

Invited Article

# Advance Care Planning: Contemporary Issues and Future Directions

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## Abstract

Advance care planning (ACP) is widely considered an essential step toward achieving end-of-life care that is consistent with the preferences of dying patients and their families. ACP comprises a living will and a durable power of attorney for health care (DPAHC); these tools enable patients to articulate and convey their treatment preferences when they are still cognitively intact. In this article, we describe the strengths, weaknesses, and correlates of ACP in the United States, with attention to race and socioeconomic disparities therein. We then discuss other public policies and community programs designed to increase both the number of older adults who articulate their preferences for end-of-life care, and efficacy of ACP for ensuring that patients' end-of-life treatment preferences are met. We describe the characteristics, strengths, and limitations of Physician Orders for Life Sustaining Treatment (POLSTs), and describe community programs, educational interventions, and public policies aimed toward increasing the prevalence and efficacy of end-of-life preparations. A key policy advance in the early 2010s has been Medicare coverage of one doctor–patient consultation session regarding end-of-life issues; we highlight the potentials and possible pitfalls of this policy. We conclude by identifying areas for future research, and highlighting practices from other nations that may help improve quality of end-of-life care in the United States.

**Translational Significance:** Advance care planning (ACP) is linked with greater use of palliative care among dying patients, lower medical expenditures at the end of life, and less distress among patients and their family members. Stark race and socioeconomic disparities in ACP rates have been documented, although recent policy advances such as Medicare reimbursement for doctor–patient consultation sessions and carefully targeted educational interventions and community programs may increase rates of planning among Blacks, Latinos, low-income adults, and others who may not have access to the professionals who encourage such preparations. The use of Physician Orders for Life Sustaining Treatment (POLSTs) may help to ensure greater clarity than living wills when conveying a dying patient's treatment preferences to health care providers.

**Keywords:** Advance care planning, Death and dying, Disparities, End of life, Epidemiology, Policy

Dying is a late-life phenomenon. Of the 2.6 million deaths in the United States in 2016, roughly three-quarters were to older adults ages 65+ ([Federal Interagency Forum on Aging](#)

[Related Statistics, 2016](#)). Late-life death typically follows a long-term chronic illness like cancer or heart disease, with most dying adults experiencing physical discomfort,

functional decline, and cognitive impairment in the final weeks or months of life. Most older adults die in hospitals or nursing homes rather than at home, and many rely on medical technologies and aggressive treatments that increase the length—although not necessarily the quality—of their lives (Teno et al., 2013). Against this medical and technological backdrop, older adults often must make difficult decisions about the kinds of treatments they receive, so health care providers encourage them to convey their preferences for end-of-life care when they are still relatively healthy and cognitively intact (IOM, 2014). These preparations, widely referred to as advance care planning (ACP), are considered an essential step for achieving a “good death” in which physical pain and emotional distress are minimized, and the patient’s and family members’ treatment preferences are respected (Carr & Luth, 2016). ACP also is linked with reduced use of aggressive, costly and futile treatments at the end of life and greater use of palliative care, practices linked with both superior patient and survivor well-being (IOM, 2014). However, ACP has well-known practical limitations, leading policy makers to develop new practices such as Physician Orders for Life-Sustaining Treatment (POLSTs) (National POLST Paradigm, 2017a) and Medicare-reimbursed doctor-patient consultation sessions regarding end-of-life choices (Belluck, 2014). We describe the current state of knowledge on ACP, highlighting its strengths, limitations, correlates, and policies and programs designed to increase its effective use. We conclude by identifying avenues for future research, with an eye toward enhancing older Americans’ quality of death.

## Advance Care Planning: Background and Components

Dying patients and their caregivers frequently name patient involvement in end-of-life decision making as a core component of a “good death” or “dying well” (Byock, 1996; Steinhilber et al., 2000). Medical ethicists also emphasize the importance of patient autonomy, and propose that health care providers should share, and in some cases delegate, medical decision making to dying patients and their families (President’s Council on Bioethics, 2005). In practice, however, many dying older adults are unable to communicate their treatment preferences because they are incapacitated when the decision is required. An estimated 45%–70% of older adults facing end-of-life treatment decisions are incapable of making those decisions themselves (IOM, 2014). As such, difficult decisions about stopping or continuing treatment often fall upon family members who may be distressed or may disagree among themselves about an appropriate course of care (Kramer, Boelk, & Auer, 2006). When family members and health care providers cannot agree on a plan of action, the default decision is to continue treatments which may be financially and emotionally depleting for family members, and may compromise the patient’s quality of life.

