

The Evolution of End-of-Life Care

Ethical Implications for Case Management

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ABSTRACT

Purpose and Objectives: This article:

1. discusses historic milestones of the death with dignity movement,
2. provides legislation, reimbursement, and programming updates,
3. discusses the influence of shared decision making, and
4. explores ethical implications of the evolution of end-of-life care for case managers.

Primary Practice Setting(s): Applicable to all health care sectors where case management is practiced.

Findings/Conclusion: Few topics are more intimate and multifaceted for case managers than engaging with today's culturally diverse patient populations around end-of-life processes. The already prominent focus of this issue has been further elevated by a series of events to receive public attention. These include the Institute of Medicine's 2014 report—*Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*, rising numbers of patients around the globe requesting to end life on their own terms, and corresponding death with dignity initiatives and legislation.

Another vital factor in the end-of-life equation involves how the latest generation of shared decision making influences the management of treatment dialogues among practitioners, patients, as well as insurance companies. Case managers are at the intersection of these complex interactions, working to achieve ethical, as well as legal accountability to the patient, employer, and profession while balancing personal perspectives.

Implications for Case Management Practice: Professionals strive to effectively intervene with patients and their support systems facing end-of-life care decisions. It is essential case managers actively consider the intricacies of ethical practice and current contexts including death with dignity legislation, shared decision making, and shifts in regulations and reimbursement for end-of-life care.

Case management's ethical envelope will continue to be pushed. To that end amid shifting societal constructs, professionals must have mastery of applicable codes, standards, principles, and rules essential for adherence to ethical practice.

Key words: care coordination, case management, death with dignity, end-of-life, nursing, shared decision making, social work, transdisciplinary

An end-of-life evolution is sweeping across the health care industry. Increased numbers of elderly Americans, structural barriers in access to care for certain populations, and a fragmented health care system have impacted the provision of quality care near the end of life (Institute of Medicine, 2015). On a global scale, the concern is just as significant, with more than 20 million persons in need of palliative care at the end of life annually. Eighteen million die in unnecessary pain and distress, also impacting the health and well-being of their family members and caretakers (The Worldwide Hospice and Palliative Care Alliance, 2016a).

The assurance for patients to receive high-quality care at the end of life has achieved national status as an important health care goal (Michelson & Steinhorn, 2007). Intense media attention is targeted on advocacy by patients and their families to seize control of the dying process, with heightened

attention to pass reflective legislation. Even the language used by industry stakeholders has shifted as the terms of death with dignity, code comfort, and celebration of life have replaced the traditional verbiage of euthanasia, code blue, and funeral, respectively.

A new age of reimbursement has appeared. Year 2016 ushered in Medicare payment codes for doctors and other practitioners to consult with patients on how they would like to be cared for as they are dying (Pear, 2015). Although even when individuals and

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families are aligned, the societal norms, expectations, and requirements are not always consistent with the patient's wishes and choices (Institute of Medicine, 2014). As a result patients, their families, involved practitioners, and at times insurance companies are in a proverbial tug of war to seize control of the treatment process. Case managers sit poised at the ethical, and often legal, crossroads of these challenges.

This article explores the intricacies of ethical case management practice via a comprehensive exploration of this pivotal topic. Focus will be on milestones of the death with dignity movement, plus a review of societal constructs and fiscal drivers influencing how end-of-life care is addressed. The ethical context of practice for professional case managers will also be explored, with application to new models of decision making to support practice.

DEFINITIONS

There is no exact definition for either the interval referred to as end of life or what end-of-life care is (Izumi, Nagae, Sakurai, & Imamura, 2012). Several formal meanings can be found, which refer to care for people in decline who are deemed to be terminal or dying in the foreseeable (near) future (Canadian Institute for Health Information in Fowler and Hammer, 2013)

A number of terms aligned with end of life, or end-of-life care, appear across the literature. As they are used throughout this article, it is important to provide accurate definitions at this juncture, to ensure clarity. Included in this listing are:

- death with dignity,
- euthanasia,
- hospice,
- palliative care
- physician-assisted suicide, and
- right to die.

These terms and their definitions are presented in Box 1.

HISTORY OF THE DEATH WITH DIGNITY MOVEMENT

In 1906, the first euthanasia bill was drafted in Ohio. Although it did not succeed, the legislation marked the start of the modern death with dignity movement. A comprehensive listing of historic events is provided

BOX 1

Definitions Aligned With End of Life Care (References as Noted)

Death with dignity: The philosophical concept that a terminally ill client should be allowed to die naturally and comfortably, rather than experience a comatose, vegetative life prolonged by mechanical support systems (Mosby's Medical Dictionary, 2009).

Euthanasia: The act or practice of killing or permitting the death of hopelessly sick or injured individuals (as persons or domestic animals) in a relatively painless way for reasons of mercy (Merriam-Webster, 2016a).

Hospice: End-of-life care provided by health professionals and volunteers. They give medical, psychological, and spiritual support. The goal of the care is to help people who are dying have peace, comfort, and dignity. The caregivers try to control pain and other symptoms so a person can remain as alert and comfortable as possible.

