

Failure of the Current Advance Care Planning Paradigm: Advocating for a Communications-Based Approach

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Abstract The purpose of advance care planning (ACP) is to allow an individual to maintain autonomy in end-of-life (EOL) medical decision-making even when incapacitated by disease or terminal illness. The intersection of EOL medical technology, ethics of EOL care, and state and federal law has driven the development of the legal framework for advance directives (ADs). However, from an ethical perspective the current legal framework is inadequate to make ADs an effective EOL planning tool. One response to this flawed AD process has been the development of Physician Orders for Life Sustaining Treatment (POLST). POLST has been described as a paradigm shift to address the inadequacies of ADs. However, POLST has failed to bridge the gap between patients and their autonomous, preferred EOL care decisions. Analysis of ADs and POLST reveals that future policy should focus on a communications-based approach to ACP that emphasizes ongoing interactions between healthcare providers and patients to optimize EOL medical care to the individual patient.

Keywords Bioethics · End of life care · Medical jurisprudence · Advance directives · Advance care planning · Living wills · Informed consent · Resuscitation orders · Terminal care · Health communication · Physician orders for life-sustaining treatment · POLST · Cardiopulmonary resuscitation · Life support care · Palliative care · Decision making

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Introduction

An advance directive (AD) is a legal, written healthcare directive, or living will, for end-of-life care (EOL) preferences. ADs may also include an appointment, or written refusal of appointment, of a proxy decision maker (Health and Services 2008). The purpose of an AD is to allow an individual to maintain autonomy in EOL medical decision-making even when incapacitated by disease or terminal illness. Elements that may be included in an AD are an individual's preference regarding the use of life-sustaining technologies such as dialysis or ventilator machines, cardiopulmonary resuscitation (CPR), artificial nutrition, and palliative care. Physician Orders for Life Sustaining Treatment (POLST) forms are physician orders for seriously ill or frail patients that guide treatment regarding CPR, extent of medical treatment, and artificial nutrition.

The core ethical values of advance care planning (ACP) are patient autonomy, informed decision-making, and individual control over the dying process (Johnstone and Kanitsaki 2009). The intersection of advancing medical technology, ethics of EOL care, and state and federal law has driven the development of the legal framework for ADs. A review of the history of this intersection and the current state of affairs from an ethical perspective reveals how the current legal approach to ACP through ADs is an inadequate tool to provide patients with EOL care autonomy. POLST has attempted to bridge this gap with physician orders based on patient preferences. Patient confusion about EOL planning and treatment has limited the effectiveness of ADs and POLST as tools for autonomy. Future policy and development should focus on increased communication between patients and healthcare providers and improved patient understanding regarding EOL care decisions.

Methodology

An Ovid Medline search was performed for this systematic review using keywords “MOLST”, “POLST”, and the intersection of “Advance Directives/ethics” and “Advance Directives/Legislation and Jurisprudence”. The search was limited to articles written in the English language. No date limitations were utilized although the majority of resulted articles were published within the last 20 years. The search strategy yielded 264 results of which 195 were considered relevant based on review of title and abstract. The reference lists in each article retrieved were reviewed for additional relevant references that were not resulted in the original search strategy. In addition, relevant non-peer reviewed reports, articles and other documents were utilized. A total of 77 articles were chosen to be cited in this paper. Articles that were not chosen to be cited either contained no information relevant to a discussion on ADs, contained only redundant information similar to the cited articles, or contained outdated information superseded by more recent information. No articles included were considered to have risk of significant bias.

Discussion

History

Historically, death occurred outside of healthcare institutions. With advances in medical care, death increasingly occurred in institutions such as hospitals and nursing homes, with 50 % of deaths in 1949 and 80 % of deaths by 1980 occurring in institutions (Jacobs and Martyn 1984). During this time, the major causes of death also transitioned from acute, rapidly fatal illnesses, usually infectious in nature, to chronic, progressive illnesses such as cancer, dementia and heart disease, allowing for a prolonged dying process. In institutional deaths, patients may continue to be treated even when they are unable to make decisions regarding their healthcare. These factors contributed to a sense of a loss of control over the process of death.