In an effort to prevent problematic, futile, or contested end-of-life care, practitioners encourage adults to informally express and formally document their treatment preferences when they are still of sound mind and body (IOM, 2014). These efforts have been facilitated by the passage of the Patient Self-Determination Act (PSDA) in 1990; the Act requires all health care facilities receiving reimbursement from Medicare or Medicaid “to ask patients whether they have advance directives, to provide information about advance directives, and to incorporate advance directives into the medical record.” An advance directive typically comprises a living will and durable power of attorney for health care (DPAHC) designation. A living will articulates the treatments that an individual would want (or not want) at the end of life, such as ventilators, feeding tubes, or cardiopulmonary resuscitation (CPR). A DPAHC legally designates a specific individual (also referred to as a “surrogate” or “proxy”) to make decisions on behalf of the patient in the event that he or she is incapacitated (Carr & Luth, 2016). Most older adults select a spouse or long-term partner, followed by a child, or other close relative as DPAHC (Carr & Khodyakov, 2007). Spouses tend to be more knowledgeable than adult children regarding a patient’s preferences (Parks et al., 2011), with wives more knowledgeable than husbands (Zettel-Watson, Ditto, Danks, & Smucker, 2008).

Despite widespread professional endorsements, public awareness and education campaigns (Hammes, 2003), popular books (Gawande, 2014), and public policies (Patient Self-Determination Act of 1990, 1990) encouraging ACP, formal ACP has well-documented limitations. Criticisms of the living will include: the content may be unclear; one’s stated preferences may not be relevant to the patient’s condition, especially for dying older adults who drafted their living wills years earlier; and physicians may not have access to the document at the critical decision-making moment. Physicians also may be reluctant to follow the orders stated in the living will for fear of legal liability; in general, physicians believe their liability risk is greater if they do not attempt resuscitation than if they provide it against patient wishes (Burkle, Mueller, Swetz, Hook, & Keegan, 2012). Family members may not know or agree with the document’s content, or may not know how to translate vague preferences into specific clinical practices (Ditto et al., 2001).

DPAHC appointments also have practical limitations. Legally-appointed proxies have decision-making authority, yet may make decisions that create distress or disagreement among family members (Khodyakov & Carr, 2009). Surrogate decision makers’ knowledge of patient preferences is usually no better than chance (Shalowitz, Garrett-Mayer, & Wendler, 2006), with surrogates typically perceiving that the patient’s preferences mirror their own (Moorman & Inoue, 2013). Older adults might not inform the legal proxy of their preferences because they believe (erroneously) that their loved ones intuitively understand

their preferences (Coppola, Ditto, Danks, & Smucker, 2001).

For some older patients, the proxy's limited knowledge may be unproblematic; they may prefer that their family members do what they feel is best, rather than strictly follow the patient's stated preferences (Moorman, 2011). Others may trust their physicians to make decisions for them (Su, 2008). Still, the patient's deference to a specific decision maker's wishes may create distress or conflict for concerned family members who do not hold decision-making power. Family members not designated as decision maker also may create difficulties; clinicians often encounter the "daughter in California" phenomenon, whereby a family member—especially one who resides far away from the dying patient and has had little engagement in a patient's end-of-life care—enters the family conversation at the patient's final stage of life. They try to undo, contest, undermine, or alter the decisions made by local family members who had been engaged in the patient's care for a much longer duration. These family disagreements, in turn, may compromise health care providers' ability to provide quality care (Kramer & Yonker, 2011). Given these well-documented limitations of formal ACP, some practitioners assert that informal conversations with significant others and care providers are the most critical component of end-of-life planning (Doukas & Hardwig, 2003). Discussions help to facilitate care consistent with the patient's wishes; family members cannot adequately represent their dying relative's preferences if they do not know what those preferences are.