Palliative care: An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening and chronic illnesses, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. It:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten or postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient's illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- Will enhance quality of life, and may also positively influence the course of illness;
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

(The Worldwide Palliative Care Alliance and the World Health Organization, 2014)

Physician-assisted suicide: Suicide by a patient facilitated by means (as a drug prescription) or by information (as an indication of a lethal dosage) provided by a physician aware of the patient's intent (Merriam-Webster, 2016b).

Right to die: Asserting or advocating the right to refuse extraordinary medical measures to prolong one's life when one is terminally ill or irreversibly comatose (Dictionary.com, 2016).

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in Box 2. Several famous names were among the landmark decisions to follow; among them Karen Ann Quinlan, Dr Jack Kevorkian, Nancy Cruzan, and Terry Shiavo. In 2014, Brittney Maynard became the newest addition to that list. Although each historic situation received great attention in the media mode of the times (e.g., newspapers, magazines, and television) most occurred before social media or its current level of maturity. The tragically brief life of this vibrant, 29-year-old woman unfolded across the Internet with a profound and vivid presence.

Brittney and her husband were married 1 year and thinking about starting a family when she was diagnosed with a Grade 2 astrocytoma, a form of brain

cancer. She had a partial craniotomy and resection of her temporal lobe, though the cancer soon returned. Within months, Brittney's diagnosis was elevated to Grade 4 and she received a prognosis of 6 months to live. After assessing the information provided and her end-of-life options, Brittney and her family made a dramatic decision. They moved from their home and support system in San Francisco to Oregon, one of five states that authorized death with dignity at the time. The other states were Washington, Montana, Vermont, and New Mexico (The Brittany Fund, 2016).

Although the death with dignity movement began well over a century earlier, Brittney's brief life and very public death propelled it forward at warp speed. Those

BOX 2

Death With Dignity Movement Milestones (Adapted From Death With Dignity National Center, 2015a)

1906—First *euthanasia bill* drafted in Ohio, which does not succeed.

1976—NJ Supreme Court allows Karen Ann Quinlan's parents to disconnect the respirator, saying this affirms the choice Karen herself would have made. The case becomes a legal landmark. Karen lives until 1985.

1976—*California Natural Death Act* passed; gives legal standing to living wills and protects MDs from being sued for failing to treat incurable illnesses.

- 10 U.S. states pass natural death laws.

1980—*Hemlock Society* founded, advocating for legal change and distributes how-to-die information. This launches the campaign for assisted dying in America.

1983—The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research supported a parent's refusal of medical treatments in most instances.

1984—Advance care directives are recognized in 22 states and the District of Columbia.

1990—The American Medical Association adopts a formal position that with informed consent, physicians can withhold or withdraw treatment from a patient who is close to death, and may discontinue life support of a patient in a permanent coma.

- Dr Jack Kevorkian assists in the death of Janet Adkins, a middle-aged woman with Alzheimer's disease.
- The Supreme Court decides the Cruzan case, its first *aid in dying* ruling; competent adults have a *constitutionally protected liberty interest* that includes a right to refuse medical treatment.
- Congress passes the *Patient Self-determination Act*, requiring hospitals receiving federal funds tell patients they have a right to demand or refuse treatment.

1994—Advanced directives are now in 50 states.

1995—Surveys find MDs disregard most advance directives. *JAMA* reports MDs unaware of the directives of three fourths of all elderly patients admitted to a New York hospital; the California Medical Review reports three fourths of all advance directives were missing from Medicare records in that state.

2005—Terry Schiavo, aged 41, who for over 10 years was in a persistent vegetative state, is allowed to die by removal of life support; national/international controversy surrounds this passive euthanasia, involving the courts, Congress, and President Bush.

2008—Washington State residents vote to pass ballot initiative I-1000, the Washington Death with Dignity Act, on November 4, 2008, by a margin of 51% to 49%.

2013—Vermont Governor Peter Shumlin signed a bill to make Vermont the third state in the United States with a Death With Dignity law on May 20.

2015—California approves the End of Life Option Act, signed into law in October.

Federal law does not specifically protect the act of euthanasia or prohibit the practice altogether. State law only establishes the right to death with dignity, with four states having said legislation in place at the time of this article's publication.

with vested interest, both health care professionals and lay persons, actively followed Brittney's poignant journey on a daily basis across their mobile devices. Video interviews, articles, as well as blogs detailed the completion of each item on this young woman's bucket list. On November 1, 2014, with family and friends at her side, Brittney Maynard took medications prescribed by her physician and ended her life.

Federal law does not specifically protect the act of euthanasia or prohibit the practice altogether. State law only establishes the right to death with dignity, with four states having said legislation in place at the time of this article's publication:

1. Oregon—Death With Dignity Act, 1994
2. Washington—Death With Dignity Act, 2008
3. Vermont—Patient Choice and Control at End of Life Act, 2013
4. California—End of Life Option Act, 2015

(Death With Dignity National Center, 2015b)

Two other states have passed related laws in the past decade. The Montana Supreme Court issued a ruling in late 2009 that broadened the state's Rights of the Terminally Ill Act to include physician-assisted suicide. However, Montana statute does not provide a regulatory framework for physician-assisted suicide. The ruling does protect physicians from prosecution as long as they have the patient's request in writing.

