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# Well-Being at the End of Life

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advance care planning, death and dying, hospice, inequality, life course, well-being

## Abstract

This review proposes that the end of life is a uniquely contemporary life course stage. Epidemiologic, technological, and cultural shifts over the past two centuries have created a context in which dying has shifted from a sudden and unexpected event to a protracted, anticipated transition following an incurable chronic illness. The emergence of an end-of-life stage lasting for months or even years has heightened public interest in enhancing patient well-being, autonomy, and the receipt of medical care that accords with patient and family members' wishes. We describe key components of end-of-life well-being and highlight socioeconomic and race disparities therein, drawing on fundamental cause theory. We describe two practices that are critical to end-of-life well-being (advance care planning and hospice) and identify limitations that may undermine their effectiveness. We conclude with recommendations for future sociological research that could inform practices to enhance patient and family well-being at the end of life.



## INTRODUCTION

Over the past two centuries, death has transitioned from a sudden and unexpected event, perceived as beyond human control, to a protracted, anticipated, and partially controllable transition that follows a chronic illness diagnosis, usually in old age (Warraich 2017). Historical changes in when, where, and from what causes people die have set the stage for the emergence of a new life course stage: the end of life. For most US adults, the end of life, or the period between the onset of major illness and death, encompasses experiences that include physical discomfort, difficulty breathing (dyspnea), reliance on life-extending but often intrusive technologies, waning mental acuity, and existential questions about one's purpose and legacy (Gawande 2014, Warraich 2017). Family members must grapple with exhausting caregiving responsibilities, distress from watching a loved one suffer, and anxiety regarding medical decisions (Carr 2003).

We propose that the end of life is a contemporary life course stage that is distinct from old age. The end of life, like other stages such as adolescence or childhood, is a late-twentieth-century social construction, reflecting historical, technological, institutional, and cultural contexts. Yet the end of life differs from other established life course stages in that it lacks a definitive or agreed-upon starting point (Lunney et al. 2003b, Rao et al. 2009). In this review, we identify challenges and ambiguities in identifying when an individual enters the end of life, describe key components of well-being among dying patients and their families, and highlight racial and socioeconomic disparities therein. We describe how two practices, advance care planning (ACP) and hospice use, can enhance well-being at the end of life, and we identify limitations that weaken their effectiveness (Carr & Luth 2017). The review concludes by highlighting areas of research in which sociologists are ideally suited to advance the understanding of end-of-life well-being.

## END OF LIFE: A CONTEMPORARY LIFE COURSE STAGE

The end of life is a uniquely contemporary life course stage, a product of historical changes in the epidemiology of death, technological innovations that extend the length (although not necessarily the quality) of life, and cultural shifts that privilege autonomy and self-determination rather than fatalism in the face of illness and death (Carr 2012a, Olshansky & Ault 1986). Just as modern childhood developed following the establishment of compulsory schooling and child labor laws in the early twentieth century (Mintz 2004), and just as the transition to adulthood stage emerged against the backdrop of rising levels of education and delayed entry to the labor force, marriage, and childbearing in the late twentieth century (Arnett 1998), we propose that the end of life is a social construction rather than a clear-cut clinical state. Yet the end of life differs from other life course stages in that scholars and practitioners have not established a consensus definition nor a definitive demarcation of when this stage starts (Hui et al. 2014). Whereas entrance to other stages is signified by widely accepted markers of physical maturation such as the onset of puberty (adolescence), legal milestones like reaching age of majority (adulthood), and eligibility for public programs such as Medicare (old age), when exactly the end of life starts is matter of perspective. We describe the historical context that has given rise to this stage and identify the diverse (and contested) ways that scholars and practitioners have conceptualized, operationalized, and studied the end of life.

## Historical Roots

In the eighteenth through early twentieth centuries in the United States, most deaths struck quickly after one fell ill, typically from infectious diseases like diphtheria and pneumonia (Omran 2005). Rates of infant and child death were high, with 10% of infants dying before age one

(Cent. Dis. Control Prev. 1999). Technological and medical advances throughout the twentieth and twenty-first centuries have driven the transition from death as an unexpected and swift event to dying as an expected and protracted process. Improved sanitation and nutrition, childhood immunization, effective treatments for infections, and other medical advances have largely eradicated deaths from infectious disease and have led to substantial decreases in child and infant mortality, resulting in dramatic increases in overall life expectancy (Olshansky & Ault 1986, Omran 2005). In 1900, life expectancy at birth in the United States was 47; by 2013, it reached 76 for men and 81 for women (Arias et al. 2017). Death in the twenty-first century overwhelmingly befalls older adults after a prolonged period of chronic illness. Three-quarters of US deaths today are among adults aged 65 and older, two-thirds of which are attributed to chronic illnesses such as heart disease, cancer, and stroke (Xu et al. 2016). The living–dying interval, or the period between the onset of major illness and death, may last for weeks, months, or even years, raising widespread concern about the well-being of patients and families during this period (Pattison 1977). The end of life is typically marked by spells of pain, dyspnea, emotional distress, fear of being a burden, and diminishing cognitive capacities (Warraich 2017). Family members must manage caregiving demands, difficult decisions regarding medical treatments, the pain of watching a loved one suffer, and anxiety about what the future holds (Carr 2012a).