Conversations about one's general values are useful because few individuals know precisely how and of what cause they will die, making it difficult to specify particular interventions that they would want or not want at the end of life. A conversation about broad goals (e.g., "I do not want to be a vegetable") and global preferences (e.g., "I do not want to be hooked up to machines") may provide family members a general roadmap for representing their loved one's wishes even in the absence of a formal living will articulating one's specific plans for clinical care (Doukas & Hardwig, 2003). These conversations also may facilitate decision making in cases where the patient has not legally appointed a DPAHC. Most states have default systems for authorizing proxy decision makers. State laws vary, but these systems prioritize the immediate family—starting with spouse, followed by adult child, sibling, and other relatives (American Bar Association, 2009). Frank conversations about a patient's values may empower and inform state-authorized proxies when making difficult decisions about their loved one's care.

However, timing is critical, as some discussions may be "too little, too late." Conversations regarding end-of-life issues often are triggered by a patient's health crisis such as a hospitalization or heart attack (Pfeifer, Mitchell, & Chamberlain, 2003). When discussions occur following triggering events, the patient (and family) may be too

distressed to make an informed or appropriate decision about imminent care needs. Despite concerns regarding the efficacy and effectiveness of formal ACP tools, their use increases the chances of attaining some core components of a "good death," including greater use of hospice or palliative care (Silveira, Kim, & Langa, 2010); reduced use of invasive or futile treatments such as feeding tubes or ventilators (Nicholas, Langa, Iwashyna, & Weir, 2011); a heightened sense of decision-making control (Edwards, Pang, Shiu, & Chan, 2010); a greater likelihood of dying at home rather than in an institution (Silveira et al., 2010); and fewer instances of receiving treatments discrepant with one's wishes (Detering, Hancock, Reade, & Silvester, 2010).

Advance care planning also is associated with better outcomes for family members, including reduced decision-making burden, and fewer anxiety and depressive symptoms (Stein et al., 2013). Hospice use is an important pathway linking ACP with survivor well-being; bereaved family members whose loved one used hospice care have reduced risks of mortality, depression, and traumatic grief (Iwashyna & Christakis, 2003). However, even when the decedent had an advance directive in place, some family members may still report inadequate support during the dying process (Teno et al., 2007) or family conflict in cases where the living will was deemed unhelpful or problematic (Khodyakov & Carr, 2009).

Advance care planning is generally protective for both patients and family members, yet its impact on end-of-life medical expenditures is less clear. Studies based on large population-based samples generally show no significant effect (Kelley et al., 2011; Nicholas et al., 2011), whereas studies focused on specific disease groups such as advanced cancer patients suggest that ACP is linked with significantly reduced medical expenditures in the last six months of life (e.g., Zhang et al., 2009). Among older patients with advanced cancer, end-of-life medical costs are one-third less for persons who had an advance directive calling for limited care (Zhang et al., 2009). Intensive care unit (ICU) use is a key pathway linking ACP with reduced medical expenditures (Khandelwal et al., 2015). Researchers and policy makers agree that standard ACP tools cannot guarantee a good death, although their benefits outweigh their costs (IOM, 2014).

## ACP Trends and Differentials

ACP is intended to improve the quality of death for all Americans, yet in practice, it is largely undertaken by older adults of higher versus lower socioeconomic status (SES), Whites versus Blacks, and socially integrated versus isolated older adults. ACP rates also vary by age, marital and parental status, and other psychosocial factors. Only one-third to one-half of all adults in the United States have completed advance directives, although rates are as high as 70% among adults aged 65+ and persons with terminal illness (Carr & Moorman, 2009; Silveira et al., 2010).

ACP rates have increased sharply since 1990; the proportion with a written advance directive more than doubled from 16% in 1990 to 35% in 2013 (Pew Research Center, 2013). Experts attribute this increase to the passage of the Patient Self-Determination Act (1990), prominent cases of contested end-of-life decisions such as that of Terri Schiavo, media programs like Bill Moyers' PBS Series *On Our Own Terms*, best-selling books like Atul Gawande's (2014) *Being Mortal*, and public awareness campaigns such as "Five Wishes" (Aging with Dignity, 2017). The Five Wishes, for example, is a user-friendly advance directive created by the nonprofit organization Aging with Dignity. The document can be obtained online, and is written in nontechnical language that includes identification of a proxy and preferences for medical and nonmedical treatment, comfort care, and one's spiritual and interpersonal needs.

