

End of Life Care's Ongoing Evolution

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ABSTRACT

Purpose/Objectives: This article will focus on the following objectives specific to end-of-life care for professional case management:

1. Discuss recent industry topics that influence care processes.
2. Explore the opioid epidemic's impact on pain management.
3. Identify terms associated with end-of-life and life-limiting care.
4. Understand types of advance directives and care defining tools.
5. Define the purpose of psychiatric advance directives.
6. Discuss the shifting diagnostic face.
7. Discuss how inclusion manifests for the lesbian, gay, bisexual, transgender, queer/questioning (LGBTQ) population.
8. Explore challenges working through adolescent decision making and treatment.
9. Review regulation and reimbursement shifts across the industry.
10. Identify the use of artificial intelligence.
11. Discuss the value of ethics committees in health care organizations.
12. Define the Four Cs of Care Considerations.
13. Identify ethical principles for consideration by the workforce.

Primary Practice Settings: Applicable to all settings across the transitions of care where case management practice occurs.

Findings/Conclusions: Continuing shifts in society's cultural landscape, ongoing emphasis on value versus volume, and other industry fiscal imperatives continue to evoke an evolution in end-of-life care. The attainment of successful outcomes by professional case managers with those populations will be dependent on awareness and comprehension of regulations, legislation, and reimbursement; the influences of ongoing industry trends; availability of emerging resources; and ongoing technological advances. Ethical excellence remains at the core of case management across the interprofessional workforce and the transitions of care.

Implications for Case Management Practice: The professional case management workforce is tasked to effectively intervene across diverse client populations, with their caregivers and support systems. This action spans every life stage and illness course. With end-of-life care treatment and processes continuing to receive prime industry attention, case managers must be knowledgeable of the moving parts of this arena. Awareness of the ethical edges of each professional's sandbox is essential to quality-driven case management practice.

Key words: advanced directives, algorithm, artificial intelligence, compassionate wean, Death with Dignity, dementia, end of life, ethics, hospice, implicit bias, inclusion, LGBTQ, life-limiting care, palliative care, POLST, reimbursement, value-based care

It has been 4 years since my last article on the evolution of end-of-life care was published (Fink-Samnack, 2016). A dramatic cultural transition was in motion, geared to enhance the quality of end-of-life care rendered by health care organizations and providers. Regulatory and reimbursement changes by the Centers for Medicare & Medicaid Services (CMS) were implemented for hospice and palliative care programs. Further diagnoses and disease states were added for coverage, with insurers engaged in their traditional game of "follow the leader" as they updated and expanded existing benefits, in response to the CMS revisions. Fresh terminology was introduced to stakeholders that reframed a value neutral stance and more positive approach for end-of-life concepts identified across populations. Examples of this terminology included but were not limited to:

- aid-in dying versus euthanasia;
- comfort versus cure;
- death with dignity (DWD) versus end of life;
- life-limiting versus end of life or terminal;
- compassionate wean versus terminal wean; and
- celebration of life versus funeral

The care pendulum has continued to shift, with the end-of-life realm a vibrant and fluid business. The costs of care at the end of life have continued to rise and influence the sustainability of each practice

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setting, across the transitions of care. Health care systems and organizations strive to incorporate value-based care (VBC) methodologies to mitigate the value versus volume gap. Proactive attention to respect for client-centric care choices is more closely monitored than ever to ensure compassion, empathy, and sound shared decision-making processes. Every provider and practitioner interfacing with these client realities wrestles industry imperatives of length of stay, readmissions, and return on investment. The professional case manager stands poised at the ready to proactively address the diverse intricacies of each client circumstance, ethical and legal dilemmas accompanying the many moving parts of these situations.

