

# End-of-Life Planning and Health Care

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## INTRODUCTION

Death is a universal experience, yet the nature of death and dying has changed dramatically throughout the past two centuries; these changes have important implications for how individuals think about and prepare for both their own end-of-life and the final days of their loved ones (Carr, 2012a). Throughout the nineteenth and early twentieth centuries, most deaths occurred with little warning, typically due to short-term infectious diseases (Omran, 1971). In the

contemporary United States and most wealthy developed nations, death typically befalls older adults following a long-term chronic illness, often accompanied by physical pain, functional decline, and cognitive impairment (Olshansky & Ault, 1986). Most older adults die in hospitals or nursing homes rather than at home, and many rely on medical technologies and aggressive treatments that may increase the length – although not necessarily the quality – of their lives (Teno et al., 2013). For most older adults, then, it is more accurate to conceptualize the

“end of life” as an anticipated and protracted albeit unpredictable process (i.e., dying) rather than a discrete and sudden event (i.e., death) (Carr, 2012a; George, 2002).

These shifts in the timing and cause of death have created a context in which older adults are encouraged to actively prepare and plan for their end of life, conveying to significant others and health care providers their preferences regarding how, where, and under what medical care regimens they would like to die (AMA, 2012; IOM, 2014). Such preparations are widely regarded as 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, 2003; Steinhauer et al., 2000; Teno, Gruneir, Schwartz, Nanda, & Wetle, 2007). Yet emerging research identifies psychosocial, economic, structural, and cognitive barriers to effective end-of-life planning (Carr, 2012b,c, 2013; IOM, 2014), leading policy makers to develop new practices such as Physician’s Order for Life-Sustaining Treatment (POLST) (National POLST, 2012) and Medicare-reimbursed doctor–patient consultation sessions regarding one’s options and preferences for end-of-life care (Belluck, 2014; IOM, 2014; Pear, 2011).

In this chapter, we describe how older adults die in the contemporary United States, and describe the practices that individuals, families, health care providers, and policy makers may use to help increase the chances that dying patients and their families experience a “good death.” We begin by describing the changing demographic, technological, and cultural contexts of death and dying throughout the twentieth and twenty-first centuries. We underscore that for current cohorts of older adults, the time period between onset of terminal illness and death may be unpredictable, posing challenges for practitioners and patients in their efforts to prepare for the dying process (Christakis, 2001; Gawande, 2014; George, 2002). We then

describe the specific practices that older adults and their families may engage in to prepare for the end of life, with an emphasis on both formal/legal preparations such as the use of advance directives, and informal preparations such as discussing one’s general preferences and values with loved ones and health care providers. However, we also point out limitations of formal advance care planning (ACP) that may weaken its effectiveness in promoting a “good death” for dying patients, and we show how both access to and willingness to engage in ACP are powerfully shaped by cultural, religious, and economic factors (Carr, 2011, 2012b,c; Sharp, Carr, & MacDonald, 2012). These disparities in ACP are linked to inequities in end-of-life experiences, including the use of hospice and palliative care, costs related to one’s medical care, and family conflicts surrounding the dying process (Carr, 2012b,c; Kramer & Yonker, 2011). We then describe recent innovations and emerging controversies in end-of-life care including debates over POLSTs, Medicare-funded doctor–patient consultations regarding end-of-life care (Belluck, 2014; Pear, 2011), and legalization of physician-assisted suicide (PAS) (Eckholm, 2014). We conclude by suggesting avenues for future research, highlighting areas in which social science research may be particularly effective in complementing and extending findings based primarily on clinical samples and contexts.

## DEATH AND DYING IN THE UNITED STATES

### Demographic and Epidemiologic Contexts

An “epidemiologic transition” occurred over the past two centuries in which infant and child deaths were replaced by later-life deaths, and infectious diseases were replaced by “lifestyle-related” chronic diseases as the leading causes of death (Olshansky & Ault, 1986; Omran, 1971).

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In the nineteenth and early twentieth centuries, deaths occurred primarily due to infectious diseases, such as diphtheria and pneumonia; death occurred relatively quickly after the initial onset of symptoms. Throughout the twentieth century, improved sanitation and nutrition, immunization for communicable diseases, effective treatments for infections, and other medical advances dramatically reduced mortality among younger persons, and increased life expectancy (IOM, 2014). While median life expectancy in 1900 was just 46 years old, it approached 80 years old in 2009 (Arias, 2014). Roughly three-quarters of the 2.4 million deaths in the United States in 2010 were persons ages 65 and older (Federal Interagency Forum on Aging Related Statistics, 2013). The leading causes of death among older adults are chronic and progressive illnesses that can persist for months if not years prior to death, including: heart disease (1 156 deaths per 100 000 people), cancer (982 per 100 000), chronic lower respiratory diseases (291 per 100 000), stroke (264 per 100 000), Alzheimer's disease (184 per 100 000), and diabetes (121 per 100 000) (Federal Interagency Forum on Aging Related Statistics, 2013).