Rates of ACP are especially low among older Blacks and Latinos, relative to Whites. Estimates vary across samples, but most research finds that Whites are two to three times as likely as Blacks and Latinos to have an advance directive, with a much narrower gap for end-of-life discussions (Carr, 2011). However, these disparities have declined considerably over the past decade (Koss & Baker, 2017a). This narrowing may partly reflect cohort changes; one recent study of adults under age 64 found that race gaps in advance directive use were negligible (Carr, 2012a). Explanations for race disparities in ACP among current cohorts of older adults include: ethnic minorities' limited access to medical and legal professionals who assist in preparing such documents; literacy or language barriers; beliefs that formal ACP is unnecessary because family members will make decisions collectively on behalf of the patient; historically rooted distrust of physicians and medical institutions; and adherence to religious beliefs that "God will decide" when it is time for a patient to die (Carr, 2011; 2012a; West & Hollis, 2012). Some Blacks and Latinos believe they do not need a living will because they desire all possible interventions at the end-of-life (Pew Research Center, 2013), and assume (incorrectly) that living wills limit rather than request treatment (Barnato, Anthony, Skinner, Gallagher, & Fisher, 2009; Mack et al., 2010).

This lack of ACP may prevent minority patients from receiving the treatments they desire. For example, among cancer patients who desire aggressive treatments, Blacks are one-third as likely as Whites to receive care that is consistent with their preferences (Loggers et al., 2009). Medical expenditures in the last six months of life are considerably higher for Blacks and Latinos, relative to Whites (Hanchate, Kronman, Young-Xu, Ash, & Emanuel, 2009). Fully 85 percent of these observed higher costs for Blacks and Hispanics are accounted for by their greater usage of intensive (and costly) invasive treatments. Thus, barriers to ACP among Blacks and Latinos are linked to costly intrusive treatments as well as the failure to receive desired treatments.

Very few studies examine SES differentials, yet emerging research shows that older adults with lower levels of education, income, assets, and home ownership rates are less likely than their more advantaged counterparts to do formal ACP, although no differences are found for discussions (Carr, 2012b). Older adults with assets to protect are more likely to do estate planning than their less wealthy counterparts. A visit to one's lawyer to do complete one's will often triggers the completion of related documents, including living wills and DPAHC appointments (Carr, 2012b). Low rates of estate planning also partly explain race disparities in ACP among older adults, and reflect racial disparities in wealth and home ownership (Koss & Baker, 2017b). Adults with lower levels of education and literacy also are less likely to do ACP, in part because they are reluctant to make decisions about treatments they don't fully understand (Porensky & Carpenter, 2008; Waite et al., 2013).

Social relationships also shape ACP, such that people with supportive family relationships are more likely than those with troubled relationships to execute advance directives (Carr, Moorman, & Boerner, 2013). Psychological, religious, and attitudinal factors also may pose obstacles to ACP. Older adults with higher levels of death anxiety are less likely to do plan for end-of-life (Carr & Moorman, 2009). Those who have witnessed the painful or prolonged death of loved one are more likely to do ACP, perhaps in an effort to avoid a similar fate (Carr, 2012c). Religious beliefs also affect ACP; those who adhere to Fundamentalist beliefs (Sharp, Carr, & MacDonald, 2012), who believe that the length of their life is in God's hands, who rate religion as "very important," and whose religious beliefs guide their behavior are less likely to do formal ACP (Garrido, Idler, Leventhal, & Carr, 2013; Pew Research Center, 2013). Highly religious persons tend to desire all possible treatments at the end of life, because they believe that God will either sustain them or let them die "when the time is right" (Johnson, Kuchibhatla, & Tulsy, 2008).

Taken together, research shows stark race and socioeconomic disparities in formal ACP but not informal discussions – an activity that can be undertaken at no financial cost, and that does not require interactions with health care or legal professionals (Carr, 2012b). These patterns suggest that economic, informational, and structural barriers may be a more daunting obstacle to end-of-life planning among ethnic minorities and poorer adults than are cultural or attitudinal factors. These obstacles are potentially modifiable factors that may be addressed by innovative public policies, community initiatives and educational programs designed to place decision-making responsibility in the hands of older patients and their families, regardless of their personal resources. We next describe recent innovations to promote ACP, highlighting the extent to which these approaches may be effective in increasing ACP rates of all older adults, rather than just the most advantaged.