This article will provide a view of the contemporary end-of-life care priorities for case management's interprofessional workforce, encompassing DWD legislation, evolving reimbursement structures, plus fresh models and resources to leverage care. Attention will be placed on the latest generation of trending topics to influence this domain as organ donation, added diagnoses for attention, comfort care amid the opioid age, integration of artificial intelligence, and adolescent decision making. The impact of VBC and the quality of care decisions will be addressed. Focus will also be placed on the ethical angle of inclusion as key tenet, especially for the LGBTQ community. It should also be noted that although the term "client" is primarily used throughout the article, some content speaks to the verbiage "patient" in deference to the reference. Any of these latest societal trends can easily force case managers to push beyond the ethical edges of their sandbox and professional comfort zones.

EVIDENCE AND COSTS

A Global Phenomenon

Involvement of the client, plus their support system in decision making about end-of-life care choices and treatment has been advocated as a cornerstone of person-centric care practices. Yet, the initiation of these necessary dialogues reflects a more reactive approach. Attention to end-of-life care is an international challenge, with elevated medical costs identified across the globe. A study conducted in eight countries through Project Hope (French et al., 2017) revealed per capita medical spending in the last 12 months of

life reaching \$80,000 in the United States, more than \$60,000 in Denmark and the Netherlands, and more than \$50,000 for Germany. Although the study indicated that the costs were not as high as expected, the question of cost can be a relative term. The question beckons: what is considered a *reasonable* price point in the scope of end-of-life care treatment?

There is a wide variation in the pricing for life-limiting care efforts. It can cost approximately seven times more for a person to die in a hospital than the amount to die at home. The average cost of care for persons who spend the last month of life in a hospital is \$32,379. Many of these deaths occur in intensive care units, where client charges can exceed \$10,000 per day. In these settings, terminally ill populations can be easily subject to high-cost treatments with potentially low-value technology. This combination can present as a complete mismatch, particularly when care is viewed as futile by any of the involved stakeholders (Arcadia Health Solutions, 2016). How does one equate the severity of pain and suffering with the amount of money spent on their care? A professional case manager attuned to appropriate resource management can easily struggle in these misguided treatment team dialogues. Figures 1 and 2 detail the location of where people died and the cost of that experience.

Medicare beneficiaries with poor prognoses can be subject to a litany of medical consultations, tests, and treatments. The end result involves the incurring of exorbitant bills, with little or no increase in the individual's longevity (Obermeyer et al., 2014). Deference to initiate conversations on palliative and hospice care continues to fall to the primary care physician despite industry emphasis on client autonomy, empowerment of more proactive discussions, and adoption of more

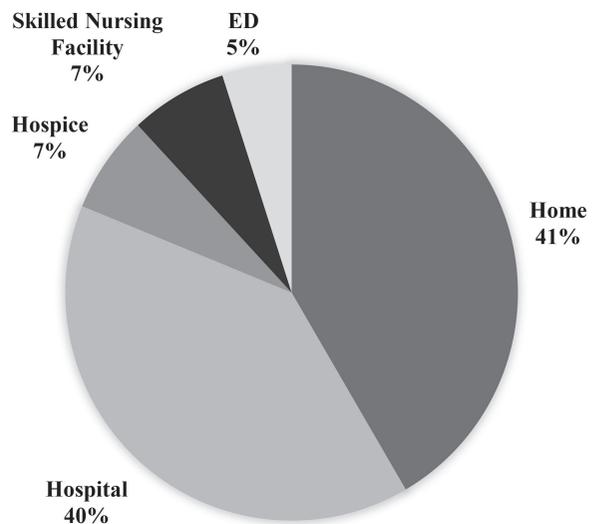


FIGURE 1
Setting where people died. ED = emergency department.