Later-life deaths today rarely occur shortly after the onset of chronic illness, thus the "living-dying interval" (Pattison, 1977) between diagnosis and death is typically marked by compromised quality of life including comorbid conditions, functional impairment, mobility limitations, impaired cognitive functioning, physical discomfort, and the need for assistance with activities of daily living (ADLs) and instrumental activities of daily living (IADLs). In 2009, more than 40% of persons ages 65 and older required assistance with an ADL or IADL (Federal Interagency Forum on Aging Related Statistics, 2013). The number of older Americans with serious cognitive impairment is also high and rising; the number of older adults suffering from Alzheimer's disease and related dementias is expected to grow from 5.5 million in 2010 to 8.7 million in 2030 (HHS/ASPE, 2013).

However, the timing and onset of decline vary widely across disease groups, thus "dying" is a highly heterogeneous (and unpredictable) experience even among older adults with chronic illness. "Dying" is not a medical or diagnostic term, and an individual with a terminal illness could survive anywhere from a few days or weeks to several years (IOM, 2014). Researchers have developed conceptual and empirical models to characterize distinctive patterns of dying (Lynn & Adamson, 2003). Contemporary models have their roots in Glaser and Strauss' (1965) classic writings on the "trajectory of dying." This work was among the first to specify that patients' dying trajectories are based on two core properties: duration, or the time period between illness onset and death; and "shape" of one's trajectory, which may include components such as spikes in symptoms, periods of recovery, and rapidly decreasing levels of functional ability. Researchers generally agree upon three "typical" dying trajectories for patients with progressive chronic disease: a steady progression and a clear terminal phase (e.g., cancer); gradual decline punctuated by episodes of acute deterioration, some recovery, and a seemingly unexpected death (e.g., heart or respiratory failure); and prolonged and gradual decline or "dwindling" (e.g., dementia, frail older adults) (Lynn & Adamson, 2003; Skolnick, 1998). Knowledge of a dying patient's anticipated future trajectory has the potential to guide practitioners as they plan a course of treatment (Murray, Kendall, Boyd, & Sheikh, 2005), to shape patients' preferences regarding the use or rejection of particular treatments (Weeks et al., 1998), to facilitate family members' preparations for their loved one's impending death (Carr, House, Wortman, Nesse, & Kessler, 2001), and to guide decisions regarding the use of and Medicare reimbursement for hospice care (IOM, 2014).

Yet in practice, dying trajectories are fraught with high levels of uncertainty. Many patients' actual trajectories do not conform to "typical"

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patterns, making it difficult for physicians to offer accurate prognoses (Christakis, 2001). Physicians may be reluctant to share their prognoses with patients and their families, for fear of upsetting or misinforming them (Christakis & Lamont, 2000), especially in cases where dying patients show a strong desire to continue living (Finucane, 2004). To compensate for these concerns, physicians may either fail to provide patients with prognoses, or provide overly optimistic estimates of survival. The closer and more long-standing the physician–patient relationship, the more likely that the physician will make an inaccurate prediction regarding a patient’s survival or will shield patients from this potentially distressing information (Christakis & Lamont, 2000). Consequently, dying patients and their kin often report high levels of uncertainty about the patient’s survival and symptomatology, which may impede the formation of well-informed preferences regarding end-of-life care (Fried, Bradley, & O’Leary, 2006).

## Cultural Context of Death and Dying

### *Medicalization of Death and Dying*

Shifts in the timing and leading causes of death have been accompanied by a cultural transformation: the medicalization of aging and dying. Dying has become an increasingly “medicalized” process, where death is viewed as something to be stopped or delayed, rather than accepted as a natural part of the life cycle (Aries, 1981; McCue, 1995). Throughout the twentieth century, medicine became highly professionalized, with a heightened emphasis on scientific research aimed at finding a “cure,” and an increase in the prestige and authority afforded to physicians (Conrad, 1992; Starr, 1982).

Medicalization processes carry two important implications for end-of-life care. First, the location of medical care shifted from the patient’s home to a clinical environment, with an increasing reliance on sophisticated

technologies, pharmaceuticals, and interventions targeted toward curing symptoms and forestalling death. For example, the development of mechanical ventilation and intensive care units (ICUs) allows patients to use life-sustaining interventions that cannot be easily provided outside a clinical setting. For this reason, the modal place of death shifted from the home to medical institutions during the twentieth century, despite the fact that the majority of Americans say that they would like to die at home (IOM, 2014). In 2009, 25% of older adults died in an acute care hospital, 28% died in a nursing home, and just one in three died at home. Fully one-third of all recent decedents spent time in an ICU in the month prior to death (Teno et al., 2013). Some critics have noted that by “sequestering” dying patients away from their homes and communities, the medical establishment is creating a culture that denies and hides death, heightens death anxiety, and isolates sick and dying persons at precisely the time when they most need interpersonal interaction (Aries, 1981; Elias, 1985).

Second, the increasing professionalization of medicine throughout the twentieth century created a context in which dying patients and their families would cede to physician knowledge and decisions, leading to high levels of reliance on invasive and costly interventions intended to sustain one’s life span (IOM, 2014; Starr, 1982). Qualitative research shows that doctors heavily influence both the treatments patients choose, and patients’ willingness to seek out or forego life-sustaining technologies (Sudnow, 1967; Timmermans, 2009). Through much of the twentieth century, physicians’ training emphasized saving and sustaining lives (Starr, 1982), which partly shaped their reluctance to withhold life-extending treatments (Farber et al., 2006), and their tendency to shield patients from dire prognoses (Christakis & Lamont, 2000).