## Public Policy and Educational Interventions

### POLSTs (Physician Orders for Life Sustaining Treatment)

POLSTs (Physician Orders for Life Sustaining Treatment) offer a possible corrective to the limitations of living wills and DPAHC designations. They were introduced in Oregon in 1991 and are used in some format or are under development in 48 states as of 2017 (National POLST Paradigm, 2017a). POLSTs are completed by a patient in consultation with health care providers during the course of one's clinical encounter. The document is signed by a physician; thus, health care providers are required to follow the content of the orders (National POLST Paradigm, 2017b). By contrast, a patient may complete a standard living will on their own or with their family or lawyer, without necessarily consulting their health care provider. Some patients fail to share their living will with their health care provider, instead leaving the document in a safe deposit box, the glovebox of their car, or even taped to their refrigerator. Because the POLST is completed during the clinical encounter, it remains in the patient's medical records (Yung, Walling, Min, Wenger, & Ganz, 2010).

POLSTs are appropriate for seriously ill individuals expected to die within 12 months (Hickman et al., 2011). POLSTs provide doctor's orders regarding the specific treatments to be administered or withheld in medical scenarios that are common at the end of life, such as cardiopulmonary resuscitation (CPR) or feeding tubes (Schmidt, Zive, Fromme, Cook, & Tolle, 2014). The document also indicates whether a patient desires comfort measures only such as pain and breathing relief; limited interventions including antibiotics and intravenous (IV) fluids; or full treatment including intubation and mechanical ventilation (Schmidt et al., 2014).

POLSTs have several advantages over advance directives (for a full review, see Bomba, Kemp, & Black, 2012). Completion rates tend to be higher; studies of nursing home residents in four states show POLST completion rates are two to three times higher than advance directive completion rates, with no racial disparities evidenced (Hickman et al., 2011; Jennings et al., 2016). The widespread use of POLSTs may reflect the fact that they pose fewer obstacles to completion than living wills. Unlike living wills which must be executed by the patient, POLSTs can be completed by designated family members in consultation with the health care provider, if the patient is incapacitated (Hammes, Rooney, Gundrum, Hickman, & Hager, 2012). POLSTs are typically completed weeks before death, and reflect the current wishes of dying patients and their family, whereas advance directives often are completed months or even years before needed (Zive, Fromme, Schmidt, Cook, & Tolle, 2015). POLSTs also stipulate specific treatments that require little interpretation by practitioners (Hickman et al., 2011; Schmidt et al., 2014); empirical assessments show a 95 percent concordance rate between the care

received at the end of life and the treatments articulated in the document (Hickman et al., 2011; Hammes et al., 2012). By contrast, studies have found weaker concordance for living wills, in part because doctors may be reluctant to withhold treatment; either because it is inconsistent with their training to treat and sustain life, or because they fear legal liability (Burkle et al., 2012). For example, one study of advanced cancer patients found that 13 percent received life-extending treatment in the last week of life despite having a stated preference for palliative or comfort care (Mack, Paulk, Viswanath, & Prigerson, 2010).

Despite these strengths, POLSTs have their limitations. Patients may not necessarily have high-quality conversations with their health care provider when completing the POLST together (Jennings et al., 2016). Although POLSTs were designed to eliminate some of the guess work of end-of-life decision making, the content may still require interpretation in the clinical setting. One analysis found that 10% of POLSTs have contradictory content, such as a patient completing a DNR yet also wanting full treatment (Schmidt et al., 2014). Given these potential contradictions, clinicians may misinterpret a POLST's content and deny treatment that was desired (IOM, 2014). POLSTs also require a valid clinician's signature; one recent study found that 1 in 10 POLSTs lacked this signature (Jennings et al., 2016).

### Medicare Coverage of ACP Consultation

In late 2015, the Centers for Medicare and Medicaid Services (CMS), the agency that runs Medicare, finalized regulations that allow Medicare to pay physicians and other qualified health care professionals for providing ACP consultation to beneficiaries. Prior to the implementation of this policy change on January 1, 2016, Medicare coverage rules allowed reimbursement for ACP consultation under very limited circumstances, focused largely on those with terminal illness. This partially explains why, prior to the policy's implementation, only 27% of older adults had discussed their treatment preference with a physician, although 88% believe it is important to do so (Kaiser Family Foundation, 2015). This Medicare benefit may help to ensure that all older adults have the opportunity to discuss their treatment preferences with a health care provider, regardless of their economic or personal resources. These conversations also may help to minimize uncertainty and ambiguities in POLST completions. However, the Institute of Medicine (2014) urges careful monitoring of these consultation sessions to ensure that they are effective. Specifically, experts call for the development of quality of care metrics, and tying insurance reimbursement to these metrics. Ideally, these indicators would capture alignment among the patient's goals, values, and preferences, the documented treatment plan, and the treatment ultimately delivered (IOM, 2014).