In 1938, the Euthanasia Society of America started as a small special interest group to advocate for the rights of terminally ill patients in the end stages of life. That small group has evolved into a national movement with diverse religious and political supporters who advocate the right-to-die (Jacobs and Martyn 1984). The attorney Luis Kutner was the first to introduce the concept of an AD as a “living will” in 1969. Kutner proposed a living will document as a way for a person to document their EOL health care preferences prior to becoming incapacitated and unable to express these wishes. This document would allow incapacitated persons to retain autonomy over their bodies and be permitted to die if in a persistent vegetative state (PVS) (Kutner 1968).

As medical technology advanced, the management of the intensive care patient became increasingly interventional (Vincent 2013) and the first intensive care units (ICUs) were established in the 1950s as places in the hospital where life-sustaining technologies were utilized, heralding the development of critical care medicine as a specialty. Advances in medical technology through the 1960s and 1970s gave rise to commonplace use of mechanical ventilation and artificial hydration and nutrition in ICUs. This further blurred the distinction between life-saving and death-prolonging interventions, fueling ethical controversies surrounding the end stages of life and biotechnologies.

Development of the Legal Framework

The intersection of law, ethics, and EOL technologies was the focus of widespread public controversy with the landmark case of Karen Ann Quinlan heard by the New Jersey Supreme Court in 1976. This was the case of a 21 year-old girl who was found in a coma of unknown origins. After 5 months, her parents began legal proceedings because physicians refused to remove her from the mechanical ventilator that was assisting her breathing. The NJ Supreme court heard the case on appeal and upheld the right of Karen’s father as her guardian and therefore surrogate decision-maker, and his decision to withdraw life-sustaining technologies (In re Quinlan 1976). This set a legal precedent in the right-to-die controversy and drew

attention to living wills as a way for persons to decide how biotechnologies would affect their future, individual dying process.

That same year, California passed the California Natural Death Act, the first law to give force to living wills. During the ensuing years, appellate cases were decided and state statutes were passed to establish a body of law guiding EOL issues generated by medical technology.

The controversy of the dying process was brought into the public eye again with case of Nancy Cruzan, a 24 year-old who was left in a PVS after a car accident in 1983. Cruzan's parents sought the courts' permission to withdraw the feeding tube that was providing Nancy with nutrition, an action that would lead to her slow deterioration and death. The Missouri Supreme Court ruled in favor of the state upholding that that preservation of life should proceed "without regard to its quality" (*Cruzan by Cruzan v. Harmon* 1988). In 1990, the U.S. Supreme Court overturned this ruling, regarding the actions of the state of Missouri as unjust and unconstitutional. The court acknowledged the "modern circumstances of death" and upheld the constitutional right to be free from unwanted life-sustaining technologies, thus allowing withdrawal of Nancy's feeding tube (*Cruzan v. Director, Mo. Dept. of Health* 1990).

Current State of Affairs

Legislation regarding ADs continued on a state-by-state basis. By 1992 all 50 states had some form of AD, establishing the formal instruments of ADs. Most states have a "combined directive" that allows a single document to function as a living will and designate a healthcare proxy (Olick 2012).

Federal legislation has been minimal, consisting mostly of the Patient Self-Determination Act (PSDA) in 1990 and the addition of "end-of-life planning" to the Medicare preventive physical examination in 2008, the purpose of both being information and education. The PSDA requires Medicare and Medicaid provider organizations to do 5 things: (1) comply with state laws regarding ADs, (2) provide written information to patients regarding their state laws on ADs, (3) maintain written policies and procedures on ADs, (4) document whether or not a patient has an AD, and (5) educate staff and community on ADs. The "end-of-life" planning addition to Medicare added a requirement regarding AD discussions to the one-time, initial preventive physical examination available to newly enrolled Medicare beneficiaries (Sabatino 2010). Most of the history of AD laws has focused on standardized legal forms and associated requirements and limitations, such as witnessing or notarizing. Sabatino characterizes this contractual approach to ADs as the "legal transactional approach" (Sabatino 2010).