The epidemiologic transition in the causes and timing of death has been accompanied by a cultural shift: the medicalization of death and dying (Field 1994). In the eighteenth and nineteenth centuries, death was considered a normal part of life, and most people died naturally in their homes. In sharp contrast, contemporary death is viewed as a problem to be staved off as long as possible, with patients and practitioners often relying on biomedical innovations and heroic measures that extend the length yet not the quality of life (Ariès 1981). Roughly 20% of older adults today die in an acute care hospital, while 25% die in a nursing home (Teno et al. 2018). One-third spend time in an intensive care unit (ICU) in the month before death, being kept alive via feeding tubes and other interventions that do not improve a patient's health, well-being, comfort, or prognosis (Huynh et al. 2013; Teno et al. 2013, 2018). This medicalized context of death betrays patients' preferences; three-quarters of Americans prefer to die at home (Nat. Cent. Health Stat. 2011), and 80% of older adults with chronic diseases would like to avoid hospitalization and intensive care at the end of life (Dartm. Inst. Health Policy Clin. Pract. 2018).

### Defining End of Life

Defining the end of life poses a significant challenge to researchers, practitioners, patients, and their families (Fowler et al. 1999). Importantly, the end of life is distinct from old age, even though studies purportedly of the end of life often rely on samples of older adults (Ardelt & Edwards 2015, Bravell et al. 2010). Conflating the end of life with later life is problematic for two reasons. First, while most people experience the end of life during old age, the two are not perfectly correlated. Of the 2.7 million US deaths in 2015, 32% were to persons ages 85 and older, 24% to persons ages 75–84, and 19% to persons ages 65–74 (Murphy et al. 2017). Yet the remaining 25% of deaths befell infants, children, and young and midlife adults. Children, adolescents, and young adults typically die of sudden causes, including accidents and suicides, yet many also die from protracted illnesses. Cancer is the leading cause of death for midlife adults (ages 45–64), and a top-four cause of death for all age groups under age 45 (Xu et al. 2016). Thus, persons of all ages are vulnerable to a prolonged end-of-life experience (for an excellent review of issues facing dying children and their families, see Behrman & Field 2003).

Second, not all older adults are at the end of life or experiencing symptoms of illness and distress. Although more than 80% of adults aged 65 and older have at least one chronic illness



and 60% have two or more, 20% are considered disease-free (Schafer & Ferraro 2011). Analyses of Medicare data show that 7% of persons aged 65 and older die suddenly, meaning an absence of illness or frailty before death (Lunney et al. 2003a). Recognizing the imperfect association between age and the end of life, researchers focus on subpopulations at plausible risk of imminent death based on their health status, including patients with advanced chronic illness (Singer et al. 1999, Steinhauser et al. 2000a), residents of acute care nursing facilities (Singer et al. 1999), and those in ICUs (Angus et al. 2004).

The methods used for studying the end of life may be retrospective, relying on recollections from the decedent's survivors, or prospective, relying on dying persons' own reports in the months leading up to death (Fowler et al. 1999, Rao et al. 2009). In retrospective studies, researchers identify recent decedents from sources such as obituaries, death records, or surveys and then interview a proxy regarding the decedent's experiences during a specific time period before death (Carr 2003, Hogan et al. 2001, Teno et al. 2001). For example, the National Health and Aging Trends Study (NHATS) asks proxies about the decedent's physical symptoms and whether they were treated with dignity and respect during the last month of life (Luth 2017, Sharma et al. 2017, Teno et al. 2015).

These retrospective assessments provide the most widely used resource for studying the end of life, yet they are susceptible to both positive and negative recall bias (Fowler et al. 1999). Bereaved family members who are depressed or angry may offer negatively biased assessments, whereas those who were closely involved in caregiving may offer more positive appraisals to affirm their belief that they did all they could to help the decedent (Carr 2003, Rao et al. 2009). Methodological studies that compare reports from multiple proxies, such as spouses and children, or compare proxy reports with medical record data find that proxy reports of subjective factors, such as the decedent's pain or psychological distress, are particularly subject to bias. However, proxy reports are more reliable in evaluating concrete or observable conditions such as dyspnea or treatments received (McPherson & Addington-Hall 2003).

Researchers also use medical records and Medicare claims data as retrospective indicators of institutional dimensions of end-of-life experiences. The Dartmouth Atlas, a widely used source of information on end-of-life indicators like hospice and ICU use, place of death, and length of hospitalization, is based on Medicare beneficiaries' claims data obtained from the Centers for Medicare and Medicaid Services (CMS) (Smith et al. 2009). These data also can be used to document medical expenditures during the last year of life, a topic of intense concern among policy makers (see Aldridge & Kelley 2015, French et al. 2017).

Prospective studies of end-of-life experiences use longitudinal studies such as the Established Populations for Epidemiologic Studies of the Elderly, the Health and Retirement Study, or NHATS. Researchers can identify study participants who have died and then retrospectively classify the decedent's responses on earlier waves of the survey according to their distance from death—the duration between death and last participation in the survey. This approach enables researchers to identify indicators of end-of-life well-being such as social integration or depressive symptoms during a particular time frame such as the last year of life (Gerstorf et al. 2010, Idler et al. 2009).