As a result, patients may passively accept or fail to reject invasive and futile treatments proposed by their physicians. “Futile care” refers to

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interventions that are unlikely to help patients and that may cause them harm or discomfort (IOM, 2014). One recent study found that critical care clinicians themselves believed almost 20% of their patients received care that was futile (Huyhn et al., 2013). Similarly, an estimated one-third of nursing home patients in the final stages of dementia are given feeding tubes, although the practice does not prolong patients' lives and may cause infections (Mitchell, Teno, Roy, Kabumoto, & Mor, 2003). Despite widespread reliance on invasive treatment, attitudinal surveys suggest that older adults would choose to reject treatment if it held no hope for a cure. In 2013, 71% of persons ages 65–74 and 62% of those ages 75 and older say they would “tell their doctor to stop treatment so they could die” if they “had a disease with no hope of improvement and were suffering a great deal of pain” (Pew Research Center, 2013).

For much of the twentieth century, older adults with advanced chronic illnesses “relied almost unquestioningly on their physicians' judgments regarding treatment matters, trusting that physicians would act in their patients' best interests as a matter of professional and personal ethics” (IOM, 2014, pp. 3–5). The use of breathing and feeding tubes and powerful drugs has sustained older adults' lives, although with well-documented emotional, physical, and financial costs. Terminally ill persons (Singer, Martin, & Keltner, 1999), their families (Pierce, 1999), and health care providers (SUPPORT Investigators, 1995) have reported considerable dissatisfaction with end-of-life care, attributing their dissatisfaction to the fact that dying older adults often are non-ambulatory, short of breath, unable to eat, in pain, and unable to recognize family members. The economic costs imposed by end-of-life care also present a substantial threat to older adults, their families, and the federal government. An estimated 13% of the \$1.6 trillion spent on health care annually in the United States is for individuals in their last year of life (IOM, 2014).

### ***The Movement toward Patient Autonomy***

In response to heightened concerns about costly overtreatment and futile care at the end of life, policy makers and practitioners recently developed initiatives to place greater decision-making latitude in the hands of patients and their families (Daschle, Domenici, Frist, & Rivlin, 2013; IOM, 2014). Most notably, in 1990 the US Congress passed the Patient Self-Determination Act (PSDA), which 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” (HHS, 2008), facilitating patients' ability to make decisions about their own medical care.

Another reaction against the highly medicalized context of end-of-life care has been escalating interest in and use of hospice care. Hospice is a comprehensive, socially supportive, pain-reducing, and comforting alternative to technologically elaborate, medically centered interventions (IOM, 2014). The modern hospice movement was founded in the United Kingdom in the 1950s by Dame Cicely Saunders, a physician, nurse, and social worker. The first hospice was established in the United States in 1971 by Florence Wald, the dean of the Yale School of Nursing, who had been inspired by a lecture Saunders delivered. Hospice promotes palliative (or “comfort”) care for people with a terminal illness or at high risk of dying in the near future. Hospice has grown rapidly in popularity over the past two decades, with the number of sites increasing at about 3.5% a year during the first decade of the twenty-first century (National Hospice and Palliative Care Organization [NHPCO], 2012). In 1997, 17% of all deaths in the United States occurred under the care of hospice; by 2011, this proportion more than doubled to 45% (NHPCO, 2012). The increase partly reflects attitudinal shifts favoring quality of life over length of life

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(Pew Research Center, 2013), and an increased allocation of Medicare funds to hospice services in an effort to reduce the costs associated with high-tech treatments among dying older adults. Medicare beneficiaries who are certified by a physician to have a terminal illness and life expectancy of 6 months or less may elect non-curative medical and support services including hospice (CMS, 2013). Although hospice care typically involves withholding or withdrawing medical treatments that may sustain one's life, it is not a form of euthanasia or PAS. The latter, as we shall describe below, involves proactive steps to hasten death among terminally ill patients (AMA, 2012).

In sum, the movement toward a physician-controlled, highly medicalized death in the mid- to late-twentieth century gave rise to widespread concerns regarding the loss of patient autonomy and reliance on costly, invasive, and often futile treatments at the end of life (Carr, 2012a; IOM, 2014; Steinhauser et al., 2000). Mounting efforts to encourage ACP and to increase both desire for and public awareness of hospice services are indicative of an emerging cultural and social imperative to achieve a "good death," or a death that is "free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards" (National Research Council, 1997, p. 24). However, as we will see in the next sections, access to ACP and patient-centered care at the end of life are difficult to achieve, given pervasive socioeconomic and practical barriers (IOM, 2014).

## ADVANCE CARE PLANNING

### Components and Limitations

Philosophical writings on the "good death" emphasize the central role of patient autonomy

(Byock, 1996), while empirical studies show that patient "involvement in decision making" is one of the most frequently mentioned components of a good death (Steinhauser et al., 2000). Bioethicists concur that physicians should share, and in some cases delegate, medical decision-making control to dying patients and their families (President's Council on Bioethics, 2005). In practice, however, many dying persons are unable to convey their preferences for medical treatments because they are incapacitated when the decision is required (IOM, 2014). According to recent estimates, 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 to 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 course of action, the default decision is to continue treatments which may be financially and emotionally draining for family members, and physically distressing to the patient (IOM, 2014).