With public awareness, laws in every state, and federal legislation promoting institution of state laws, it seems that widespread application of ADs would have addressed the EOL issues created by medical technology. However, in a report to Congress in 2008, the Office of Disability, Aging and Long-Term Care Policy, summarized a large body of data showing that only 18–36 % of Americans have completed ADs. Completion rates for the chronically or terminally ill are not much higher than the general population, with about one in three having an AD (Health

and Services 2008). A study published in 2014 showed no increase in completion rates despite the demographic trend showing an aging population (Rao et al. 2014). Such a low completion rate of ADs has led some ethicists to conclude that the living will has failed and should be abandoned (Fagerlin and Schneider 2004).

Physician Orders for Life-Sustaining Treatment

The POLST Paradigm originated in Oregon in 1991 in response to concerns that patients' EOL care preferences were not being consistently honored. POLST was developed as a tool to help honor patients' wishes during the EOL. It has gained national momentum and, as of March 2016, the National POLST Paradigm Task Force (NPPTF) had endorsed 18 of 49 state programs. POLST is considered a paradigm shift from a legal document to medical orders, activated by the signature of a physician or nurse practitioner. POLST is different from most physician orders that are no longer valid as soon as the patient leaves the institution in that POLST orders are to be followed by medical personnel at other institutions (Mirarchi et al. 2015b). In contrast to ADs that are typically completed during a time of health, POLST forms are completed when patients are seriously ill or frail and expected to die within a year. Table 1 outlines the difference between ADs and POLST. POLST forms build on the standard practice of writing code status orders. POLST forms are similar among states and Table 2 shows the typical sections included in POLST forms (Hickman et al. 2015).

Domains of Effectiveness

The claim that ADs have failed necessitates an evaluation of the success of ADs. ADs have been shown to decrease the use of mechanical ventilation (Cook et al. 2003; Sinuff et al. 2004), feeding tubes (Mitchell et al. 2003), hemodialysis (Fissell et al. 2005; Sinuff et al. 2004), and interventional procedures (Saczynski et al. 2012); and increase the use of hospice (Teno et al. 2007; Gozalo and Miller 2007).

Table 1 Comparison of advance directives and POLST

	Advance directives	POLST
What is it?	A legal document	Physician orders
Who is it for?	All adults	Serious ill or frail patients
When is for?	Future care	Near future care
Where is completed?	Any setting including medical	Medical setting
What does it do?	Appoints surrogate and states preferences for EOL care	Creates medical orders to guide care
Can a surrogate complete it?	No	Yes, if the patient lacks capacity
Is a witness or notary required?	Yes	No

Table 2 Sections typically included in POLST forms

Section	Options
(A) Code status	Full code (attempt CPR) or do not resuscitate (DNR)
(B) Level of medical intervention	Comfort measures, limited additional interventions, or full treatment
(C) Antibiotics (sometimes included in B)	Comfort focused, limited antibiotics or full antibiotic treatment
(D) Artificial nutrition	None, a defined trial period, or long-term use

Additionally, ADs have been shown to decrease EOL expenditures by Medicare (Nicholas et al. 2011). This suggests that the failure of ADs is in completion rates, not in the outcomes that demonstrate the ethical purpose of ADs of autonomy in EOL care.

The POLST paradigm appears to address the issue of low completion rates. In a telephone survey of 356 nursing facilities in Oregon, 71 % reported using POLST for at least half of their residents (Hickman et al. 2004). In a review of Oregon death records of 58,000 decedents who died of natural, non-traumatic causes in 2010–2011, 30.9 % had POLST forms in the Registry that had been completed during 2010 or 2011 (this did not include forms completed in 2009 before the legislative mandate to submit forms) (Fromme et al. 2014). In a retrospective review of medical record and death certificate data of 400 adults, Hammes et al. reported that 67 % of patients had POLST at the time of death whereas 22 % had only a POA documented (Hammes et al. 2012).