These diverse approaches to studying the end of life reflect the fact that there is no consensus nor a gold standard diagnostic marker of when the stage begins (Hui et al. 2014, Kennedy et al. 2014). Biomedical researchers are attempting to devise biomarker indicators of disease progression (Reid et al. 2017, Simmons et al. 2017) and statistical algorithms based on electronic medical records (Rajkomar et al. 2018) that can reasonably predict the future life span of terminally ill persons, with the hopes that these indicators will inform care delivery and physician prognoses. Prognoses, or predictions regarding the patient's likely life span or the probability that the patient

will die from a particular illness within a given time period, can be critical to patient and family well-being (Lamont & Christakis 2001).

From a patient's perspective, a biological indicator of disease stage or a computer-generated projection of life span may be far less meaningful than the assessment of their trusted physician that their condition is severe and worsening, available treatments would be futile, and future time horizons are limited (Clayton et al. 2007). This information may guide decisions regarding care and provide patients and families an opportunity to prepare practically and emotionally for the end of life (Christakis 2000).

Despite the value and importance of physician prognoses, studies consistently demonstrate that they are often inaccurate or are delivered too late to effectively guide treatment decisions (Christakis 2000). One prospective cohort study of 343 doctors found only 20% of prognostic estimates in hospice patients were accurate (Christakis et al. 2000), while another found that physicians' accuracy in predicting cardiac patients' survival barely reached 50% (Warraich et al. 2016). These inaccuracies reflect the lack of a gold-standard marker of disease progression and practitioners' limited training in prognostication (Clayton et al. 2007). Psychosocial factors also prevent practitioners from making predictions or impel them to communicate overly optimistic prognoses as a way to soothe patients and their families. Christakis (2000) estimates that overly optimistic predictions outnumber pessimistic ones by a ratio of five to one, especially when the practitioner had a close-knit or long-term relationship with the patient. Death remains a topic that is difficult to confront honestly and directly, even among seasoned practitioners (Clayton et al. 2007).

Inaccurate or absent prognostication may indirectly hurt dying patients and their families. Nearly all terminally ill patients say that "knowing what to expect" (98%) and "naming a decision-maker" (96%) are very important (Steinhauser et al. 2000a), although the optimal timing of such preparations hinges on accurate prognosis. Medical decisions regarding the appropriateness of particular treatments such as antidepressants, statins, or morphine are based on estimations of the patient's future symptoms and plausible life span. Referrals to hospice also may come too late, in the final days of the patient's life. Very short hospice stays deprive patients and family of the emotional support and palliation they need, a concern revisited later in this review (Smith & Glare 2016).

## WELL-BEING AT THE END OF LIFE: COMPONENTS AND DISPARITIES

Understanding the components of and influences on end-of-life well-being is a critical concern among ethicists, practitioners, policy makers, and dying patients and their families (Byock 1997, *Inst. Med.* 2015). Philosophical writings (Byock 1997, Emanuel & Emanuel 1998); structured surveys and focus groups with terminally ill patients, family members, and practitioners (Steinhauser et al. 2000a,b); in-depth interviews with dying patients (Singer et al. 1999) and palliative care professionals (Rao et al. 2009); content analysis of commonly used survey items that assess well-being of patients (Rao et al. 2009) and their family caregivers (Lendon et al. 2015); and formal statements from professional organizations (Field & Cassel 1997, *Inst. Med.* 2015) show remarkable convergence in their definitions of what it means to have a reasonable-quality end of life or a good death (although, for a contrarian view suggesting divergent values among different stakeholders, see Meier et al. 2016). The attributes considered most essential to dying well across these diverse sources cohere closely with a statement from the Institute of Medicine (Field & Cassel 1997, p. 4) that a good death is "one that is free from avoidable distress and suffering, for patients, family, and caregivers; in general accord with the patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards."



Drawing on these themes, we focus on three core components of a good death or dying well: physical comfort and freedom from pain, perceived quality of end-of-life care, and the place and medicalization of death. An extensive psychological literature also explores cognitive, emotional, and existential well-being (see Bäckman & MacDonald 2006, Chochinov & Cann 2005, Shneidman 1995). We highlight aspects of end-of-life well-being that vary based on race and, to a lesser extent, socioeconomic status (SES). Race and SES disparities in well-being are documented at every life course stage, including the end of life (House et al. 2005, Kawachi et al. 2005). Fundamental cause theory provides a framework for understanding these disparities; status benefits like money, knowledge, power, and social connections can enhance multiple aspects of well-being, yet these resources are protective only to the extent that they can be used to gain an advantage (Phelan et al. 2010). Although status, power, or racial privilege may help patients and families to advocate for appropriate pain medication, those resources may be of little value for more subjective aspects of end-of-life well-being.

### Physical Comfort and Freedom from Pain

Dimensions of physical well-being such as being free of pain and breathlessness and being kept clean consistently rank at the top of patients', family members', and care providers' lists of important end-of-life attributes (Steinhauser et al. 2000a) and are at the core of formal guidelines for practitioners providing end-of-life care (Inst. Med. 2015, Teno et al. 2001). Despite its importance, physical comfort is elusive at the end of life. One-half to two-thirds of older patients experience some pain during their last month of life, with considerably higher rates among those with arthritis, musculoskeletal conditions, depression, and cancer (Patel et al. 2013). One-third rate their pain as moderate or severe (van den Beuken-van Everdingen et al. 2007). Similarly, 50–60% experience dyspnea in the final two weeks of life (Teno et al. 2015). Pain and dyspnea increase the risk of depression among dying patients (Zimmer & Rubin 2016) and their caregivers (Chi et al. 2016).