In an effort to prevent problematic, futile, or contested end-of-life care, practitioners encourage adults to express and document their treatment preferences when they are still in good health (AMA, 2012; IOM, 2014). Adults may convey their treatment preferences *formally* through an advance directive, which comprises a living will and/or a durable power of attorney for health care (DPAHC) appointment, or *informally* via discussions with significant others. A living will states the treatments that an individual would want (or not want) at the end of life; such treatments might include ventilators, feeding tubes, or cardiopulmonary resuscitation. A DPAHC is a legal document designating a specific individual (also referred to as a "surrogate" or "proxy") who will make decisions on behalf of the patient in the event

that he or she is incapacitated. The vast majority of older adults select a spouse or long-term partner, followed by a child, or other close relative as DPAHC (Carr & Khodyakov, 2007). Spouse proxies 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 (AMA, 2012), public awareness and education campaigns (Hammes, 2003), popular books (Gawande, 2014), and public policies (PSDA, 1990) targeted at encouraging ACP, formal ACP has well-documented limitations (Drought & Koenig, 2002; Fagerlin & Schneider, 2004). Criticisms of the living will include: the content or stated preferences may be unclear; the treatment preferences stated 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 (Coppola, Ditto, Danks, & Smucker, 2001; Ditto et al., 2001). For example, many advance directives begin with the statement "If I have a terminal condition, then ...." This statement requires a physician to make an evaluation of whether the patient's condition is terminal. Until that determination is made, the content of the advance directive does not hold, despite what the patient and family had hoped. 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). Moreover, 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 are

granted decision-making authority, yet some may make decisions that create distress or disagreement among family members (Doukas & Hardwig, 2003; Khodyakov & Carr, 2009). Moreover, surrogate decision makers' knowledge of patient preferences is usually no better than chance (Coppola et al., 2001; Shalowitz, Garrett-Mayer, & Wendler, 2006), and may strongly reflect the surrogate's own preferences (Moorman & Inoue, 2013). As one study concluded, "surrogates are not perfect ambassadors of patient preferences" (Vig, Taylor, Starks, Hopley, & Fryer-Edwards, 2006, p. 1688). Older adults may (erroneously) believe that their loved ones "intuitively" understand their preferences, so they do not see a need to explicitly inform the legal proxy of their views (Coppola et al., 2001).

For some patients, the proxy's limited knowledge is unproblematic; they may prefer that their family members do what they feel is best, rather than abide by 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 makers also may trigger distress or disagreement; clinicians often share anecdotes illustrating 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 – may enter the family conversation at the patient's final stage of life. These individuals may try to undo, contest, undermine, or alter the decisions made by local family members who had been engaged in the care and decision-making process for a much longer duration (Molloy, Clarnette, Braun, Eisemann, & Sneiderman, 1991). These family disagreements, in turn, may inhibit interdisciplinary health care teams' ability to provide quality end-of-life care (Kramer & Yonker, 2011).

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Given these well-documented limitations of formal ACP, some practitioners suggest that informal discussions with significant others and care providers are the most critical component of end-of-life planning (Doukas & Hardwig, 2003). Recent analyses of couple-level data from the Wisconsin Longitudinal Study reveal that discussing end-of-life issues with one's spouse is associated with correctly identifying one's spouse's end-of-life treatment preferences (Moorman & Carr, 2008). In general, discussions can help to facilitate care consistent with the patient's wishes; Winter and Parks (2012, p. 741) find that "those who avoid ... end-of-life conversations are the least likely to have treatment wishes respected, because their proxies are unlikely to know their wishes."

Conversations about an older adult's general values also may be useful because few individuals know precisely how and of what cause they will die, making it difficult to specify particular medical interventions that they would want (or not want) at the end of life, such as feeding tubes or chemotherapy. A general conversation about values (e.g., "I don't want to be a vegetable") and global preferences (e.g., "I don't 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 (Doukas & Hardwig, 2003). Discussions also may facilitate decision-making in cases where the patient has not legally appointed a DPAHC. Most states have established default systems for authorizing proxy decision makers. State laws vary, but such lists prioritize the immediate family – starting with spouse, followed by adult child, sibling, and other relatives (American Bar Association, 2009; Kohn & Blumenthal, 2008). 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, research also shows that the timing of discussions is critical, as some discussions

may be "too little, too late." Discussions regarding end-of-life issues are typically triggered by a patient's health-related event such as a hospitalization, a period of ineffective mechanical ventilation, a problematic level of forced expiratory volume, or a rapidly deteriorating nutritional status (McGrew, 2001; Pfeifer, Mitchell, & Chamberlain, 2003). When discussions about end-of-life care occur following such "trigger" events, the patient (and family) often is too distressed to make an informed or appropriate decision about imminent care needs (Hoffman, Wenger, Davis, Teno, & Connors, 1997).

Recognition of the importance of timely, in-depth conversations among dying patients, their family members, and health care professionals was partly the impetus for the 2010 House bill that would have reimbursed clinicians for the time spent discussing end-of-life issues with Medicare-beneficiary patients and their families (America's Affordable Health Choices Act of 2009). However, as we will discuss below, unfounded and incendiary rumors surrounding "death panels" led to the deletion of this benefit from the Affordable Care Act (ACA) in 2011 (Belluck, 2014). Other recent initiatives intended to increase the timeliness, rate, and quality of conversations regarding end-of-life care include the development of POLSTs, which we elaborate on later in this chapter.