Patient Understanding of End-of-Life Options

Studies have reported that patients have a very poor understanding of EOL therapies and terminology, raising ethical concerns regarding the informed decision-making of ADs and POLST. Marco et al. conducted a study to assess the level of understanding of common EOL terminology in emergency department patients and visitors. Participants were asked to define 10 EOL terms. Only 7.3 % were able to correctly define 7 or more terms. The most commonly understood term was “Do Not Resuscitate” (DNR), but even this was only correctly defined by 56 % of participants. CPR was only correctly defined by 26 % (Marco et al. 2010). In another a survey study of hospitalized patients, 31 % incorrectly believed CPR may involve surgical opening of the chest (Thorevska et al. 2005). In a study of ICU patients and surrogates, less than half could explain the purpose of CPR and most were unable to identify chest compressions and assisted breathing as components of CPR (Wilson et al. 2014). Not only is there a poor understanding of elements of procedures, but also the prognosis after them. One study reported that elderly patients overestimate the rate of survival to hospital discharge after in-hospital CPR by nearly 300 % (Miller et al. 1992).

The argument has been raised that ADs do not meet the standard for informed refusal of treatment because they fail to meet the criterion of sufficient information (Shaw 2012). This is particularly true in an era of rapidly advancing medical technology. As technologies advance, a person's decision about wanting life-prolonging interventions that may have improved efficacy, comfort, or prognosis, may change. The result of poor understanding, or deficient informed decision-making, regarding EOL terminology and therapies is a breakdown in the purpose of ADs. ADs often poorly reflect patient actual wishes (Upadya et al. 2002; Wilson et al. 2014). In a survey study, Nauck et al. found incongruities between verbally expressed preferences and the contents of written ADs in more than half of participants (Nauck et al. 2014). The authors noted that most of these participants had not involved a physician in the making of their ADs.

As POLST forms use terms such as DNR and CPR that patients poorly understand, it is reasonable to assume that they would have a poor understanding of POLST terminology. Some forms, such as the Oregon POLST, also include even more technical jargon such as “advanced airway interventions”, “CPAP” and “BiPAP”. This use of jargon may increase overall patient confusion and impair the decision making process. In one study evaluating the use of POLST by hospice staff with primary responsibility for ACP, the most commonly reported problem with POLST was difficulty understanding and explaining the form (28 % of respondents) (Hickman et al. 2009). It follows that if a substantial proportion of trained staff do not understand the POLST form then laypersons are at an even greater risk of not understanding the choices they are making. Others have argued that the limited checklist over simplifies complex decisions (Buck and Fahlberg 2014).

While patient comprehension of POLST forms is an area that warrants future research, poor comprehension by some is suggested by incongruent choices in different sections of the form. Schmidt et al. conducted an analysis of the order combinations in sections A and B of 31,294 POLST forms completed in Oregon in 2012 (Schmidt et al. 2014). Order combinations that would require further clarification in a time of crisis were not uncommon—Attempt CPR/Comfort Measures (0.04 %), Attempt CPR/Limited Interventions (7.3 %), DNR/Full Treatment (3.9 %). Attempt CPR/Comfort Measures, chosen by 11 people, is not medically feasible. Attempt CPR/Limited Interventions is confusing to healthcare providers because Limited Interventions excludes intubation and mechanical intervention. The authors pose the question: For a patient in severe respiratory distress that could lead to death, does a physician refrain from intubating but standby and perform CPR if/when cardiac arrest occurs? The authors did not include an analysis of congruities of antibiotics or artificial nutrition with sections A and B.

Provider Confusion Surrounding Patient Choices and Forms

A poll conducted by the California Healthcare Foundation in 2011 reported that only 44 % of Californians who had lost a loved one in the past year felt that their loved one's EOL preferences were completely followed and honored by medical providers (California Health Care Foundation 2012). DNR orders are of particular concern. Studies have reported that patients with a DNR order but who still desire

full treatment are less likely to be hospitalized, less likely to receive care consistent with quality assurance measures, and are treated less aggressively, which raises ethical concerns regarding healthcare providers' understanding of patient treatment choices (Jesus et al. 2014).