Pain can be treated effectively with medication. Studies of patients dying at home and in nursing homes show that the use of opioids, including morphine, increases the patient's quality of life and does not hasten death unnecessarily (Sykes & Thorns 2003). Most proxies report adequate symptom management; NHATS data show that just one in four proxies report that their loved one had unmet needs for pain in the last month of life, regardless of the decedent's race (Sharma et al. 2017, Teno et al. 2015). Opioids are not a panacea for all dying patients, however, as side effects, including nausea, constipation, and minor cognitive impairment, are common (Chau et al. 2008).

Although proxy reports suggest no black–white differences in untreated pain, data provided by patients and medical records suggest that black patients fare worse than whites with regard to pain and palliation. This disparity is not unique to the end of life. Population-based studies show that black patients are two-thirds as likely as white patients to receive prescription analgesic pain killers for chronic painful conditions, traumatic injuries, and surgery (Meghani et al. 2012), and Medicare expenditures for pain medications are lower in geographic areas with high proportions of black residents (Tait & Chibnall 2014). Studies of the last week of life show that dying black patients are only 60–70% as likely as white patients to receive opioids or other pain killers (Burgio et al. 2016).

Many factors account for these disparities, including implicit prejudice among practitioners such as erroneous beliefs that black patients are more likely to abuse pain killers and have a higher pain tolerance relative to whites (Hoffman et al. 2016). White and Asian doctors also may underestimate the pain symptoms presented by black patients (Cintron & Morrison 2006). Institutional racism also has been implicated; pharmacies in historically black neighborhoods may fail to stock

adequate supplies of pain medication, making it difficult for family caregivers to acquire the medications dying patients need (Green et al. 2003, Morrison et al. 2000). Some researchers have proposed cultural explanations, suggesting that black patients may not request pain medications because they believe that suffering is part of God's test and should be endured without medications (Burgio et al. 2016). Concerns regarding addiction, undesirable side effects, and being viewed as a complainer also have been suggested as reasons behind black patients' underuse of opioids at the end of life (Anderson et al. 2009).

### Quality of End-of-Life Care

The second cluster of attributes considered important at the end of life focuses on quality of care, including being treated with dignity by practitioners, receiving accurate information regarding what to expect about one's physical condition and treatments, being able to trust and communicate with practitioners, and receiving medical treatments that are appropriate and in accordance with one's wishes (Rao et al. 2009, Steinhauer et al. 2000a). Most data show that patients and their proxies evaluate interpersonal and subjective aspects of care quite positively. NHATS data show that more than 80% of proxies reported that they and their loved one were always treated with respect, did not receive unwanted care, were involved in decision-making, and were informed about the patient's condition (Teno et al. 2015). However, nearly half reported considerable dissatisfaction regarding practitioners' capacity to meet the patient's psychosocial or religious needs (Sharma et al. 2017). Moreover, just half reported that the patient's end-of-life care was "excellent," and 10% rated overall care as fair or poor. The discrepancy between these overall ratings and the positive appraisals of specific aspects of care suggest the centrality of pain control and physical comfort when proxies provide an overall assessment of their loved one's end of life (Steinhauer et al. 2000a).

Few studies of subjective aspects of end-of-life care reveal race or socioeconomic differences. Analyses of proxy reports in the NHATS found no racial or SES differences regarding subjective aspects of care, including being kept informed, having spiritual concerns met, receiving care concordant with patient wishes, and having sufficient patient and family member input to end-of-life decisions (Luth 2017, Sharma et al. 2017). These results are consistent with a key theme of fundamental cause theory; social and economic resources are protective only in situations in which they can be used to gain an advantage (Phelan et al. 2010). Although status and power may help one advocate for appropriate pain medication, those resources may be of little value in preparing emotionally and spiritually for the end of life.

### Place and Medicalization of Death

Most patients prefer to spend their final days at home surrounded by loved ones, with strong preferences for avoiding time in an ICU being "connected to machines" (Carr 2012b, Teno et al. 2018). Hospital and ICU deaths tend to be highly medicalized and marked by the receipt of aggressive care, including intubation and mechanical ventilation, feeding tubes, and cardiopulmonary resuscitation (Barnato et al. 2009). Recent data suggest a movement away from an institutionalized death. Between 2000 and 2015, acute care hospital deaths declined from 33% to 20%, nursing home deaths dipped slightly from 27% to 25%, and home or community deaths (including assisted-living facilities) increased from 30% to 40% among Medicare beneficiaries (Teno et al. 2018). However, ICU use in the last month of life increased from 24% to 30%, signaling an increase in the intensity of care.

A home death is widely considered better than an institutional death for the patient and family, especially if in-home hospice services are used. Family members of deceased cancer patients who



died in an ICU say their loved one had poorer quality of life, and more physical and emotional distress, relative to those who received less-intensive care. The caregivers themselves also reported heightened risk of posttraumatic stress disorder and prolonged grief disorder following the death (Wright et al. 2008). Transfers in care, such as moving from a nursing home to an ICU, also impede well-being. Dying patients average 3.1 transfers in the last three months of life (Teno et al. 2013). These abrupt shifts may lead to fragmented care because the old and new care teams have limited communication about the patient's health conditions, treatments, and personal history (Gozalo et al. 2011). These moves can also be disruptive and disorienting for patients and their families, as they adjust to unfamiliar surroundings, new treatments, and new teams of care providers (Coleman & Boulton 2003).