New Mexico's statutes continue to list assisted suicide as a fourth-degree felony though it is a state in transition. The practice was first made legal through the courts in early 2014 when the second District Court in Albuquerque ruled New Mexico physicians may legally prescribe lethal drugs to assist terminally ill people with suicide. The state's attorney general declined to challenge the ruling, letting it stand. However, in September of 2015, the New Mexico Court of Appeals ruled against the 2014 ruling. It is expected the law will be appealed (Death With Dignity National Center, 2015b).

The current map noting the status of related legislation across the states is available on the Death With Dignity website at <https://www.deathwithdignity.org/take-action/>.

ESCALATING COSTS

Glaring variations have been identified in how medical resources are distributed and used for this patient population. In 2009 alone, Medicare paid \$50 billion for doctors and hospital bills during the last 2 months of patients' lives (CBS News, 2009). By 2012, end-of-life health care costs skyrocketed out of proportion. Forty-three percent of Medicare recipients were found to spend more than the total value of their assets, excluding their home, on out-of-pocket medical costs. More than 25% spent everything they had, including their homes (Rosenberg, 2012).

Although death is considered part of the life cycle and the journey toward physical dying begins with the inception of living, thinking and talking about one's own death usually remain in the background, at least until its prospect becomes more probable or imminent (Institute of Medicine, 2015). Patients with chronic illness in their last 2 years of life account for approximately 32 percent of total Medicare spending, much of it going toward physician and hospital fees associated with repeated hospitalizations (The Dartmouth Atlas of Health Care, 2016).

Compared with other countries, spending on end-of-life care in the United States was at approximately \$18,500 for hospital care in the last 6 months of life. Canada and Norway had higher rates at \$21,840 and \$19,783 per patient, respectively. Belgium, England, and the Netherlands were considerably lower at \$15,699, \$9,342, and \$10,936, respectively (Bekelman et al., 2016). In the end-of-life arena, opportunities exist for savings by simply reducing, if not avoiding acute care services altogether. These services are ones that patients and families often do not want and for that matter are unlikely to benefit them (Institute of Medicine, 2015).

Hospice care in America reduced Medicare expenditures during the last year of life by an average of \$2,309 per hospice patient. With an estimated 1.5–1.6 million patients receiving hospice services in 2012, this poses considerable savings (Leonard, 2012). From a resource allocation perspective, countless studies speak to the cost-effectiveness of enhancing care at the

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end of life through use of hospice and palliative care (Bekelman et al., 2016; Institute of Medicine, 2015; Leonard, 2012; Smith, Brick, O'Hara, & Normand, 2014). The need for expansion of benefits and reimbursement options is evident.

POPULATION SHIFTS

Older Adults

Experts anticipate there will be more than 84 million U.S. adults older than 65 years in the United States by the year 2050. More than 25% of these adults have given no thought to how to manage end-of-life care. As longevity becomes more common and disease leading to early and frequent death becomes less prevalent, patients easily become lulled into the belief that death may be postponed or even avoided. This concept leads the majority of persons to rely on their primary care providers for direction to the best care plan when end-of-life decision making is actually required (Institute of Medicine, 2015).

More than 40% of patients who die with cancer are admitted to the ICU in the last 6 months of life, more than twice that of many countries (Bekelman et al., 2016). Many are not physically or cognitively able to make their own decisions (Institute of Medicine, 2015) For 70% of Canadians, hospitals remain the provider of end-of-life care (Fowler & Hammer, 2013). Among the patients in the United States who indicated they preferred to die at home, 55% still died in the hospital. The evidence suggests that patients often prefer a more conservative pattern of end-of-life care than they actually receive, and that a patient's wishes can be less influential than the practice patterns at the hospital where care is delivered (The Dartmouth Atlas of Health Care, 2016).

Pediatrics and the Initiative for Pediatric Palliative Care

Approximately 55,000 pediatric deaths occur in the United States annually. More than 56% of those deaths occur in hospitals, with most in the pediatric and neonatal intensive care unit. Eighty-nine percent of parents whose children died of cancer reported their child suffered from at least one bothersome symptom in their last month of life (e.g., pain, fatigue, or dyspnea) (Michelson & Steinhorn, 2007). The estimated number of children in need of palliative care at the end of life is almost 1.2 million worldwide (The Worldwide Palliative Care Alliance and The World Health Organization, 2014).

The Initiative for Pediatric Palliative Care (IPPC) was launched in 1998 as a research, quality improvement, and education effort. The goal was to enhance a family-centered care approach for children living

with life-threatening conditions (IPPC, 2016). From 2005 through 2009, the IPPC conducted over 20 education retreats across the United States and Canada. The over 2200 targeted stakeholders included interdisciplinary teams and parents of children with life-threatening conditions from across the transitions of care, including but not limited to:

- hospitals,
- hospice,
- home care organizations,
- neonatal units,
- community coalitions, and
- other groups serving children and families.