Survey studies have demonstrated variability in POLST form interpretation by emergency providers that may impact patient care. In a survey of physicians who provide emergency care, respondents were presented with POLST forms and clinical scenarios in which a critically ill patient arrested. Respondents were required to assign a code status to the patient and indicate treatment decisions they would make in the situation. For clinical scenarios involving a POLST form indicating DNR and either full treatment or limited interventions, between 59 and 84 % of respondents chose DNR as the appropriate code status. Up to 20 % of respondents indicated they were unsure of the code status. For clinical scenarios involving a DNR POLST, decisions to perform resuscitative efforts such as defibrillation or intubation varied from 25 to 74 %. The authors concluded an absence of consensus among physicians for the majority of survey questions (Mirarchi et al. 2015b).

In a study with the same design but surveying emergency medical technicians and paramedics, the authors reported a similar lack of consensus regarding what treatment a POLST form indicated (Mirarchi et al. 2015a). One of the benefits of POLST touted by its advocates is that, as physician orders, it can be followed by paramedics whereas ADs cannot; however, misinterpretation of forms may compromise patient autonomy. POLST comprehension is arguably more important for paramedics than for physicians because paramedics are required to follow protocols, whereas physicians are expected to exercise clinical judgment.

In a review study of the Oregon POLST Registry of 2010, the authors concluded that “out-of-hospital and ED [emergency department] care was generally concordant with previously documented end-of-life orders”. Of note, 16 % of patients with a pre-hospital or emergency department arrest who had an attempt CPR POLST order did not have resuscitation. The article does not provide any insight into whether this lack of resuscitation was inappropriate, possibly due to confusion regarding the POSLT, or appropriate, based on futility (Richardson et al. 2014).

When a patient is transferred from one care location to another, orders from the transferring institution become void. Healthcare providers of receiving institutions have expressed confusion over the validity of POLST as they are orders signed by a physician not credentialed at that institution (National POLST Paradigm Task Force 2014). According to the NPPTF, federal Medicare law does not require that orders be signed by a physician who is credentialed at the institution (National POLST Paradigm Task Force 2014). However, § 482.22 states “The hospital must have an organized medical staff that operates under bylaws... The medical staff must adopt and enforce bylaws to carry out its responsibilities. The bylaws must... Include a statement of the duties and privileges of each category of medical staff” (42 U.S.C. § 482.22 Condition of participation: Medical staff). As order writing is an element of hospital bylaws, often by state law, it follows that hospital orders must be written by a member of the hospital staff. While POLST is not a hospital order, confusion

among healthcare providers as to the validity of POLST written at an outside facility is foreseeable.

Variability in state legislation pertaining to POLST creates other potential sources of physician confusion. State laws vary with regard to elements such as liability and duty-to-comply statutes, whether the form must be printed on a particular color paper, if facsimiles, paper and/or electronic copies are valid, and if POLST supersedes an AD or a power of attorney.

Disparities

Population-based data demonstrate racial and educational disparities in the completion of ADs. Knowledge about ADs and higher completion rates have been associated with higher levels of education and income (Rao et al. 2014; High 1993a, b; García et al. 2000). Racial disparities have been reported in the general population and among nursing home residents with regard to living wills, DNR orders, and designation of a healthcare proxy (García et al. 2000; Rich et al. 2009; Rao et al. 2014; Morrison et al. 1998; Loggers et al. 2009). A national HealthStyles mail survey of adults in 2009–2010 reported that non-white responders were less likely to have ADs (Rao et al. 2014). A 1996 nationally representative survey of nursing home patients that controlled for health and other demographic factors reported that African Americans were one-third as likely to have living wills and one-fifth as likely to have DNR orders compared to Caucasians. Hispanics were found to be one-third as likely as Caucasians to have DNR orders but equally likely to have living wills (Degenholtz et al. 2002).

A study investigating the reasons for racial disparities in AD completion rates in nursing home patients reported that not only were black residents less likely to have an AD, but they were also less likely to have discussed their treatment preferences (Rich et al. 2009; Hopp and Duffy 2000). This disparity suggests a need for examination of cultural differences in EOL care communications in ACP. Cultural regard of the use of legal documents and personal lawyers may also hinder completion of ADs. For example, Japanese view legal documents as “confrontational” and formal ADs as an interference in decisions to made among families and physicians (Bitto et al. 2007).