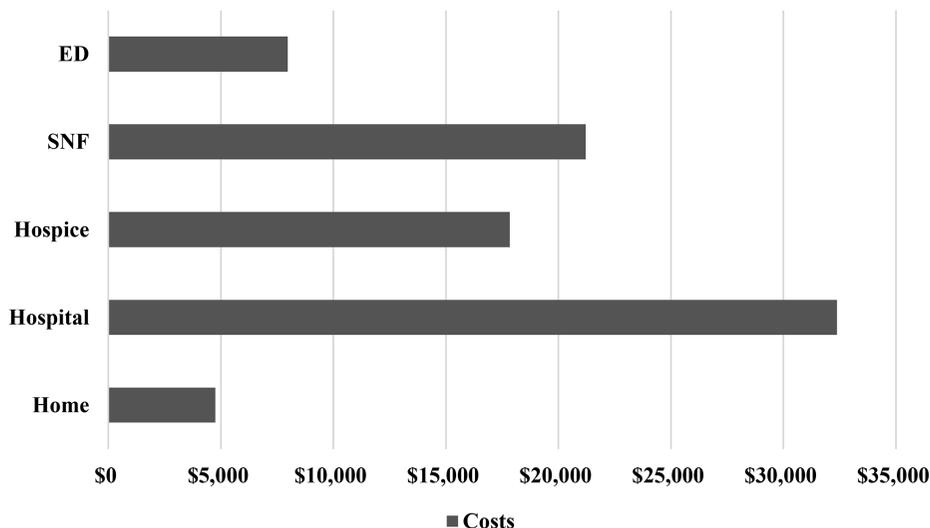


FIGURE 2

Cost comparison of death by setting. Data from Arcadia Health Solutions (2016). ED = emergency department; SNF = skilled nursing facility.

formalized client-centric programs and models (e.g., physician orders for life-sustaining treatment [POLST], Respecting Choices, shared decision making; Bélanger et al., 2016; Institute of Medicine, 2015; Sedig, 2016).

End-of-life treatment costs are also attributed to excessive hospitalizations and emergency department (ED) visits, particularly for those persons with chronic illnesses. Assorted industry reports tout heavy ED utilization for persons with chronic illnesses to the tune of more than \$8.3 billion annually—close to 30% of unnecessary visits (Premier, 2019). There has been considerable attention in the literature to debt incurred by Medicare beneficiaries, particularly with industry focus on the cost burdens incurred because of high drug pricing and co-pays. One study (Kyle, Blendon, Benson, Abrams, & Schneider, 2019) listed cancer among those conditions impacting the pockets of beneficiaries the most. The other diagnoses listed are associated with chronic diseases (e.g., heart disease, diabetes, stroke), several of which often prompt referrals to palliative care for symptom relief and pain management, if not ultimately hospice programs when treatment is futile or no longer desired. One condition listed in the study was a category identified as, Composite “Big 4.” The category includes one of four prevalent high-morbidity illnesses (e.g., diabetes requiring insulin, heart disease, heart failure, and heart attack). For the 742 persons sampled, profound financial hardships were detailed because of the expenses incurred by their illness(es):

- 36% using up all or most of their savings;
- 23% unable to pay for necessities such as food, heat, and housing; and
- 45% reporting emotional or psychological distress. (Kyle et al., 2019)

Of great concern can be the transfer process endured by clients at the end of life as they experience repeated readmissions across the transitions of care. Studies reveal that one out of eight Medicare beneficiaries who died was transferred between hospitals and skilled nursing facilities multiple times in his or her last year of life (Cheney, 2019). Many of these transitions occurred because of unclear or limited communications among providers with the client, or family. What resulted was inadequate clarification of the person’s clinical status or prognosis. Dialogues about end of life can be viewed by practitioners as time-consuming, with time a commodity health care professionals do not have.

The value of time and specifically the cost of a practitioner’s time are one reason why those current procedural terminology (CPT) codes allowing for Medicare reimbursement of advance care planning discussions were introduced in 2016. Yet, in spite of introduction of the availability of this 2016 Medicare reimbursement, the benefit remains grossly underutilized used by practitioners. A mere 14% of providers billed Medicare using the new codes (Heath, 2019). Roughly 25% of all Medicare spending still pays for care rendered during the final year of life. Persons who are diagnosed with multiple chronic diseases spend at least \$57,000 annually on their health care, with care for these persons in the last 2 years of their life accounting for 30% of all Medicare spending (Jha, 2018; Whitcomb, 2016).