(IPPC, 2016)

The IPPC developed six key quality domains, each with unique goals and quality indicators:

1. Support of the family unit;
2. Communication with the child and family about treatment goals and plans;
3. Ethics and shared decision making;
4. Relief of pain and other symptoms;
5. Continuity of care; and
6. Grief and bereavement support.

The IPPC was also instrumental in developing expectations for the way in which hospitals should intervene with the pediatric patient population. These are shown in Figure 1

Five education modules were designed by the IPPC to facilitate individual clinician learning and strengthen an institution's programs and services:

1. Engaging with children and families;
2. Relieving pain and other symptoms;
3. Analyzing ethical challenges in pediatric end-of-life decision making;
4. Responding to suffering and bereavement; and
5. Improving communication and strengthening relationships.

(IPPC, 2016)

The Ethical Intersection: Death With Dignity Meets Shared Decision Making

Studies show concerning trends about the decision-making process, which underlies how diagnosis and treatment dialogues progress:

- Patients express frustration and dissatisfaction with care because they do not feel they have adequate input into the decisions clinicians are making about their health and their lives;
- Patients often do not know enough about their treatment options to make informed decisions, and/or may not understand the evidence base underlying decisions they are being offered;

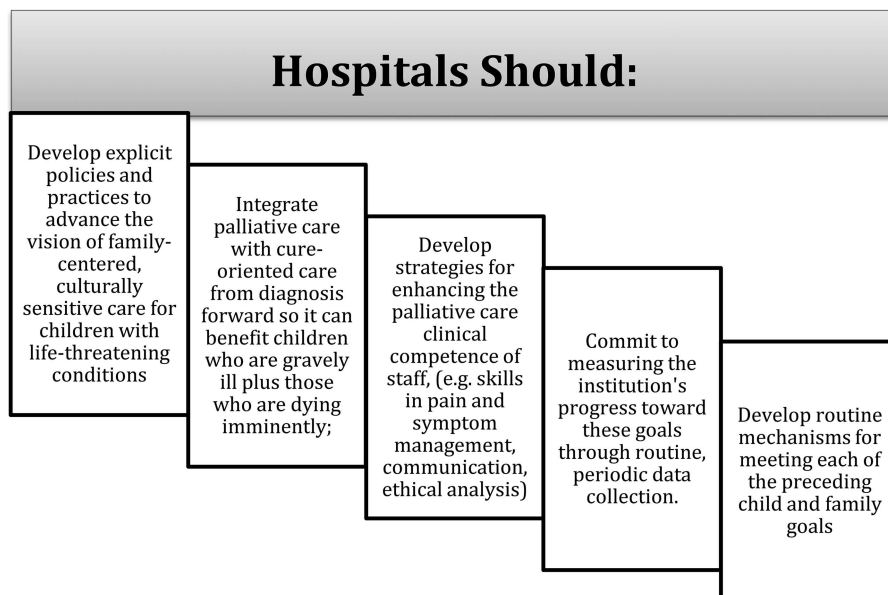


FIGURE 1
The Initiative for Pediatric Palliative Care hospital recommendations. Adapted from IPPC, 2016.

- Providers are not always supportive of patient involvement in the decision-making process; and/or
- Clinicians may be supportive of the concept of shared decision making, but do not know how to make it happen.

(Agency for Healthcare Research and Quality, 2015)

Shared decision making (SDM) provides a vehicle to honor both the provider’s expert knowledge and the patient’s right to be fully informed of all care options, and the potential harms and benefits. Consistent with the principles of patient-centered care, SDM is defined as a collaborative process that allows patients and their providers to make health care decisions together, taking into account the best scientific evidence available, as well as the patient’s values and preferences (Informed Medical Decisions Foundation, 2016a). The concept of SDM supports autonomy through building strong relationships among all stakeholders of the care process while respecting individual competence and interdependence on others (Elwyn et al., 2012).

SDM aligns with the ethical tenets, codes, and standards across a number of disciplines, which comprise case management (American Nurses Association [ANA], 2015; Commission for Case Management Certification [CCMC], 2015; Case Management Society of America [CMSA], 2010; NASW, 2008). All speak to the priority placed on patient self-determination as a goal that the treatment team must support individually and collectively, when feasible (Elwyn et al., 2012). However, involved professionals across the care team may at times find themselves

challenged by patient choices that, medically, do not seem in the patient’s own best interest. The basic premise for the provision of health care implies there is an illness, treatment, and subsequent improvement in health, a return to wellness or recovery from injury (Terra & Powell, 2012). Yet, this premise is grossly challenged for the providers and patients engaged in end-of-life care and treatment. For this population, conflict emerges between the ethical tenets of:

- Autonomy: to respect individuals’ rights to make their own decisions
- Beneficence: to do good
- Fidelity: to follow through and to keep promises
- Justice: to treat others fairly
- Nonmaleficence: to do no harm

(CMSA, 2010)

Those case managers in the trenches have engaged with the patient who chooses to stop treatment earlier than the provider recommends. In opposition, a patient or family may request to “do everything possible,” actions that do little to alter the poor prognosis and/or ultimate outcome. Other situations can baffle professionals, such as the patient who does not want to be involved in the decision-making process at all or defers all treatment choices to family, friends, or even the physician. Whether related to denial or another defense mechanism, the patient’s behavior provides moments of pause for case managers, as well as other treatment providers.