Similar racial disparities have been reported for POLST as have been reported for ADs. In a study of 90 nursing facilities in Oregon, Wisconsin, and West Virginia, Hickman et al. reported that whites were more likely than non-whites to have POLST (50 vs 35 %) (Hickman et al. 2010). Of those with POLST, whites were more likely than non-whites to be comfort measures only (43 vs 33 %). Of those without POLST who had traditional code status orders, whites were more likely to be DNR than non-whites (74 vs 52 %).

In a demographic study of 58,000 decedents in Oregon, Fromme et al. reported that whites were more likely to have POLST than non-whites (Fromme et al. 2014). Furthermore, non-whites of Asian, Hawaiian or Pacific Islander descent were even less likely than African Americans to have POLST (23 vs 27 %).

Policy Development and a Communications-Based Model

The purpose of AD laws is to facilitate EOL care for incompetent patients; however, the legal requirements have been accused of being “counterproductive” (Lo and Steinbrook 2004). The shortcomings of the legal approach to ADs have been illustrated by the low rate of AD completion in the general population and among the terminally ill, the poor understanding of EOL therapies among patients, the disparities among racial and socioeconomic classes, and the challenges raised by rapidly advancing medical technologies.

A study of cancer patients in 2000 showed that only 9 % of patients had discussed ADs with their oncologists and only 23 % of the remaining patients indicated they wished to do so, demonstrating the current lack of physician-patient communication surrounding ADs. Despite this, the majority supported a policy in which house staff discussed ADs as a routine part of admission history (Lamont and Siegler 2000), showing a desire for a more holistic approach to EOL planning.

The POLST paradigm was developed as a potential solution to the inadequacies of ADs. POLST has been effective in increasing the number of patients with ACP documentation. However, patient understanding of POLST forms and the implications of their choices is unclear. POLST forms use the same terminology that patients have been reported to poorly understand. Hospice staff themselves have difficulty understanding and explaining the form. Discerning patient wishes as interpreted from POLST forms is challenging to emergency healthcare providers. POLST has also failed to bridge cultural gaps and racial disparities persist.

POLST conversations are often initiated by non-physician facilitators who prepare the document for the clinician to review and sign. In hospice and nursing facilities, social services and nurses typically prepare the POLST form (Hickman et al. 2015). This protocol raises the concern that POLST could lead to decreased as opposed to increased EOL conversations between physicians and patients. Conversations with social workers has been shown to improve patient understanding of EOL options for ADs. However, social workers discussing AD EOL options with patients is fundamentally different than them writing the orders for EOL care for a physician to sign.

The solution to the shortcomings of both ADs and POLST is a paradigm shift in the approach to ACP to a communications-based model focusing on direct provider-patient interaction. The purpose of ACP is to afford individuals autonomy over their own death. This requires a complex decision making process. Currently, the completion of an AD document does not require conversations with a healthcare provider, and physicians are frequently unaware of their patients’ ADs (Virmani et al. 1994), a finding which emphasizes the current isolationist approach to ADs. To facilitate this paradigm shift, Lo and Steinbrook call for a simplification of state laws to allow for completion of ADs during office visits and permissibility of oral designations of healthcare proxies (Lo and Steinbrook 2004). Although the 1993 Uniform Health-Care Decisions Act recognized almost any kind of written or oral statement as a valid AD, by 2010 only 15 states recognized some form of oral directive. Permission of oral directives encourages communication between physicians and patients and provides greater accommodation for cultures reluctant to involve the legal system and

individuals with various literacy levels. Fried and Drickamer support ACP as an integral part of healthcare and believe that it should be supported with reimbursement policies for physicians (Fried and Drickamer 2010).