THE LATEST GENERATION OF END-OF-LIFE TRIALS AND TRIBULATIONS

Definitions and Constructs

The face of end-of-life care has continued to shift over the past several decades, particularly amid life-sustaining

BOX 1

Advance Directives and Trending Terminology

Advance Directives

Legally executed documents by which a person makes provision for health care decisions in the event that in the future he or she becomes unable to make those decisions.

Living will:

Allows a client to document his or her wishes concerning medical treatments at the end of life. Before a living will can guide medical decision making, two MDs must certify:

- The client is unable to make medical decisions.
- The client is in the medical condition specified in the state's living will law (such as "terminal illness" or "permanent unconsciousness").
- *Other requirements also may apply, depending upon the state.*

Medical power of attorney (AKA: POA, health care proxy):

Allows the client to appoint a trusted person as his or her health care agent (or surrogate decision maker), who is authorized to make medical decisions on the person's behalf. Before a medical power of attorney goes into effect, a person's MD must conclude that he or she is unable to make his or her own medical decisions. In addition:

- If a person regains ability to make decisions, the agent cannot continue to act on the person's behalf.
- Many states have additional requirements applying only to decisions about life-sustaining medical treatments (e.g., prior to a client's agent refusing life-sustaining treatment on the client's behalf, a second MD may have to confirm the primary MD's assessment that the client is incapable of making treatment decisions)

Physician orders for life-sustaining treatment (POLST):

A medical order for the specific medical treatments a client wants during a medical emergency. POLST forms are appropriate for individuals with a serious illness or advanced frailty near the end of life. They have different names from state to state.

Prehospital medical care directive:

Focused on several aspects of a resuscitation even (e.g., defibrillation, chest compressions, assisted ventilation, intubation, and advanced life support medications).

Psychiatric advance directive:

Psychiatric advance directives are a legal instrument used to:

- Document a competent person's specific instructions or preferences regarding future mental health treatment
- Allows appointment of a health proxy to interpret those preferences during a crisis
- Also plan for the possibility that someone may lose capacity to give or withhold informed consent to treatment during acute episodes of psychiatric illness.

Note. From Muller (2019); National Resource Center on Psychiatric Advance Directives (n.d.); National Hospice and Palliative Care Organization (2018a); and POLST.org (2018).

technologies and treatments. Terminal or compassionate weans occur with greater frequency, whether in response to the presence of a clear advanced directive, living will, or determination by treating practitioners of care deemed futile. Increased attention is placed on the legal documents to guide the actions and decision making of clients, providers, and involved family members. For those who need a refresher of the various available documents and terms associated with end-of-life care, refer to Boxes 1 and 2. Perhaps the client has endured years of treatment, discomfort, and decreased independence. It becomes a comfort to family and friends that their loved one is no

longer a victim to their illness; ultimate control by the client claimed. Occurrences such as these can be difficult for clients, caregivers, and providers to accept, though ultimately rationalized by those persons involved.

Yet, as the industry works to account for the various complexities accompanying each life-limiting care situation, new populations and challenges have appeared. This latest set of trending topics presents rare dilemmas for the health care industry to address—each situation a thread to another generation of factors yet to come. Case managers often find themselves in the middle of these situations, working to counter

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BOX 2

Definitions Aligned With End-of-Life and Life-Limiting Care

Death with Dignity: 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.

Euthanasia:

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.

Hospice:

Considered to be the model for quality, compassionate care for people facing a life-limiting illness or injury

- involves a team-oriented approach to expert medical care, pain management, and
- emotional and spiritual support expressly tailored to the patient's needs and wishes.
- Support is provided to the patient's loved ones as well.

Life-limiting illness:

A term used to describe an incurable condition that will shorten a person's life, although he or she may continue to live an active life for many years. There is no precise definition for this terminal stage, but it is typically used for a person considered to be within the last 12 months of life, or where his or her medical condition or diagnosis (e.g., chronic illness) will lead directly to death.

Palliative care:

Approach that improves the quality of life of patients and their families facing the problem associated with life-threatening and chronic illnesses, through 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's care;
- offers a support system to help patient's 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; and
- 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.

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.

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.