The privilege of dying at home varies by race. Roughly 40% of black but just 25–30% of white persons die in institutions, although rates vary by region and cause of death (Flory et al. 2004). These disparities are attributed to three causes. The first is cost. To die at home, family members often need to invest in home health aides or other helpers to assist with the round-the-clock tasks of caring for a dying person. Black and Latino patients are less likely than white patients to be able to afford home health services out of pocket or have access to them through private insurance, although low-income persons may have some in-home health services covered by Medicaid (DeNavas-Walt et al. 2004).

Second, terminally ill black patients are less likely than whites to have a coresidential family caregiver who is available to assist with transportation, homemaking services, and personal care. Having a family caregiver is closely tied with demographic factors, such as being married or having children nearby, and economic factors, like having a family member who can afford to reduce work hours in order to provide care (Natl. Acad. Sci. Eng. Med. 2016). These gaps partly reflect family structure; blacks are less likely than whites and Hispanics to marry and stay married, and they may give rather than receive care from family members, even toward the end of life (Manning & Brown 2011).

Third, black patients are more likely than whites to report preferences for aggressive end-of-life care, which can only be delivered in an institutional setting (Barnato et al. 2009). Among terminally ill patients, blacks are more likely than whites to say that they want resuscitation and intubation (a breathing tube) (Johnson et al. 2010). Similarly, half of black adults, yet just 20% of whites, said medical staff should do everything possible to save a patient's life in all circumstances (Pew Res. Cent. 2013). However, black patients' stated preferences for aggressive care may not capture their actual desires and may instead reflect vigilance toward and distrust of a health-care system that has historically deprived them of treatments they wanted and needed (Rhodes & Teno 2009).

## **POLICIES AND PRACTICES TO ENHANCE END-OF-LIFE WELL-BEING**

Dying patients and their families emphasize the importance of being prepared emotionally and practically for the death and freedom from physical and emotional pain (Steinhauser et al. 2000a). Attainment of these goals can be facilitated by two practices: ACP and the use of hospice services (Inst. Med. 2015).

### **Advance Care Planning**

ACP is considered an essential step for achieving a good death, characterized by adherence to the patient's and family members' values and treatment preferences, minimal physical and emotional pain, and reduced decision-making burden for family members (Carr & Luth 2017). The



centerpiece of ACP is an advance directive, which comprises a living will and a durable power of attorney for health care (DPAHC) designation. A living will articulates the specific treatments an individual would want or reject at the end of life, such as ventilators or feeding tubes. A DPAHC legally designates an individual (also referred to as a surrogate) to make decisions on behalf of the patient should he or she be incapacitated (Carr & Luth 2017). Most adults select a spouse or long-term partner, followed by a child or other close relative, presuming that their closest kin best understand and will carry out their preferences (Carr & Khodyakov 2007).

Despite widespread professional endorsements, public awareness, and education campaigns encouraging ACP, completion rates are relatively modest yet increase with age and as one's health worsens. A systematic review of 150 studies based on nearly 800,000 subjects published between 2011 and 2016 reported that just 37% of US adults had completed an advance directive (Yadav et al. 2017). However, rates are as high as 70% among adults aged 65 and older, those with terminal illness, and recent decedents (Carr & Moorman 2009, Silveira et al. 2014). ACP rates have increased sharply for all age groups in recent decades. The proportion of adults with an advance directive more than doubled from 16% in 1990 to 35% in 2013 (Pew Res. Cent. 2013), while rates among older adults increased from roughly 33% to 72% between 2000 and 2010 (Silveira et al. 2014).

These increases reflect structural and cultural factors. The passage of the Patient Self-Determination Act in 1990 was a pivotal event; the Act requires that all federally funded health-care facilities provide patients the opportunity to execute an advance directive. Additionally, as part of the Affordable Care Act in 2016, CMS began reimbursing physicians for discussing end-of-life treatment preferences with their Medicare patients (Armour 2015). Cultural factors promoting ACP include a heightened emphasis on autonomy and self-determination among US adults, a preference for quality rather than duration of life, and a desire not to place undue decision-making burden on family (Carr & Luth 2017).

The positive consequences of ACP are widely documented. ACP is linked with lower rates of hospitalization, ICU admissions, and aggressive treatment (Nicholas et al. 2011, Teno et al. 2007, Wright et al. 2008). ACP also is associated with superior psychosocial outcomes, including greater satisfaction with quality of care; improved communication among patient, family, and practitioners; shared decision-making; better preparation for what the dying process entails; and a greater likelihood of receiving care that is concordant with one's wishes (Detering et al. 2010, Silveira et al. 2010). Following death, bereaved family members report less stress, anxiety, and depression, due in part to their preparedness and role in decision-making (Detering et al. 2010).

Despite these many positive consequences, the living will and DPAHC have well-known limitations. Criticisms of the living will include the content being unclear; one's stated preferences not being relevant to the patient's condition, especially for older adults who drafted their living wills years earlier; and physicians not having access to the document at the critical decision-making moment (Inst. Med. 2015). Family members may not know or agree with the document's content or may not know how to translate vague preferences into specific clinical recommendations (Ditto et al. 2001).