The most successful strategies to increase completion of ADs have been reported to be direct patient-healthcare professional interactions over multiple visits (Ramsaroop et al. 2007). Interventions that involve passive patient education with written materials have been shown to have little or no effect on completion of ADs (Brown et al. 1999; Reilly et al. 1995; Sulmasy et al. 1996). Interventions that involve direct interactions with healthcare providers or social workers have been shown to be the most effective (Meier et al. 1996; Pearlman et al. 2005). This direct interaction has been reported to be particularly effective when the healthcare provider was well known to the patient (Duffield 1998). In one study, group education provided by a social worker was more than twice as effective as individual education, but both were significantly more effective than written materials alone (Dipko et al. 2004).

Videos depicting goals of care options including life-prolonging care technologies (e.g., intubation and mechanical ventilation) and alternatives such as home comfort care have been reported to be an effective communication modality. Videos were reported to improve understanding of ADs and increase EOL conversations among patients, families, and providers (Toraya 2014). In randomized trials, patients with advanced cancer reported that they were comfortable watching the videos and that the videos increased their knowledge regarding EOL care (El-Jawahri et al. 2010; Volandes et al. 2012, 2013; Epstein et al. 2013). Compared to participants who only heard a verbal description, participants who viewed the video were more likely to prefer comfort care and avoid CPR (El-Jawahri et al. 2010; Volandes et al. 2012, 2013; Epstein et al. 2013) and mechanical ventilation (Volandes et al. 2012).

Education has been shown to not only increase completion rates of ADs, but also affect choices. After receiving education on CPR, 37 % of patients with living wills indicating they wanted CPR stated that they would not want CPR (Thorevska et al. 2005). The importance of education on burden of treatment (i.e., length of hospital stays, extent of testing, and invasiveness of interventions) and possible outcomes is important to patients. In a questionnaire study of persons older than 60 years of age, who had a limited life expectancy due to chronic disease, almost all study participants chose a “low-burden therapy” that would restore their current health if the alternative without treatment was death. In contrast, almost 90 % of the participants did not wish to receive a “low-burden therapy” with an outcome of severe cognitive impairment. As the likelihood of adverse outcomes increased, fewer participants indicated that they would choose treatment (Fried et al. 2002).

Similarly, in an interview study of elderly people, 41 % said they would want CPR prior to education on the probability of survival (10–17 %) and only 22 % said they would want CPR after education on the probability of survival (Murphy et al. 1994). There has recently been more attention to the terminology used to describe EOL care. It has been proposed that the traditional “Do Not Resuscitate” (DNR) be replaced with “Allow Natural Death” (AND). Studies conducted with both neutral participants and actual surrogate decision makers have shown that participants are

more likely to consent to an AND than a DNR (Venneman et al. 2008; Barnato and Arnold 2013), stressing the importance of semantics in communication.

Finally, physician hesitation toward ACP discussions emphasizes the need for required EOL conversations and adequate policies to facilitate communications-based discussions. Physicians have been reported to be reluctant to discuss EOL care plans with patients. Physicians have indicated reluctance to initiate EOL discussions when a patient appears well, does not have symptoms, or has not exhausted all treatment options (Keating et al. 2010). Lack of time has also been cited as a major barrier to discussions (Ramsaroop et al. 2007). Many physicians also feel poorly prepared to conduct EOL conversations and ACP has been identified as an area of medical education that deserves greater focus (Block 2002). These findings provide support for future policies that afford physicians appropriate time and training to conduct communications-based ACP.

Conclusion

The continuing evolution of medical technology has turned death into a variable process that can be individualized with a variety of potential treatments. The purpose of ACP is to empower individuals to choose what medical interventions they desire. For most, the nature of these treatments remains undefined or poorly understood, and current ACP practices insufficiently address this knowledge gap.

Future policy should focus on enhancing direct communication between healthcare providers and patients in an ongoing ACP process. Robust communication improves patient understanding of technologies and therapeutic options, verifies that patients' actual desires are consistent with those expressed, facilitates cross-cultural understanding, and decreases literacy barriers between patients and formal documentation. Ongoing communication allows for patient preferences to change with time, health, and advancing technology. Communication is relationship-based and encourages self-reflection. Potential next steps in policy to facilitate communications-based ACP are to make ACP a routine, reimbursable aspect of medical care and permissibility of documentation of discussions between patients and healthcare providers as a legal form of AD.

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