Situations surrounding the behavior of other professionals equally manifest and cause ethical reflection for case managers. Consider the following scenario:

Dana is a case manager embedded in a primary care practice. She is assigned to work with Dr Simon, a new physician. Dr Simon is an empathic practitioner, though heavily invested in a cure vs. care mentality. He is always looking to fix the situation for every patient. However, the situation before him is far from fixable, and thus untenable. Dr Simon is scheduled to meet with Jenna, a 48-year-old woman and her spouse, Lionel, to discuss the treatment plan for Jenna's new diagnosis of Stage 4 ovarian cancer.

What results is an office visit spent answering questions about experimental treatment protocols that Lionel found on the Internet. Dr Simon gets little chance to speak and is happy to see the 15 minutes allotted for this patient visit fly by. It saves him the emotional angst of letting this family know the sad reality of Jenna's limited options. After the visit, Dana questions Dr Simon's plan to discuss Jenna's treatment course and choices. He responds, "No worries, Dana. We will address this during the next visit."

Jenna is hospitalized emergently later in the week for increased pain and intractable vomiting. After Dr Simon's partner, Dr Kyle, provides orders to the hospitalist on duty, he calls Dana: "I know you saw Jenna with Dr Simon earlier in the week, so perhaps you can help me understand something. I would expect Jenna to have more information about the severity of her diagnosis, however this is not the case. Tell me what happened during the office visit?"

Using SDM provides an essential lens into how the human condition impacts patient care. Health care's strong focus on social determinants (e.g., access to health care services, social support, exposure to crime/violence, language, and literacy), plus shifting cultural patient demographics, mandates greater efforts of the care team to communicate openly between those who render and receive care. Communication with patients about end-of-life issues is strongly influenced by cultural norms. As a result, cultural awareness is a pivotal factor for case managers to acknowledge when intervening in death with dignity discussions.

For example, death is rarely discussed openly in many East Asian communities. Although withholding information from patients is uncommon in North America, there can be a differential understanding of the intent of therapies at the end of life. Those on the clinical team may provide palliative therapies, whereas patients and families still understand the care rendered to be an attempt at a cure (Fowler & Hammer, 2013).

Five states have passed legislation to make SDM policy including Maine, Massachusetts, Minnesota, Vermont, and Washington. Another three states have SDM legislation pending: California, Connecticut, and Oregon. The remaining states have no SDM legislation proposed or passed at the time of this writing. An updated map is available at the Informed

Medical Decisions website (<http://www.informed-medicaldecisions.org/shared-decision-making-policy/state-legislation/map-shared-decision-making/>)

The Three-Step Model

In the context of SDM, the three-step model (Elwyn et al., 2012) offers a foundation for professionals to engage in a structured process that promotes sharing of key information with patients and families while respecting their individuality. Through the subsequent steps of deliberating and exploring the diagnosis and treatment options, these three phases support the ability of both patients and treatment teams to develop informed preferences regarding their care in a collaborative manner. The model accounts for the fluid nature of these discussions and the overall care process.

For the purposes of this article, the original three-step model is revised for case management with an added fourth step, called Touch Back. This revision provides those involved in the conversations and requisite decision making, an equal opportunity to review where dialogues end and define further information required to keep the decision process advancing forward. Figure 2 provides a rendering of the four-step model for case management.

MOVING FORWARD: REIMBURSEMENT INITIATIVES

Medicare

Historically, the hospice benefit was first added in 1983, with the goal to provide comprehensive, interdisciplinary care for beneficiaries in the last 6 months of their lives. Outcomes vary on utilization of the benefit, particularly due to lack of claims data for those patients enrolled in Medicare Advantage plans (Taylor, Bhavsar, Harker, & Kassner, 2015). On one hand, outcomes revealed for cancer patients enrolled in Medicare who died in 2013 that only 47% used hospice services (Institute of Medicine, 2015). On the other hand, it has been identified that one in two beneficiaries use hospice care prior to their death (Taylor et al., 2015). Change has been warranted for decades per experts (Fowler & Hammer, 2013; Institute of Medicine, 2015; Taylor et al., 2015), with 2016 yielding three timely policy changes.