Note. Adapted from Dictionary.com (n.d.); Merriam Webster (2108a, 2018b); Mosby's Medical Dictionary (n.d.); National Hospice and Palliative Care Organization (2018b); and Worldwide Palliative Care Alliance and World Health Organization (2014).

moral distress by juggling the ethical balls of clinical, personal, and professional ethics.

Organ Donation

Technological advances have expanded health care options though they have equally brought a new dimension of ethical dilemmas to the end-of-life arena. Mechanical ventilation and other innovation can be viewed by health care consumers as a bridge to recovery, particularly for anyone whose physical or cognitive functioning does not allow for his or her body to function independently, without added device support. For example, consider the family who visits their comatose, ventilator-dependent loved one daily in the hospital. As the ventilator provides each breath, the family watches the person's chest rise and

fall, as if breathing. They remain optimistic about their loved one's recovery. The case manager and treatment team know the unfortunate reality; without the ventilator, the person would most likely not survive. Yet, the merits of technology become viewed as a double-edged sword, potentially compromising end-of-life intervention by sustaining bodily functions. These situations provide a false sense of security to the involved support systems.

Organ donation is among the latest twist to the end-of-life debate. It is one thing when death occurs suddenly, if not unexpectedly, and organ donation follows. These are emotional events, even when the victim has self-identified as an organ donor. However, when organ donation is planned at the end of a more enduring disease state, it is another matter entirely. Much was the case of David Adox, presented in Box 3.

BOX 3

The Case of David Adox

In 2014, Dave Adox was a 44-year-old man diagnosed with amyotrophic lateral sclerosis.

Along with his husband, Danni Michaeli, a plan was put in place. Mr. Adox wanted to donate his organs when his time came to die; he would go to University Hospital in Newark, where he was treated and have his ventilator disconnected.

Physicians at the facility reassured Mr. Adox that he could ask to come off the ventilator any time. The hospital ethics committee approved the plan and Mr. Adox's advanced directives were clear.

In March 2016, Mr. Adox, his family, and friends had a celebration of life to prepare for the next part of the journey.

During that weekend, the hospital attorneys stopped the plan for fear that the act resembled assisted suicide.

Ultimately, the couple reached out to six area hospitals. LiveON NY, an organ procurement organization in New York City stepped in.

On May 18, 2016, at Mount Sinai Hospital, Mr. Adox and his husband were able to move forward with the plan as originally defined.

Industry impact: Increasing focus on the development of policies at hospitals to allow dialogues with patients diagnosed with amyotrophic lateral sclerosis and other degenerative neurological disorders about organ donation as part of their dying.

Note. From Shakerdige (2016).

The concept of a planned organ donation that leads to death as the only possible outcome poses major ethical implications for all stakeholders. The Adox case broadly challenged the ethical tenets of nonmaleficence, along with fidelity and justice. Traditionally, when organ donation is the plan, a distinct team of physicians or an organ procurement team is consulted. In this way, engagement of the family in a separate discussion on the client's wishes and potential organ donation can occur. The process is carefully orchestrated to avoid the presence of any conflict of interest, whether real or perceived. Every effort is undertaken to avoid the implication that the final decision of the support system was coerced in any way by providers of care, whether for financial or other self-interest (e.g., payment for organs by other entities, prioritizing positioning on a transplant list, direct donation of organs to a preferred client).

Organ shortages for transplantation have evoked a series of recent concerns, where persons needing organs pay large sums of money to be prioritized on transplant lists. Precipitating factors contribute to the organ dearth including a limited pool of eligible donors and difficulty converting those eligible donors into actual donors. Close to 60% of Americans are registered as organ donors, with more than 113,000 individuals on the national transplant waiting list. Waiting lists for donation are lengthening, with over 20 people dying each day waiting for a transplant (Human Resources and Services Administration, 2019). The American Society of Transplantation (2019) has a series of guidelines that clearly detail optimal processes.