## ACP Benefits and Consequences

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; Teno et al., 2007); reduced use of invasive or futile treatments such as feeding tubes or ventilators (Mack, Weeks, Wright, Block, & Prigerson, 2010; Nicholas, Langa, Iwashyna, & Weir, 2011; Teno et al., 2007; Wright et al., 2008);

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heightened perceptions of patient control over the end-of-life process (Edwards, Pang, Shiu, & Chan, 2010); a greater likelihood of dying at home rather than in an institution (Nicholas et al., 2011; Silveira et al., 2010); and fewer instances of receiving treatments that are discrepant with the patient's wishes (Detering, Hancock, Reade, & Silvester, 2010).

ACP also is associated with superior outcomes for dying patients' family members, including a reduced decision-making burden, and fewer anxiety and depressive symptoms (Detering et al., 2010; 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 at the end of life 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 receiving inadequate support during the dying process (Teno et al., 2007) or may report increased levels of family conflict in cases where the living will was deemed unhelpful or problematic (Khodyakov & Carr, 2009).

Research on the impact of a patient's ACP on end-of-life medical costs is equivocal. In general, studies based on large population-based samples 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 among older decedents in the last 6 months of life (e.g., Zhang et al., 2009). Nicholas and colleagues (2011) found that median fee-for-service Medicare spending in the last 6 months of life did not differ significantly between those who had versus those who did not have a "treatment-limiting" advance directive; in both subgroups, the median expenditure level was roughly \$21 000. By contrast, among patients with advanced

cancer, end-of-life medical costs were roughly one-third less for persons who had a treatment-limiting advance directive (Zhang et al., 2009). Intensive care unit (ICU) use is a key pathway linking ACP with reduced medical expenditures; ACP is associated with lower rates of ICU stays, which in turn is linked with lower care costs. One recent study found that the cost of a terminal hospitalization with an ICU stay averaged \$38 000, compared with just \$13 000 if an ICU was not included (Zilberberg & Shorr, 2012). On the whole, scholars and policy makers agree that standard ACP tools are neither a panacea nor a guarantee of a "good death," although the potential benefits far outweigh the potential costs (IOM, 2014).

### Trends and Differentials

Rates of ACP vary widely by age, race, socioeconomic status (SES), and other psychosocial factors. National studies show that only one-third to one-half of all adults in the United States have completed advance directives (HHS, 2008), although rates are as high as 70% among adults age 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). This trend is partly attributable to the passage of the *Patient Self-Determination Act (1990)*, high visibility cases of contested end-of-life decisions such as that of Terri Schiavo (Sudore, Landefeld, Pantilat, Noyes, & Schillinger, 2008), public awareness campaigns such as *Respecting Choices*<sup>®</sup> (Hammes, 2003) and the "Five Wishes" (*Aging with Dignity, 2014*), and media programs such as Bill Moyers' PBS Series *On Our Own Terms*. The Five Wishes, for example, is a user-friendly advance directive written in nontechnical language that includes identification of a proxy and preferences for medical and nonmedical treatment and comfort.

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Rates of ACP are especially low among Blacks and Latinos, relative to Whites. Estimates vary based on the particular study sample, 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; Kwak & Haley, 2005; Smith et al., 2008). Explanations for these differentials include: ethnic minorities' lack of access to the medical and legal professionals who may provide assistance in preparing such documents; literacy or language barriers; cultural beliefs that such documents are not needed 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, 2012b; Morrison, Zayas, Mulvihill, Baskin, & Meier, 1998; West & Hollis, 2012). Some research suggests that Blacks and Latinos believe they don't need a living will, because they tend to desire all possible interventions at the end of life (Barnato, Anthony, Skinner, Gallagher, & Fisher, 2009; Kwak & Haley, 2005; Pew Research Center, 2013), and they believe that living wills limit rather than request treatment (Barnato et al., 2009; Mack, Paulk, Viswanath, & Prigerson, 2010). Given this pervasive misperception that advance directives limit, rather than articulate requests for, particular treatments, one author noted, "advance directives, which are generally accepted in western civilization, hold little or no relevance within the [black and minority ethnic] population" (Cox et al., 2006, p. 20).

Empirical evidence suggests, however, that 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 treatments that are consistent with their preferences (Loggers et al., 2009). Further research shows a substantial racial

gap in end-of-life health care costs, where the average cost of care in the last 6 months of life ranged from \$20 166 among Whites, to \$26 704 among Blacks, and \$31 702 among Latinos in 2001 (Hanchate, Kronman, Young-Xu, Ash, & Emanuel, 2009). Fully 85% 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 ethnic minority communities are linked to costly intrusive treatments as well as the failure to receive desired treatments.

Research has focused more heavily on racial differences than social class differences in ACP, yet recent work shows that persons with lower levels of education, income, assets, and home ownership rates are significantly less likely than their more advantaged counterparts to do formal ACP, although no differences are found for discussions. Older adults with greater net worth and home owners are nearly twice as likely as those with no or few assets, and non-homeowners to engage in ACP (Carr, 2012c). Older adults with assets to protect are more likely to engage in estate and financial planning (e.g., initiating a signed and witnessed will) than are their less-wealthy counterparts. A visit to one's lawyer to do financial planning often triggers the completion of related documents, including living wills and DPAHC appointments (Carr, 2012c). Educational attainment also is linked indirectly to advance directive completion, as persons with lower levels of literacy are less likely to engage in ACP. One recent study of patients ages 55–74 found that rates of ACP were 12.5%, 25%, and 50% for those with low, marginal, and adequate literacy, respectively (Waite et al., 2013). Limited knowledge about one's specific health condition and the treatments one might receive at the end of life also may impede ACP, as individuals are reluctant to make decisions about treatments they don't understand (Porensky & Carpenter, 2008).