End-of-Life Counseling

The explicit payment for advanced care planning discussions will allow physicians and other qualified professionals (e.g., nurse practitioners and physician assistants) to conduct end-of-life counseling. Originally part of the Affordable Care Act (ACA):

- The Centers for Medicare & Medicaid Services (CMS) has approved payment for two advanced

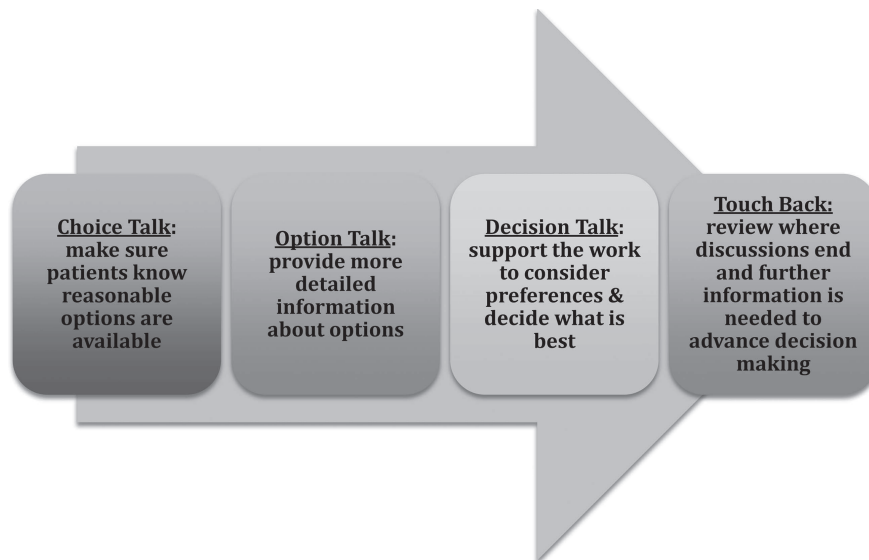


FIGURE 2

The four-step model for case management. Adapted from Elwyn et al., 2012.

care planning CPT codes in the 2016 Medicare Physician Fee Schedule proposed rule:

1. an initial code for 30 minutes of discussion on advance care planning, and
 2. an add-on code for each additional 30 minutes.
- Provided by licensed and credentialed hospital staff, in conjunction with physicians and other midlevel practitioners.

Hospice Reimbursement Reform

This will be composed of two components:

1. Shifting to a two-tiered per diem payment for hospice care (higher in the first 60 days and then lower thereafter) to replace the per diem approach that Medicare has used since the inception of the hospice benefit.
2. The addition of a retrospective Service Intensity Add-On payment to adjust for increased acuity during the last week of life.

(Taylor et al., 2015)

Medicare Care Choices Model

Under the ACA, children who are enrolled in Medicaid or the Children's Health Insurance Program are eligible to receive curative treatment and hospice care simultaneously. Curative treatment refers to health care practices that are used to treat patients with the intent of curing them, and not simply reducing their pain or stress. One commonly used example is chemotherapy, which seeks to cure cancer patients (Medicareresources.org, 2016). However adults have not traditionally been privy to the same care option, having to waive treatments for their underlying diseases in order to access their hospice benefit. (Ollove, 2015)

The CMS is amid a 5-year, 40-state test program to determine a better way to help beneficiaries come to grips with terminal illnesses and prepare to die. The March 2015 Medicare Payment Policy Report to the Congress showed only 47.3% of Medicare and 42% of dually eligible beneficiaries used hospice care and most only for a short period. These data reflect the all too common struggle in having to choose between palliative as opposed to curative care at one of the most challenging times in the beneficiary's life (CMS, 2015; Ollove, 2015).

One hundred forty-one hospices were chosen to participate in the Medicare Care Choices Model demonstration under the auspices of the Centers for Medicare & Medicaid Innovation. The demonstration is set to provide end-of-life care and counseling to dying Medicare patients at the same time those patients receive treatment to extend their lives. Delivery of services under the model will be phased in over 20 years, with approximately half of the participating hospices providing services under the model on January 1, 2016. The remaining participant hospices will initiate services starting January 1, 2018. This model is slated to end on December 31, 2020. Hospices participating in the model will be randomly assigned to Phase 1 or Phase 2 (CMS, 2015).

Under the ACA, children who are enrolled in Medicaid or the Children's Health Insurance Program are eligible to receive curative treatment and hospice care simultaneously.

The eligibility criterion for involvement in the program is for those persons with a prognosis of 6 months or less to live, who have the following diagnoses of:

- advanced-stage cancer,
- chronic obstructive pulmonary disease,
- congestive heart failure, or
- AIDS.

In addition to the diagnostic considerations, interested beneficiaries must fall into certain categories:

- Must meet hospice eligibility requirements under the Medicare or Medicaid hospice benefit.
- Must not have elected the Medicare or Medicaid hospice benefit within the last 30 days prior to their participation in the Medicare Care Choices Model.
- Must receive services from a hospice that is participating in the model.
- Must have satisfied model's other eligibility criteria.

(CMS, 2014; Ollove, 2015)

Medicare will pay the hospices up to \$400 a month per beneficiary. Success of the program will lead to expansion across Medicaid (Ollove, 2015), if not also extending it to third-party payers. A full listing of the demonstration sites can be viewed at the CMS.gov website, Medicare Choice Model Awards (<https://www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2015-Fact-sheets-items/2015-07-20.html>).

Third-Party Payers

Insurance companies have struggled along with other industry stakeholders in effectively managing the new perceptions of end-of-life care. Controversies around payment for futile care are familiar to industry stakeholders, especially case management (Muller, 2015; Powell, 2015; Terra & Powell, 2012). As Terra and Powell (2012) identify,

invoking medical futility is fraught with areas of vulnerability and implications in ethical decision making. Of concern is whether the treatment will cause more harm than good (nonmaleficence), whether it respects patients' goals and desires (autonomy), and whether the interests of patients, society, and the organization are served (justice).