To say that it is permissible for practitioners to speak with the clients about organ donation as part of their dying means forever shifting the culture of medicine. Even in light of clear attention to the legal and ethical threads of client's autonomy, a shift of this culture prompted a major outcry from the industry and its consumers. In the Adox case, advocacy and respect for the human condition were overriding factors. Client choice and beneficence were interwo-

ven with fidelity and assuring that promises were kept to the client and involved support system. However, will the actions of the Adox case serve as precedents to allow similar actions for all relative cases to follow? When any person's wishes supersede established cultural values and ethical tenets, history is a powerful teacher; challenges will remain.

Dementia as a Growing Hospice Population

Dementia now accounts for more Medicare spending on end-of-life services than any other disease. Extended life spans are a blessing and a curse. The National Hospice and Palliative Care Organization Annual Report (2019) showed a continuing increase in hospice users, up to 1.49 million persons in 2017, and a 4.5% increase from the year prior. This number includes all hospice admissions, whether the person died while enrolled, continued to receive care into the following year (e.g., home hospice recipients), and live discharges for that year. The majority of hospice recipients were female at 58.4%, which is an important consideration in light of women the vast majority of persons diagnosed with dementia (Super, Ahuja, & Proff, 2019).

The top seven costliest hospice diagnoses for Medicare spending are shown in Figure 3. Although more persons diagnosed with cancer use hospice, those clients who have dementia stay in hospice over twice as long:

- Impacting close to 13 million Americans, nearly one out of three individuals
- 8.5 million women and 4.5 million men
- Expenditures to exceed \$2 trillion.

(Super et al., 2019)

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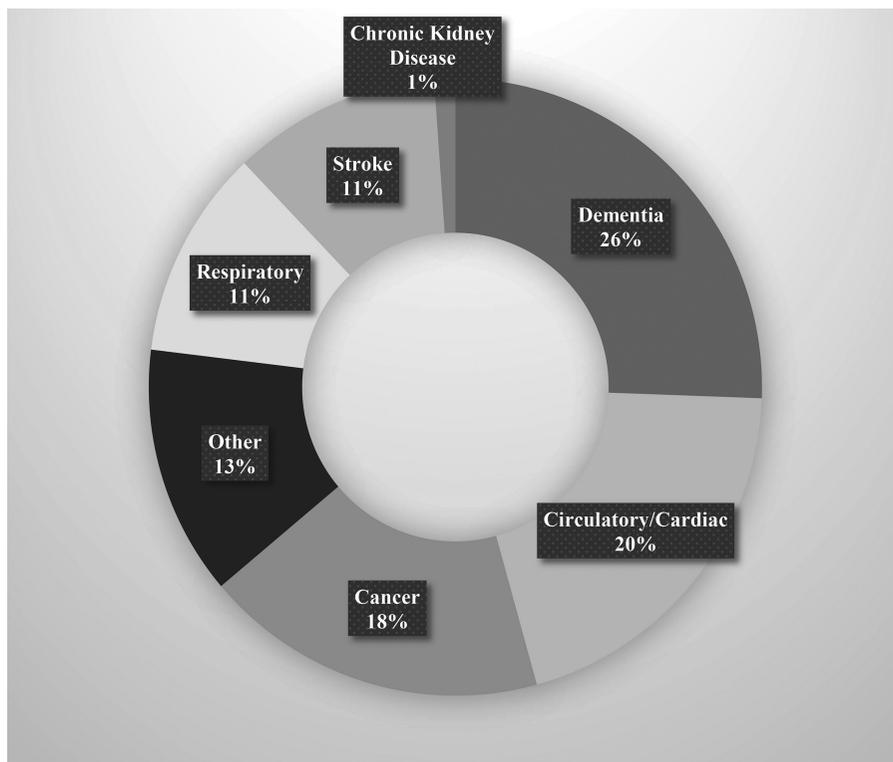


FIGURE 3
Percentage of Medicare spending on hospice by diagnosis. Data from National Hospice and Palliative Care Organization (2019).

Over the next 20 years, the demographics associated with dementia are expected to further rise. These numbers evoke powerful considerations for the industry to ensure the presence of appropriate funding for hospice and palliative care advance in tandem.