DPAHC appointments also have practical limitations. Legally appointed proxies have decision-making authority, yet they may make decisions that create distress or disagreement among family members (Khodyakov & Carr 2009). Family members not designated as DPAHC may create difficulties, trying to contest or alter the decisions made by family members with ongoing engagement in the patient's care. These family disagreements may compromise practitioners' ability to provide quality care (Kramer & Yonker 2011). Given these well-documented limitations of formal ACP, some practitioners encourage informal discussions among the patient, significant others, and care providers (Doukas & Hardwig 2003).



A conversation about broad goals (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”) provides family members with a general roadmap for representing the patient’s wishes in the absence of a living will articulating specific treatment preferences (Doukas & Hardwig 2003). Conversations also may facilitate decision-making when the dying patient has not appointed a DPAHC. Most states have default systems for authorizing proxy decision makers. State laws vary, but most prioritize the immediate family—starting with the spouse and followed by adult child, sibling, and other relatives (Am. Bar Assoc. Comm. Law Aging 2018). 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 and too late to have a meaningful impact. When discussions occur following trigger events, such as a heart attack or hospitalization, the patient and family may be too distressed to make rational decisions about care needs (Pfeifer et al. 2003).

ACP is encouraged for all, yet significant race and SES disparities exist, contributing in part to some disparities in the end-of-life well-being described earlier. Studies consistently show that older blacks and Latinos, in general (Koss & Baker 2017) and with terminal illness (Carr 2011, 2012c), are less likely than whites to complete ACP, although these gaps diminish among younger cohorts (Koss & Baker 2017) and among persons with more education (Carr 2012d) and greater wealth (Koss & Baker 2018). Few studies have explored SES differences, although Carr (2012d) finds wealth-based disparities. Wealthier persons are more likely to execute a will, which triggers the use of living wills and DPAHCs. Racial disparities are further explained by structural and cultural factors, including limited access to regular practitioners who guide ACP, religious beliefs that God should decide how and when one dies, limited knowledge about ACP, the erroneous belief that family members have the knowledge and right to make decisions on the patient’s behalf, and distrust of the medical establishment (Barnato et al. 2009, Carr 2011, Koss & Baker 2018, Sanders et al. 2016).

Yet even when black and lower-SES persons complete ACP, their preferences are less likely to be heeded relative to their white and higher-SES peers. Among advanced cancer patients in the last week of life, whites are three times as likely as blacks to receive care consistent with their stated wishes (Loggers et al. 2009). Similarly, black cancer patients with a do not resuscitate (DNR) order are just as likely as their peers without a DNR to receive life-extending treatments, whereas the DNR limited the treatments received by white patients (Mack et al. 2010). ACP is also linked with greater psychological distress among black (but not white) recent decedents, perhaps due to the racial gap in its efficacy (Luth & Prigerson 2018).

### Hospice

Hospice care is a critical contributor to patient and family well-being at the end of life and is a key mechanism linking ACP to desirable end-of-life outcomes (Silveira et al. 2010). Hospice is a comprehensive program that facilitates dying at home and emphasizes palliation (symptom relief) and comfort rather than aggressive or curative treatment. Roughly 60% of hospice patients receive services at home and the rest in hospitals or long-term care facilities, although these rates vary based on the regional availability of services (NHPCO 2018).

Hospice use, like ACP, has increased dramatically over the past three decades. In 1997, 17% of all US deaths occurred under the care of hospice; by 2016, this proportion more than doubled to 48% (Aldridge et al. 2014, NHPCO 2018). This growth reflects shifting attitudes favoring quality versus length of life, and policy shifts, most notably increased Medicare funding for hospice services as a way to reduce costs associated with high-tech medical care (NHPCO 2018).

21.10 Carr • Luth

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Although the end of life lacks a consensus definition, Medicare reimbursement for hospice services is dictated by a very specific criterion: a projected six-month survival period. Medicare pays for hospice services for beneficiaries who are certified by two physicians to have a terminal illness and less than six months to live, should the illness take its normal course (for full eligibility criteria, see <https://www.medicare.gov/pubs/pdf/02154-medicare-hospice-benefits.pdf>). If the patient lives longer than six months, then coverage may continue if the primary care provider and hospice team recertify the patient's eligibility. The hospice benefit pays for services that are not covered by traditional Medicare yet are essential to patient and family well-being, including nursing care, counseling, respite care for family, and bereavement support.

The beneficial effects of hospice are widely documented. Patients receiving hospice services have less pain, fewer admissions to ICUs, greater satisfaction with their medical care, and a better mood relative to those not using hospice (Meier 2010, Teno et al. 2010). Family caregivers also report feeling supported during the dying process (NHPCO 2018) and have reduced risks of mortality, depression, and anxiety postloss, in part because they receive bereavement support services (Christakis & Iwashyna 2003).

One major limitation is that patients may enroll in hospice when they are very close to death, reducing the benefits for themselves and their families. Experts recommend a minimum of a 90-day hospice stay to receive optimal care and support (Rickerson et al. 2005). In practice, however, the median length of stay for Medicare beneficiaries in 2016 was 24 days; 28% of hospice patients received services for one week or less, and more than half were enrolled for one month or less (NHPCO 2018). Delayed referrals have several causes, including overly optimistic physician prognoses, physician reluctance to make hospice referrals, the desire to continue aggressive treatments, and patient and family members' lack of familiarity with or reluctance to use hospice services (Christakis 2000, Schockett et al. 2005). Patients who have short hospice stays receive less pain relief (Miller et al. 2003) and have more dyspnea and poorer quality care, as assessed by their proxy (Wright et al. 2008). Shorter stays also are less beneficial for family, who must provide care over a longer period without the respite and emotional support hospice provides. Family caregivers of recent decedents with hospice stays of less than three days evidence higher rates of major depressive disorder, relative to those with longer stays (Schockett et al. 2005).