Psychological, religious, and attitudinal factors also may pose obstacles to ACP.

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Some scholars argue that this pattern reflects a “death-denying” ethos in contemporary Western society (Kellehear, 1984); empirical research shows that persons with higher levels of death anxiety are less likely to do ACP (Carr & Moorman, 2009). Individuals who have witnessed the painful or prolonged death of loved one are more likely to discuss and make preparations for their own end of life in an effort to avoid the fate experienced by their loved ones (Carr, 2012d). Religious beliefs also affect ACP; those who adhere to Fundamentalist beliefs (Sharp et al., 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 are likely to desire all treatments possible at the end of life, because they believe that God will either sustain them or let them die when the time is right: “those who believe in God do not have to plan for end-of-life care” (Johnson, Kuchibhatla, & Tulsky, 2008 p. 1956).

ACP is also linked to aspects of one’s interpersonal relationships, where persons with closer, less-conflicted relationships are more likely to execute advance directives than those with poor-quality relationships, and married older adults are more likely to appoint their spouse (versus an adult child or someone else) as their DPAHC when their marriage is marked by high levels of warmth and low levels of conflict (Carr, Moorman, & Boerner, 2013). Individuals are also more likely to both do ACP and to engage significant others in the process when they anticipate that their relationship is stable and will persist into the future. For example, on average, cohabiting individuals are significantly less likely than their married counterparts to both engage in ACP and to name their partner as their DPAHC. However, when cohabiting persons are stratified based on whether they intend to marry their partner

or whether they expect that the relationship will end, researchers have found that cohabiters who intend to marry their partner are just as likely as married persons to both do ACP and name their partner as their proxy decision maker (Moorman, Carr, & Boerner, 2014).

In sum, research on ACP shows that Whites, and those with the most economic resources, the most supportive and enduring social relationships, and who favor limited versus invasive treatments are most likely to formally state and convey their treatment preferences via the use of advance directives. However, comparable race- and SES-based disparities are either non-existent or considerably narrower with respect to end-of-life discussions – an activity that can be undertaken at no financial cost, and that does not require interactions with health care or legal professionals (Carr, 2011; Carr, 2012c; Wright et al., 2008). As such, economic, informational, and structural barriers may be a more powerful obstacle to ACP 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 designed to place decision-making responsibility in the hands of older patients and their families, regardless of their personal resources. We next describe several recent innovations, and highlight strengths, controversies, and limitations in these evolving approaches to end-of-life care.

## PUBLIC POLICY INNOVATIONS

### Physician’s Order for Life-Sustaining Treatment (POLST)

The limitations of living wills and DPAHC appointments are widely documented and led health care providers to develop an alternative approach: the POLST. This one-page document includes standing medical orders about those medical interventions a terminally ill

individual wishes to have or forego. POLSTs are advised for dying patients, typically those with less than a year to live. As such, they include preferences for current treatment, whereas living wills may stipulate preferences for treatments that may not be required for many years into the future (Bomba, Kemp, & Black, 2012). Patients complete POLSTs in consultation with their health care providers, providing instructions relevant to those decisions that typically arise in medical crises at the end of life. Because POLSTs are actual doctor's orders, other health professionals are required to follow them (National POLST, 2012).

The medical preferences articulated in POLSTs fall into three main categories: full treatment, comfort measures only, and limited additional interventions. These categories are broader than highly specific treatments named in a living will (e.g., a feeding tube) yet less broad than the general values that might be communicated to family members via discussion (e.g., "don't hook me up to a machine"), so they are particularly effective in conveying patient preferences (Bomba et al., 2012; IOM, 2014). The request for "comfort measures only" indicates that a patient's main goal is maximizing comfort rather than prolonging life span. If adequate comfort cannot be provided in the patient's home, patients are moved to a clinical setting where their needs can be met. The specific types of care provided are those that relieve pain and suffering, such as oxygen. The slightly more involved treatments named under "limited additional interventions" include antibiotics and intravenous fluids. The most intensive category of care, "full treatment," includes measures provided in the other two categories, along with medical interventions, such as mechanical ventilation (National POLST, 2012).

POLSTs are relatively new, yet are growing rapidly in use. The state of Oregon first introduced POLSTs in 1991 as a means for honoring dying patients' end-of-life preferences. As of December 2014, 44 states either used POLSTs or

were developing POLST implementation plans (National POLST, 2014). Like all ACP practices, POLSTs have limitations; one concern is that physicians may indicate a patient's preference box without having an in-depth conversation (Bomba et al., 2012). A further concern is that workers on the front lines of care, especially emergency personnel and nursing personnel at long-term care facilities may require training regarding the POLST's content, so that they do not deny treatment for remediable health problems that are not imminently life-threatening (IOM, 2014). However, emerging research generally concludes that POLSTs are effective in helping patients receive care that is concordant with their wishes (Hammes, Rooney, Gundrum, Hickman, & Hager, 2012; Hickman et al., 2011). For this reason, policy makers and health care providers strongly advocate for the use of POLSTs nationwide (IOM, 2014).