The concept of payers expanding coverage for end-of-life care is longstanding. Eighty to 100% of end-of-life care services in the United Kingdom are paid for by sources other than the patient (Siddique, 2015). In the Quality of Death Index 2015 (Economist Insights), which compared end-of-life care in 80 countries, the United Kingdom was ranked the best place in the world in which to die. The United

Reviewing the challenges identified by the Institute of Medicine (2015) is a reminder of the prominent role case management serves in working with those facing the death with dignity process.

States came in at number nine. The top 10 countries were:

1. The United Kingdom
2. Australia
3. New Zealand
4. Ireland
5. Belgium
6. Taiwan
7. Germany
8. Netherlands
9. The United States
10. France

(Economist Insights, 2015)

Several third-party payers have followed CMS's example with respect to payment changes for 2016. Blue Cross Blue Shield of Massachusetts has expanded benefits for end-of-life care, now covering the costs of visits for patients and family members with mental health professionals (e.g., psychologists and social workers). In this way the patient and family system can process decisions about treatment extent, alternatives, and other prevailing concerns they have about the care process. A homecare program is also to be phased in later in the year. The effort is viewed to have the potential to lower health care spending by providing patients with more options to replace hospital care with less expensive and often preferable alternatives, including hospice and home care (McCluskey, 2015; Taylor et al., 2015).

Implications for Case Management

Reviewing the challenges identified by the Institute of Medicine (2015) is a reminder of the prominent role case management serves in working with those facing the death with dignity process. This spans all levels of practice, whether directly functioning as the case manager, in leadership positions, and/or as a policy developer. In addition to those challenges cited through this article, several others bear mentioning. Their complexity hits case managers at their ethical, if not moral core:

- the increasing number of elderly Americans with some combination of frailty, significant physical

- and cognitive disabilities, multiple chronic illnesses, and functional limitations;
- growing cultural diversity of the U.S. population, which makes it more important for clinicians to approach all patients as individuals, without assumptions about the care choices they might make;
- a mismatch between the services patients and families need most and those they can readily obtain;
- failure of the availability of palliative care services to keep pace with the growing demand;

- wasteful and costly systemic problems, including perverse financial incentives, a fragmented care delivery system, time pressures that limit communication, and a lack of service coordination across programs; and
- the resulting unsustainable growth in costs of the current health care delivery system over the past several decades.

(Institute of Medicine, 2015)

BOX 3

Case Management Ethics Standards, Codes, Principles Application: Case Scenario

Ethics Standard: K

Case managers should behave and practice ethically, adhering to the tenets of the code of ethics that underlies his/her professional credential (e.g., nursing, social work, and rehabilitation counseling).

- Awareness of the five basic ethical tenets (see the table below).
- Recognition that a case manager's primary obligation is to his/her clients.
- Maintenance of respectful relationships with coworkers, employers, and other professionals.
- Recognition that laws, rules, policies, insurance benefits, and regulations are sometimes in conflict with ethical principles. In such situations, case managers are bound to address such conflicts to the best of their abilities and/or seek appropriate consultation.

Application

- Hudson's insight and awareness into the current ethical dilemma is exemplary. He seeks consultation of his director, Kate, while exploring the applicable codes and standards.
- Hudson and Kate discuss the challenge of maintaining professional boundaries.
- Hudson's appreciates openly dialoguing with Kate the issues (e.g., same-sex marriage, implementation of patients' advanced directives in opposition to this personal values). He recognizes his primary obligation is to Martin, and feels able to move forward with the work required to implement the plan.
- Hudson reviews the ANA Code of Ethics for Nurses and finds the relevant codes (see below)

Ethical Tenets

Beneficence

Hudson is striving to act in Martin's best interests.

Nonmaleficance

Hudson wants to be sure he is not harming Martin and Daniel, physically or emotionally.

Autonomy

Hudson consults with Kate to support his ability to intervene appropriately on Martin's behalf. He might also discuss the option to transfer Martin to another case manager if unable to reconcile his personal and professional values.

Justice

Hudson strives to be sure he practices fairly.

Fidelity

Do you see any way Hudson's actions are a violation or not?

(Adapted from CMSA, 2010)

Code of Ethics for Nurses: Ethical Provision

- The nurse practices with compassion and respect for the inherent dignity, worth, and unique attributes of every person:
 - 1.1 Respect for human dignity: A fundamental principle that underlies all nursing practice is respect for the inherent dignity, worth, unique attribute, and human rights of all individuals.
 - 1.2 Relationships with patients: Nurses establish relationships of trust and provide nursing services according to need, setting aside any bias or prejudice. Factors such as culture, value systems, religious or spiritual beliefs, lifestyle, social support system, sexual orientation or gender expression, and primary language are to be considered when planning individual, family, and population-centered care.
 - 1.4 The right to self-determination: Respect for human dignity requires the recognition of specific patient rights, in particular the right to self-determination. Patients have the moral and legal right to determine what will be done with and to their own person

(American Nurses Association, 2015)

CCMC Ethical Principles

- Board-Certified Case Managers will respect the rights and inherent dignity of all clients.
- Board-Certified Case Managers will maintain objectivity in their relationships with others.
- Board-Certified Case Managers will act with integrity and fidelity with clients and others.