Hospice is undergoing a dramatic transition, and these changes in the organization and delivery of care may undermine patient and family well-being. The number of for-profit hospice providers has increased sharply over the past three decades. While just 5% of hospice providers were for-profits in 1990, by 2013 this share reached over 60% (Rahman 2017, Stevenson et al. 2015). For-profit hospices exist within large corporate systems and are motivated to maximize efficiency. All hospices are reimbursed by Medicare at a flat daily rate, which averaged \$160 to \$200 in 2018 (see <https://www.medicare.gov/medicaid/benefits/hospice/payment/index.html>). Although care providers in for-profit hospices may be every bit as dedicated and skilled as their peers working in nonprofits, the structure of for-profit organizations may undermine the quality of care delivered.

First, for-profits generally offer a narrower range of services, leaving out potentially valuable benefits like bereavement care for family members. Second, they are more likely to provide care to patients in nursing homes or hospitals, rather than at home, because they can efficiently serve multiple patients in a single institution without providing basic routine tasks like bathing. Serving geographically dispersed home-based patients requires time-consuming travel and caregiving tasks as the patient's family members often cannot provide the same level of routine care as paid nursing home workers. Consequently, the number of hospice patients dying in nursing homes is projected to increase, betraying their desire to die at home (Rahman 2017). Third, bottom line-oriented for-profit hospices maintain lower staff-to-patient ratios, potentially compromising the quality and responsiveness of care (Aldridge et al. 2014).



In the preamble to its *Standards of Practice for Hospice Programs*, the NHPCO (2010) states that hospice “offers palliative care for all individuals and their families without regard to age, gender, nationality, race, creed, sexual orientation, disability, diagnosis, availability of a primary caregiver, or ability to pay” (<https://www.nhpc.org/ethical-and-position-statements/preamble-and-philosophy>). Yet over three-quarters of US hospices have at least one enrollment policy that could differentially restrict access to care; for example, 12% require that patients have a family caregiver at home, due to the centrality of family in caring for hospice patients (Aldridge Carlson et al. 2012). In practice, this policy limits access for those who are unmarried, childless, socially isolated, or whose family members cannot take time off work. Race gaps in hospice use also are pronounced. In 2016, 49% of white but just 36% of black Medicare beneficiaries received hospice services. Blacks also receive later referrals and have shorter spells of care (NHPCO 2018). These gaps are due in part to skepticism, lack of awareness, and misunderstanding of hospice. Black patients’ skepticism regarding hospice is believed to have deep historical roots; they tend to receive less intensive medical treatments over the life course and thus are reluctant to reject treatments available at the end of life (Brown et al. 2018, Degenholtz et al. 2003). Low rates of health literacy, especially regarding what hospice entails, also may lead black patients to reject hospice and choose more aggressive treatments (Matsuyama et al. 2011, Rhodes et al. 2006).

## FUTURE DIRECTIONS

Scholarly and public interest in the end of life has flourished over the past two decades, with particular attention paid to the economics of end-of-life medical expenditures (Aldridge & Kelley 2015, French et al. 2017), designing biological and statistical models to accurately predict end-of-life disease trajectories (Reid et al. 2017), and establishing benchmarks of end-of-life care, drawing from administrative indicators like length of ICU stays, documentation of advance directives in medical records, and place of death (Dartm. Inst. Health Policy Clin. Pract. 2018). We suggest that sociological approaches, concepts, and methods also can advance knowledge of the end of life. We highlight two major areas of research that are particularly promising for sociological analysis: social relationships at the end of life and physician-assisted suicide (PAS) as a path to patient autonomy.

### Social Relationships at the End of Life

End-of-life experiences are powerfully shaped by interpersonal relationships. Whether one completes ACP and whom (if anyone) a patient names as a DPAHC depend on the presence, stability, and quality of one’s social ties (Carr & Khodyakov 2007, Carr et al. 2013, Moonman et al. 2014). Family ties also are critical to hospice use, as some providers only accept patients with a coresidential family caregiver (Aldridge Carlson et al. 2012). The presence of supportive and nurturing relationships shapes the extent to which dying patients experience depression and anxiety rather than calm and acceptance (Qaseem et al. 2008).

However, important questions remain unanswered, especially against the backdrop of shifting family structures and rising numbers of persons facing the end of life without living or proximate kin (Kellehear 2009, Manning & Brown 2011). Sociologists, especially experts in families, demography, and social network methods, are well-suited for exploring how the dynamic nature of family relationships may affect multiple aspects of end-of-life well-being, including the effectiveness of ACP, hospice utilization rates and efficacy, the division of caregiver labor and consequences for caregiver well-being, and the complexities of negotiating end-of-life care and decision-making.

The latter poses a particular challenge among nontraditional families, including stepfamilies and unmarried partners, as well as those who are estranged from or have tenuous ties with kin.

Sociologists could help design studies that adopt an expansive definition of social ties, asking dying patients about their friendships, weak ties to neighbors and distant relatives, former romantic partners, stepchildren, or other individuals who may play an unexpectedly outsized role in end-of-life care and decision-making. The importance of these questions will intensify in the coming decades. A projected 20% of baby boomers will approach the end of life without a living spouse, child, or sibling, requiring practitioners to cast a wider net when engaging kin in end-of-life care and decision-making (Carney et al. 2016).