### Affordable Care Act

An additional way to ensure that older adults make well-informed decisions regarding end-of-life care is to revitalize the original ACA proposal to include one voluntary ACP session as a benefit included in the annual wellness visit for Medicare beneficiaries. In 2009, a bipartisan group of representatives sponsored a provision in the House version of the bill that would have authorized Medicare to reimburse doctors who counsel patients about living wills, advance directives, hospice, and options for end-of-life care (IOM, 2014). This benefit would give all older adults the opportunity to discuss their treatment preferences with a health care provider, regardless of their economic or personal resources (America's Affordable Health Choices Act of 2009). However, political uproar regarding (unsubstantiated) fear of "death panels" contributed to President Barack Obama's deletion of the proposed benefit from ACA in January 2011 (Pear, 2011). For example, House Minority Leader John Boehner and

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Representative Thaddeus McCotter (R-MI) incorrectly cautioned that the legislation “may start us down a treacherous path toward government-encouraged euthanasia” (Boehner & McCotter, 2009).

Until this bill passes, doctors may discuss end-of-life concerns with their patients but they cannot bill Medicare for this service, essentially passing the costs along to their patients. Recent data suggest that such conversations in the course of normal care are exceedingly rare; a recent analysis of data from more than 5 000 Medicare beneficiaries who have an ongoing relationship with a primary care physician found that only 1% reported having an end-of-life discussion with their doctor during the course of routine care (Keary & Moorman, 2015). However, those who had such a discussion reported higher rates of ACP, underscoring the potential efficacy of doctor–patient consultations. Debates regarding the ACA bill were revitalized in summer 2014, with advocates recognizing that this simple and relatively low-cost aspect of ACA may be one step toward promoting a better-quality death for financially disadvantaged older adults (Belluck, 2014).

### Physician-Assisted Suicide

Discussions of patient autonomy regarding end of life, including the refusal to receive particular treatments, raise debates about active and passive euthanasia. Active euthanasia refers to the “administration of a lethal agent by another person to a patient for the purpose of relieving the patient’s intolerable and incurable suffering” (AMA, 2012). Active euthanasia is illegal in all 50 US states. Passive euthanasia, or PAS “occurs when a physician facilitates a patient’s death by providing the necessary means and/or information to enable the patient to perform the life-ending act” (AMA, 2012). PAS is fundamentally different from hospice care, which may hasten death by rejecting potentially invasive life-sustaining treatments, whereas PAS actively

seeks out medications to hasten death (IOM, 2014). PAS, also referred to as “aid-in-dying,” is currently allowed in five states: Oregon (1997), Washington (2008), Montana (2009), Vermont (2013), and New Mexico (2014) although each state has different conditions under which PAS is legal (Pew Research Center, 2013). In all other states, PAS is considered a felony.

Active euthanasia is roundly criticized as an unethical approach to death and dying (AMA, 2012). Assessments of passive euthanasia are much more equivocal; roughly equal proportions of US adults disapprove (49%) versus approve (47%) of PAS (Pew Research Center, 2013). Medical, religious, and political authorities consider PAS a potentially slippery slope, whereby increased acceptance of the practice could lead to subtle pressure for particular individuals to use this option, especially cognitively impaired, oldest old, or other vulnerable populations (Meier, 2010; President’s Council on Bioethics, 2005). Data from the state of Oregon indicate that as of mid-2013 1 173 persons had requested prescriptions for barbiturates to end their lives. Two-thirds of those receiving prescriptions ultimately died from taking the prescription, with a median duration of 47 days between the time the drugs were prescribed and the time of death (Oregon Health Authority, 2014).

Further analysis of the Oregon data suggests that those seeking PAS possess both vulnerabilities that may impede and resources that facilitate independent decision-making. On one hand, individuals who seek PAS tend to have higher levels of disability, dependence on others, and poor functioning (Asch, 2005). Yet individuals opting for PAS in Oregon also tend to be white, financially well-off and well-educated; 45% had a college degree, two-thirds had private insurance, and fully 97% were white (Oregon Health Authority, 2014). Debates regarding the legalization of PAS will not be easily resolved, and will continue to scrutinize its purported advantages, such as patient control over the dying process,

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and stopping the prolongation of patient suffering, as well as its potential disadvantages, including fears that vulnerable populations will be cajoled by family members or care providers into PAS, or that incorrect or overly pessimistic prognoses will lead some patients to opt for PAS, even if they are still far from death (Barone, 2014). These debates intensified in February 2015, when the Supreme Court of Canada struck down a 22-year-long ban on PAS for patients with “grievous and irremediable” medical conditions (Austen, 2015). The reversal of the PAS ban in Canada may inform or guide future debates in the United States, as advocates continue to call for state legislation allowing PAS (Eckholm, 2014).