## Community-Based Programs

Community-based initiatives are a promising route for bringing end-of-life planning options to a broad base of older adults, often tailoring their programs to meet the distinctive social, cultural, religious, and language needs of the particular subpopulations they serve (see Figure 6-1, [IOM, 2014](#) for detailed summary chart). One of the earliest community-based programs is Five Wishes, which was started by an attorney in the 1990s. For a small fee, users can obtain online a user-friendly, jargon-free template for completing an advance directive and naming a health care proxy ([Aging with Dignity, 2017](#)). A more recent development, [The Conversation Project \(2017\)](#), provides a free booklet in nine languages that offers tips for eliciting a patient's values and structuring a meaningful discussion about end-of-life preferences. The Conversation Project, developed by the non-profit Institute for Health Care Improvement, also provides resources on naming a DPAHC, discussing preferences with a physician, and facilitating decision making for individuals with dementia or Alzheimer's disease. Informational videos also are emerging as a widely used approach for raising awareness of and increasing rates of ACP. For example, [ACP Decisions \(2013\)](#) is a physician-led organization that provides educational videos on end-of-life care and medical decisions. The videos can be viewed for free on their website or licensed for use within health care organizations.

Promising new partnerships between health care systems and religious leaders are emerging with the explicit goal of increasing rates of end-of-life planning among older Blacks. For example, The Caring Touch Ministry, is a church-based hospice education and coordination program started by Cassandra Cotton, a church leader, certified nursing assistant (CNA), and community relations coordinator at a local hospice. The Ministry provides education on end-of-life issues to congregation members, including information on precisely what palliative care is, with careful attention to addressing myths regarding comfort care ([NHPCO, 2015](#)).

Community-based initiatives heighten awareness and trigger conversations about end-of-life care by providing accessible resources to the general population. However, such programs are rarely evaluated formally, making it difficult to determine their reach and impact. ACP Decisions has received funding from the National Institutes of Health to develop and evaluate their educational videos; these assessments show that hospitalized patients who watch the videos have more accurate knowledge about CPR and intubation and are more likely to complete POLSTs and to discuss ACP, relative to those who receive verbal instructions only about treatment options ([El-Jawahri et al., 2015](#)).

## Educational Interventions in Formal Care Settings

Many educational interventions have been developed and tested in institutional settings including long-term care facilities and hospitals. Intervention studies are developed

with the explicit goal of identifying what type and form of information or incentive is most effective in encouraging ACP, and whether particular strategies are best suited for specific subpopulations including older adults with dementia, homeless adults, and those suffering from particular diseases such as cancer or end-stage renal disease ([IOM, 2014](#)). The most renowned and long-running program is Respecting Choices, which began in 1991 at Gundersen Medical Center in LaCrosse, Wisconsin. The program produces educational materials for patients; trains facilitators to discuss end-of-life issues with patients and prepare them for what lies ahead; and ensures that advance directives are available in patients' electronic medical records. Nearly all (96%) persons who die in LaCrosse, WI have an advance directive, and the program has been replicated throughout the United States and abroad ([Hammes et al., 2012](#)).

Educational videos are emerging as a particularly popular and effective form of encouraging ACP. Professionally produced videos are an important advance because some clinicians, even those with the best intentions, may not feel adequately prepared to discuss end-of-life decision making with their patients. Video support tools are designed to encourage ACP by triggering informed conversations and helping patients to envision their future circumstances, think realistically about the choices they may face, and deliberate about those choices. Randomized control studies consistently show that educational videos increase rates of both formal ACP and patients' knowledge about end-of-life issues. For instance, one study of older hospitalized end-stage renal disease (ESRD) patients in Hawaii found that ACP documentation rates increased from 3% to 40% pre- and postexposure to the video intervention ([Volandes et al., 2016](#)), while a study of older heart disease patients detected a significant increase in knowledge about end-of-life medical treatments following exposure to a video ([El-Jawahri et al., 2016](#)). (see [Chan, Sim, Zimmermann, & Krzyzanowska, 2016](#) and [Weathers et al., 2016](#) for review articles on end-of-life planning intervention studies).