Innovative data are needed to meet these research goals. Most end-of-life studies rely on a single reporter, typically a widow(er), who evaluates the patient's well-being and care. However, such studies may fail to account for potential bias in appraisals caused by a bereaved respondent's mental health at the time of assessment (Fowler et al. 1999). These assessments also reflect a single vantage point, offering an incomplete portrayal of the complexities of the end of life. Superior approaches would engage multiple reporters, such as a bereaved spouse and child, to identify levels and sources of agreement or discordance in such appraisals (McPherson & Addington-Hall 2003). For instance, generational differences in expectations for quality of care may contribute to discrepancies in two family members' appraisals of a single situation.

Within-family differences approaches also can be used to capture the complexities of the dying patient's relationships. Most survey measures of social support ask individuals to provide an aggregated assessment of how much support they receive from "family members" or "your children" yet fail to consider that a patient may have positive ties with some and negative ties with others. Within-family differences approaches obtain the focal person's appraisal of each individual tie separately; as such, these data could be useful in documenting the rationale for selecting a particular child as a caregiver or DPAHC and the extent to which one problematic tie may undermine decision-making even in otherwise high-functioning families (Suitor et al. 2017).

### Physician-Assisted Suicide

Another intriguing sociological question is whether the legalization of PAS will expand in the United States and, if so, who will adopt this option and to what end. PAS, also referred to as aid-in dying, physician-assisted dying, and passive euthanasia, 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, p. 8). This stands in stark contrast with active euthanasia, which is the "administration of a lethal agent by another person to a patient for the purpose of relieving the patient's intolerable and incurable suffering" and is illegal in all 50 states (AMA 2012, p. 8). PAS is currently allowed in California, Colorado, the District of Columbia, Hawaii, Montana, Oregon, Vermont, and Washington, with differing conditions under which PAS is legal. A consistent precondition is that the patient must have a terminal illness with a six-month survival prognosis.

Whether more states legalize PAS remains to be seen, although attitudinal data show that 72% of Americans believe doctors should be legally allowed, at the patient's and family's request, to end a terminally ill patient's life using painless means (Brenan 2018). However, this support varies by religious and political identities, with just 54% of political conservatives and 37% of weekly church attendees indicating support (Brenan 2018). Medical, religious, and political authorities consider PAS a potentially slippery slope, whereby increased availability could lead practitioners and health insurance providers to exert subtle pressure on vulnerable individuals to use this option, especially the oldest-old (ages 85 and older); ethnic and racial minorities; persons with cognitive



impairment, physical disabilities, mental illness, or stigmatized illnesses like HIV/AIDS; those with limited economic resources; and socially isolated persons (Emanuel 2002, Meier 2010, Pres. Counc. Bioeth. 2005).

Evaluations convincingly show that the small number of individuals opting for PAS disproportionately are white, financially well-off, and college-educated (Quill 2007). However, other unobserved psychosocial factors—which affect people across racial, ethnic, and socioeconomic spectrums—like personality, social support, and vulnerability to social contagion may affect choices regarding PAS (Finlay & George 2011). Given the contemporary cultural shift of increasing acceptance of suicide and the consequently rising rates of suicide in the United States, PAS acceptance and use may increase as well (Phillips & Luth 2018).

Debates regarding the legalization of PAS will continue to scrutinize its purported advantages, such as patient control over the dying process and avoiding prolonged suffering, as well as potential disadvantages, including fears that vulnerable populations will be pressured by family members or care providers into PAS, or that inaccurate prognoses may lead some patients to opt for PAS even if they are still far from death (Barone 2014). Sociologists can play a critical role in identifying political, cultural, and economic factors that influence public knowledge and perceptions, media framing, and both popular and institutional support of such legislation.

## CONCLUSION

We have proposed that the end of life is a contemporary life course stage that is distinct from both the acute event of death and old age. The end of life also is distinct from other life course stages such as childhood in that it lacks a definitive legal, biological, or clinical start point. This imprecision regarding the onset of the end of life may undermine dying patients' and their families' well-being in several ways; incorrect or overly optimistic physician prognoses often mean that formal preparations for the end of life and referrals to hospice occur at a point when it is too late to be effective.

The extent to which one experiences a good death that accords with one's preferences and is free of pain varies somewhat by race, and to a lesser extent SES, mirroring the stratification documented at earlier life course stages. Blacks and persons with fewer socioeconomic resources tend to have less knowledge of, access to, and utilization of, and experience fewer benefits from engaging in practices such as ACP and hospice care. Sociologists are poised to make important contributions to our understanding of health equity by using theories and methods to explain underlying mechanisms that contribute to these disparities, expanding on the largely descriptive work carried out in medicine and epidemiology. Sociological theory and research also may advance our understanding of the role of social relationships in contributing to and mitigating disparities in end-of-life experiences, as well as their potential for improving well-being at the end of life. A particularly timely and contested issue ripe for sociological exploration is the legal context of PAS. As PAS becomes more widely available, sociological attention to the complex political, cultural, economic, and institutional factors that guide legislation and support for that legislation will be of utmost importance. The end-of-life stage will ultimately befall all persons, regardless of age, and the challenges and opportunities provided by this time between illness diagnosis and death warrants serious sociological inquiry.

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