Application

- Hudson's diligence to the review process amplifies his commitment to ethical excellence.
- His discussion with Kate and subsequent exploratory work provide the professional grounding needed to work expertly with Martin and Daniel.

(Adapted from CCMC, 2015)

BOX 4 Resource Listing

1. Aging with Dignity: www.agingwithdignity.org
2. Compassion & Choices: www.compassionandchoices.org/
3. Death With Dignity National Center: www.deathwithdignity.org
4. Informed Medical Decisions Foundation: www.informedmedicaldecisions.org
5. Institute of Medicine: www.iom.nationalacademies.org
6. POLST (Physician Orders for Life-Sustaining Treatment): www.polst.org
7. The Brittney Maynard Fund: <http://thebrittneyfund.org>
8. The Conversation Project: theconversationproject.org
9. The Initiative for Pediatric Palliative Care: www.ipcweb.org
10. The National Hospice and Palliative Care Association/Caring Info: www.caringinfo.org/14a/pages/index.cfm?pageid=3282
11. The Worldwide Hospice and Palliative Care Alliance: <http://www.thewhpc.org>
12. The World Health Organization: <http://www.who.int/en/>
13. Respecting Choices Advanced Care Planning: <http://www.gundersenhealth.org/respecting-choices>

The value of a patient's right to self-determination is aligned directly with patient autonomy, an ethical tenet of professional case management practice (CCMC, 2015; CMSA, 2010). Self-determination can and does challenge case managers. Respecting and prioritizing the decisions of each patient in contrast to those the case manager might define for that patient is a tough balancing act. Particularly with technology and social media's ability to keep any and all stakeholders in sync with a patient's intimate treatment choices, each step in his or her road of self-determination brings a public range of emotions from acceptance to moral outrage (Powell, 2015). The more exposure these situations garner, the more passion invested by those who follow the details. The deeper the emotions, the tougher for those involved to maintain objectivity and process the actual situation at hand.

Along with walking the ethical tightrope in managing the tenet of advocacy, tension will also emerge across the additional ethical tenets of beneficence, fidelity, justice and nonmaleficence (CMSA, 2010). Consider the professional who struggles to critically think through a patient's life circumstances and treatment choices—one which may be laden with legal, as well as ethical considerations. Hudson's intervention with Martin exemplifies these dynamics:

Hudson is the case manager for Martin, a 28-year-old man with advanced amyotrophic lateral sclerosis (ALS). Martin has had three hospitalizations in the past 2 months for aspiration pneumonia. He is alert and oriented to all spheres, although warranting moderate assistance for her activities of daily living, Martin's need for suctioning has recently increased from every 4 hours to hourly, with tube feedings broached by his

physician to ensure nutritional needs are met. Martin is upset about his increased clinical needs and views them as an obstacle to any quality of life. He wants no aggressive treatment and has requested to implement his advanced directives, which mandate Martin receive no life-sustaining measures.

Martin's spouse, Daniel, requests to meet with Hudson. Daniel is distraught and says, "Don't listen to my husband. With everything Martin's going through, he's not in his right mind. Despite this illness, he can live a great life. There are so many experimental protocols. Look what Stephen Hawking accomplished! Besides, we have a 2-year-old daughter. Martin can't leave us both."

Martin tells Hudson he wants to follow Brittney Maynard's example by fulfilling the remaining items on his bucket list, then moving from New York to Vermont to end his life. "Daniel will never go for it," he adds. Hudson's clinical gut is screaming; his personal beliefs are making this situation hard enough for him to support Martin and Daniel as a same-sex couple. Add on his strong religious beliefs, and Hudson considers Martin's actions tantamount to suicide. He is unsure how to balance his personal and professional values in this situation and requests to meet with Kate, the Director of Care Coordination.

Kate says, "I'm glad you called me. The hospital CEO just gave me an earful about not allowing this patient to pull a Brittany Maynard. He is concerned about the potential media hype. This is a highly emotional situation for all involved, but as health care professionals and professional case managers, we have established resources to guide our actions."

Kate and Hudson find guidance in the CCMC Code of Professional Conduct (2015) and the CMSA Standards of Practice (2010). Hudson is a registered nurse and licensed in several states. He scours the latest ANA Code of Ethics (2015). Box 3 shows the applicable ethical tenets, standards, rules, and principles.

CONCLUSION

A decisive cultural reframing now surrounds how end-of-life care is viewed and experienced by all involved stakeholders. A robust assortment of resources is added daily for consideration; Box 4 provides a comprehensive listing for readers. The professional case management workforce is mastering new terminology, laws, initiatives, and models of decision making. Although the final destination for the end-of-life journey is unknown, case managements' role is certain—to engage in actions that ensure ethical parameters of practice are adhered to in working with the transdisciplinary metropolis of patients, families, providers, practitioners, and payers alike.

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