## CONCLUSION AND FUTURE DIRECTIONS

Dying in the twenty-first century is a prolonged process that overwhelmingly strikes older adults suffering from long-term chronic illnesses. This period between diagnosis and death is a time that older adults and their families can spend discussing and preparing for one’s impending death, with the hopes that one’s preferences will be heeded and respected by health care providers. Yet such preparations require relatively accurate knowledge regarding one’s prognosis and future health trajectory, and the means to articulate one’s preferences to health care providers who will ultimately carry out those orders. Advance directives and discussions with significant others and health care providers are considered important (albeit imperfect) steps toward achieving a “good death,” marked by minimal distress and the receipt of treatment that meshes with one’s preferences. Yet policy makers and practitioners continue to develop new tools and practices to ensure a high-quality dying experience for all, including the development of POLSTs and federally funded doctor–patient consultations regarding end-of-life issues (IOM, 2014).

Despite these important strides in end-of-life care, serious problems persist. Compelling evidence shows that the last year of life is still marked by significant levels of pain and other distressing symptoms. One recent study of proxy-reported pain and symptoms among recent decedents found that fully 61% reported that the decedent was in pain in the final year of life, while nearly one-third reported symptoms of depression and confusion prior to death (Singer et al., 2015). These disheartening results raise important questions for future research. The influential IOM (2014) report *Dying in America* highlights key areas for future investigation, focusing primarily on clinical populations and approaches; we suggest here some distinctive contributions that social scientists may make to understanding the context of end-of-life planning and health care, with particular attention to inequalities therein.

Social scientists are particularly well-suited to identify structural, cultural, informational, and interpersonal obstacles to effective end-of-life planning and discussions. First, social scientists should further explore individuals’ understanding of the concepts and practices of end-of-life planning, living wills, hospice, and palliative care; an understanding of these perceptions (and misperceptions) may provide insights into how practitioners, policy makers, and even the media can most effectively encourage meaningful preparations. For example, one explanation offered for the relatively low rates of ACP among ethnic minorities and highly religious persons is that they erroneously believe that ACP involves limiting, rather than requesting, treatments. As such, they may view ACP as “irrelevant” given their preferences for life-extending treatments (Cox et al., 2006, p. 20). This pervasive misperception may be partly explained by how information on advance directives is disseminated. Information on end-of-life planning, including living will templates, typically is provided by organizations that promote “death with dignity” such

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as Aging with Dignity, Americans for Better Care of the Dying, Dying Well, and Last Acts. These templates generally prompt individuals to indicate those treatments that they would *not* want at the end of life, thus promoting the misperception that advance directives limit, rather than request, treatments. High-profile legal cases such as Terri Schiavo also may have led individuals to believe that advance directives are orders to stop life-prolonging treatment, and that in their absence, doctors must ethically and legally continue treatment (Carr & Moorman, 2009; Sudore et al., 2008). As such, reframing messages regarding the general purpose of ACP may be instrumental in increasing rates among those preferring high levels of treatment at the end of life; social scientists could evaluate precisely which messages and frames are most effective, and how these patterns vary based on one's social location.

Second, compelling evidence shows that persons with strong family relationships are particularly likely to engage in ACP, and to be particularly effective in conveying their end-of-life treatment preferences to loved ones. However, we know very little about the ways that persons lacking such social ties approach ACP, and whom they engage in the process. In particular, little is known about the ways that childless persons, those without a long-term romantic partner, or those estranged from family members engage significant others in the end-of-life planning process. Some evidence suggests that unmarried childless persons may turn to a friend or a professional (e.g., doctor, lawyer, or clergy person) as their health care advocate (Carr & Khodyakov, 2007), yet little is known about how frequent, in-depth, or effective their conversations are. Further, it is important to identify obstacles to formally appointing a DPAHC among this subpopulation. As noted earlier, in most states, if a patient does not have a DPAHC, living will, or legally appointed guardian, then the right to make decisions falls to family members in the following order: spouse,

adult children, siblings, and other family members. As such, potential proxies who are not a family member may be overlooked, thus creating an additional obstacle to childless or unpartnered persons who would like their treatment preferences heeded.

Third, a well-documented limitation of living wills is that adults may write one at a particular point in time, and fail to update it in responses to changes in one's health, family structure, or other important contextual factors that may guide one's preferences. Life course sociologists, in particular, should explore the ways that one's preferences both for specific treatments and one's selection of a potential DPAHC change as one's illness progresses; as one experiences changes in family structure, such as widowhood, divorce, or remarriage; and as one experiences changes in family functioning – ranging from relocations of adult children, to qualitative shifts in the nature of one's relationships. Understanding the ways that both normative and non-normative changes affect older adults' treatment preferences and preferences for particular family members' engagement in end-of-life decision-making may be particularly useful to practitioners.

Fourth, most research on the end-of-life focuses on coarse subgroup differences, comparing Blacks to Whites, for instance, and paying little attention to intersectionality. For example, even within a particular racial or ethnic group, attitudes and preferences regarding the end-of-life may vary widely based on educational attainment, one's birth cohort, religiosity, and a range of other psychosocial factors. For example, recent research suggests that younger cohorts of African Americans and Latinos are no less likely than their white counterparts to engage in ACP (Carr, 2012b), and that the particular obstacles to ACP among young and midlife African American adults are distinct from those documented among their older counterparts (West & Hollis, 2012). Identifying the specific obstacles to or

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motivators of effective ACP among particular subgroups may help practitioners to move away from a “one-size-fits-all approach” when discussing and encouraging end-of-life preparations among their patients. By understanding the distinctive motivations, beliefs, fears, and obstacles of particular subgroups of patients, practitioners may be better equipped as they strive to bring a “good death” to all.

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