fee schedule. They state that this addition would benefit beneficiaries and better enable seniors and other patients to make decisions and gain more control over the type of care they receive and when they receive it (Jacob, 2015).

The use of Advanced Care Planning has shown to be effective at increasing patient autonomy. The current default of the greatest amount of life sustaining treatment may or may not align with patient wishes for their care, and that if given the opportunity and education, patients might choose a lesser intervention that was geared toward comfort, and symptom and pain management. To improve end-of-life decision-making for an increasingly multicultural and aging population, there should be an increase in the flexibility of treatment plans and allowance of decision-making strategies used with capable patients to encompass diverse perceptions of autonomy. The use of ACP has shown to greatly improve patient decision making and gives patients the ability to take charge of their own care trajectory and creates more involvement in their treatment plan. Studies show that when signed documents reflect specific targeted outcomes, it lowers patient anxiety which leads to greater overall quality of the care provided. (Warner-Stevenson & O'Donnell, 2015). A UCSF study used Medicare metrics to determine whether advanced care planning influences quality of end-of-life care and to assess if specifically expressed goals of care were received. This large population-based study of older adults found that 92% of patients stated a preference to prioritize comfort, and care received was associated with the expressed wishes of the patients, determined as a 95% confidence interval (CI). Results also show that "ACP is associated with less in-hospital death and greater hospice use" (Bischoff, Sudore, Boscardin, & Smith, p.214).

Although the use of ACP and AD greatly increases autonomy and increases patient centeredness, a 2003 Agency of Healthcare Research and Quality literature summary found that fewer than 50% of the severely ill patients that were participating in the study had an Advanced Directive on file. Only 12% of those patients with an AD had received input from a physician during its development. In instances where patients did not have an AD, physicians were only

accurate 65% of the time predicting patient preferences (Butler, Ratner, Shippee, & Kane, 2014, p. 1).

Participation in Advanced Care Planning is influenced by the Status Quo, or default rule. As is well documented in the behavioral economics literature, Douglas Hough explains “Many situations have an unavoidable initial position or “default”, and where you start makes a difference and is very powerful” (Hough, 2018, p. 13). The tendency for people to favor any option that is presented to them as the default, is known as the Status Quo Bias. Differences in the default option presented will affect rates of participation. “These departures from rational choice behavior are said to be a result of “cognitive biases” that is systematic failures to act in one’s own interest because of defects in the decision-making process” (Wright & Ginsburg, 2012, p. 1034).

The Status Quo Bias manifests itself in two ways regarding ACP. The first is that the default in the current application for Medicare doesn’t mention ACP, and anyone that does not find information on it and seek it on their own will not complete ACP, and therefore will not have an Advanced Directive that communicates their preferences for end of life care. Secondly, by default and by law, anyone who does not have a written AD will receive the maximum amount of life-sustaining treatment possible, which is also the most expensive, and in some instances may not provide value or increase quality of life. The evidence in this paper suggests that the default may not be a good indicator of preferences. By asking a question to accept or not accept the opportunity to partake in Advanced Care Planning, the Medicare beneficiary has their first introduction to the ACP concept and may seek out more information which will increase participation rates and will allow patients to communicate values and save money.

Those that contest the addition of a question regarding Advanced Care Planning and Advanced directives in the Medicare application, might argue, that asking individuals to accept or not accept their usage of ACP is nudging them toward a specific outcome, and therefore, is paternalism. Paternalism is the interference of a state or an individual with another person, against their will, and defended or motivated by a claim that the person interfered with will be better off or protected from harm. The topic of paternalism is very controversial. “The design of policies that push individuals toward better choices may limit their liberty” (Hausman & Welch, 2010, p. 123-124). One claim is that paternalism is forcing the individual to decide regarding ACP and that if they were to complete ACP, they should seek it out and complete it on their own terms. The usual justification for paternalism refers to the interests of the person being interfered with. These interests are defined in terms of the things that make a person’s life go better. “Behaviorist proposals that include mandates requiring the supply of more or better information to “debias” individual decision-maker, altering legal default rules, and imposing sin taxes, or even banning disfavored products” (Wright & Ginsburg, 2012, p. 1035) are all examples where paternalism is at work.

While inserting the question regarding ACP and AD may be paternalism, it is justified, in my opinion, by the fact that the healthcare market has inefficiencies, is plagued by asymmetric information and moral hazard, and market forces are not at work to promote efficiency and a suitable amount of spending, therefore, some paternalism may be justified, because it can promote lower spending and greater autonomy at the margin. Promoting Advanced Care Planning is form of libertarian paternalism, and is relatively weak and non-intrusive, because choice is not completely abandoned or blocked off, and liberty is still intact (Hausman & Welch, 2010, p. 124). In fact, liberty might be increased since there is a new choice.

A framework to assess the cost of decisions and errors to help policy-makers decide whether active choosing or default options are more appropriate, is eloquently written in an article by Cass Sunstein. Policy makers are consistently evaluating whether to use or promote a default rule, or a rule that establishes what occurs if individuals do not actively choose a different option. Default rules have significant effects on outcomes and have a propensity to “stick” or persist overtime. Those that desire freedom will see active choosing as preferable. Sunstein claims that in many contexts, active choosing is a form of paternalism rather than an alternative to it. When policy makers decide between active choosing and default rule, two thought processes should prevail. Number one, is the cost of making decisions versus not making them higher or lower? If active choosing is required or default rules are required are people forced to incur large costs or small ones? What are the costs of making errors in actively choosing or default rules? If the situations are extremely complex or the topics are unfamiliar, then errors may be costly and require a default. However, if the area is something that choosers know well, or the situations and needs of the individual are diverse, and policy makers lack means to create an appropriate default, active choosing is the better option (2015, p. 29-30).

Regarding Advanced Care Planning when using this framework, I believe that active choosing, and promoting active choosing is the better policy. While much of the conversation in ACP is technical, the cost of the default rule is, in most cases, greater than active choosing, since the default is the highest cost treatment trajectories. The area of choosing different treatments and interventions is something that is unique to the individual patient, and physicians and policy makers, may not be able to adequately devise a default that would encompass the variety of preferences.

The implications of using Advanced Care Planning and Advanced Directives more, are extensive. When Advanced Care Planning occurs, it promotes patient centered care and allows increases in the education the patient has about their healthcare. More education in the hands of the patient is very powerful and might encourage patients to shop around and increase the competition for services. Education is key to rational decision making. It allows doctors to cater treatment plans in line with patient values and can better streamline patient care. Advanced Care Planning and Advanced Directive usage can span greater than use for Medicare and could be used in other insurance institutions such as Medicaid, or even private insurance. It increases documentation that is accessible across many healthcare settings, promoting greater efficiency and higher quality services. Advanced Care Planning could be modified for use in creating patient centered treatment plans and long-term care plans for any number of medical problems and can allow physicians to gauge the patient's feelings and opinions throughout the treatment process. Overall, a policy that prompts an active choice regarding Advanced Care Planning and Advanced Directives, can have an impact on the amount of autonomy and patient satisfaction, and will promote more efficiency in a largely inefficient system.

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