## Directions for Future Research

Public conversations and empirical research on end-of-life care have flourished over the past two decades, yet important questions remain unanswered. We briefly suggest five main areas of research that we believe will be fruitful. First, future studies should delve more fully into the challenges faced by individuals in "nontraditional" families, including same-sex partnerships, cohabiting couples, living apart together (LAT) relationships, and reconfigured families in which at least one partner has children from a prior marriage. Given structural lags, public policies may not keep pace with social and cultural changes. State-level policies that bestow decision making in a particular order may mean that older adults who rely on someone other than a

legal spouse or biological child may require more deliberate conversations about their end-of-life preferences.

Second, research has documented race and SES disparities in ACP, but has not delved into intersections therein. Emerging research suggests that for current cohorts of young and midlife adults, racial disparities in ACP may be disappearing (Carr 2012a; Koss & Baker, 2017a). This convergence may reflect secular increases in educational attainment, declining levels of religiosity, and other factors that are important sources of heterogeneity even within a single racial or ethnic group. We suspect that among future cohorts of older adults, socioeconomic disadvantage may be more powerful than race, religion, or cultural beliefs in impeding ACP.

Third, relatively little research evaluates the efficacy of end-of-life conversations, and whether particular types of information, interpersonal dynamics, institutional settings, or the timing of such conversations are linked with efficacy in conveying older adults' treatment preferences. We encourage future studies to identify factors associated with meaningful and productive conversations among family members, clinicians, legal professionals, and others who may be instrumental in shaping older adults' ACP. The recent CMS changes that reimburse health care providers for their end-of-life conversations with Medicare beneficiaries hold great promise in enhancing the quality of end-of-life care, yet this promise hinges on the quality of the conversations that ensue.

Fourth, we believe that POLSTs hold great potential for ensuring that dying adults' treatment preferences are met, especially among populations that may lack the knowledge or connections that facilitate the use of more traditional ACP tools like living wills and DPAHC designations. However, further research is needed to demonstrate the efficacy of POLSTs, and to highlight those contexts in which they are most valuable. Assessments have focused largely on POLST utilization among nursing home residents (Hammes et al., 2012; Jennings, 2016), and less is known about usage rates and correlates thereof among community-dwelling older adults. We also believe that researchers should explore family members' perceptions of the value, efficacy, and experience of using POLSTs. Although the primary goal of ACP is to enhance the quality of an older adult's death, an equally important goal is to ease the decision-making process for family caregivers and to protect against bereaved family members' symptoms of grief and distress, which are particularly prominent in the face of a "bad death" (Carr, 2003). The voices and perceptions of family caregivers who must live with a patient's treatment decisions long after those decisions are carried out will be very valuable for scholars interested in enhancing the well-being of the millions of older adults who will inevitably outlive a family member.

Finally, international comparisons will help to identify relative strengths and weakness of ACP effectiveness and promotion efforts in the United States relative to other

wealthy nations. ACP completion rates are considerably higher in the United States than other countries. An estimated 35% of the adult population ages 18+ in the United States have done ACP, compared to rates of less than 1% (Japan, Australia) to 7%–8% (Netherlands, UK) (Aw et al., 2011; Matsui, 2007; Pew Research Center, 2013; Stewart, 2005; Van Wijmen et al., 2010). Nonetheless, lessons for improving older adults' quality of end-of-life care might be learned from considering alternative practices used in other nations. For example, despite relatively low rates of ACP completion, the United Kingdom was rated as providing the highest quality deaths out of 80 countries. By contrast, the United States ranked 9<sup>th</sup> (The Economist Intelligence Unit, 2015). A key factor contributing to the United Kingdom's superlative position is that its National Health Service (NHS) has developed and implemented a comprehensive framework for improving end of life care at the national and local levels. In addition to specific steps to facilitate more meaningful conversations between individuals and health care providers regarding end-of-life issues, additional facets include public support for a range of educational initiatives for chronically ill individuals and their caregivers, and providing palliative care training to all clinicians and staff involved in delivering end-of-life care (NHS Finance and Operations, 2016). A multipronged approach that targets not only ACP completion, but also patient and caregiver knowledge, and clinician training may be needed to enhance quality of end of life care for dying individuals.

## Conflict of Interest

None reported.

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