Psychiatric Advanced Directives

Over the past decade, psychiatric advance directives (PADs) have become increasingly popular across the states, with considerable implementation this year alone. Psychiatric advance directives are legal documents written by competent persons who live with mental illness. The document allows persons to be prepared if any mental health crisis interferes with treatment decisions by describing their treatment preferences. Psychiatric advance directives also provide individuals the ability to name someone to make treatment decisions should a person with a mental health condition be unable to make those decisions (NAMI, 2019). The two types of PADs appear in Table 1.

The disparity of PAD language and scope vary across the states. At the time of this writing, 25 states have adopted specific PAD statutes, with clear and dedicated language. A full listing of these states appears in this PAD website, appearing in the article's resource list, Box 4. Colorado, which implemented House Bill 19-1044 in August of 2019, created a distinct behavioral health order form for

adults to communicate their behavioral health history, decisions, and preferences in the event that they lack decisional capacity to provide consent to, withdrawal from, or refusal of behavioral health treatment or medication. Maryland also created a distinct advance directive for mental health treatment which allows a person to:

1. identify mental health professionals, programs, and facilities that you would prefer to provide your mental health services;
2. state preferred medications;
3. say whether you consent to your records being released to others, including other health care providers; and

TABLE 1
Psychiatric Advanced Directives: Types and Scope

| Type | Scope |
|--|---|
| Instructive Psychiatric Advanced Directive | Provides instructions about the specific mental health treatment a person wants should he or she experience a psychiatric crisis. |
| Proxy Psychiatric Advanced Directive | Names a health care proxy or agent to make treatment decisions when a person is unable to do so. |

Note. Data from NAMI (2019).

BOX 4 Resource Listing

Aging with Dignity: www.agingwithdignity.org

- Professional and client resources, education including Five Wishes Program

Agency for Healthcare Research and Quality: <https://www.ahrq.gov>

- Professional research, resources, and funding

Bazon Health Center: Mental Health Law: <http://www.bazon.org>

- Advocacy and resource information for professionals and persons living with mental illness

Center for Medicare & Medicaid Innovation (CMMI) Center

- State-by-state interactive maps on all programs, including:
 - Medicare Care Choices Model (MCCM): <https://innovation.cms.gov/initiatives/Medicare-Care-Choices/>
 - Medicare Advantage Value-Based Insurance Design (VBID) Models: Hospice Carve-in Program: <https://innovation.cms.gov/initiatives/vbid>

Center to Advance Palliative Care: <https://reportcard.cpc.org/>

- State-by-state interactive Palliative Care Report Cards

Compassion and Choices: www.compassionandchoices.org

- Professional and client-centric resources, guidance, and advance directives information

Death with Dignity: www.deathwithdignity.org

- Professional and client-centric information
- State-by-state interactive maps of death with dignity laws
- News and resources on death with dignity

Hospice Foundation of America: <https://hospicefoundation.org/About-HFA>

- Professional and client information, resources, funding

Mental Health America and Advanced Directives: <http://www.mentalhealthamerica.net/psychiatric-advance-directives-taking-charge-your-care>

- Professional and client-centric resources on advanced directives for those persons with mental illness

National Hospice and Palliative Care Organization: <https://www.nhpc.org>

- Professional and client-centric resources, guidance, programming distinctions, funding

National Institute on Aging: <https://www.nia.nih.gov/health/where-can-i-get-end-life-care>

- Professional and client resources, guidance on available programs, and services for relatives at the end of life

National LGBTQ Health Education Center/Fenway Institute: <https://www.lgbthealtheducation.org>

- Professional and client-centric education
- News and resources on LGBTQ health and behavioral health

National POLST Paradigm: <http://polst.org>

- Professional and client-focused
- State-by-state map of POLST programs
- News and resources on POLST programs

National Resource Center on Psychiatric Advance Directives: <https://www.nrc-pad.org>

- Professional and client-focused
- State by state map on Psychiatric Advanced Directives (PADs)
- News and resources on obtaining, developing, and implementing PADs

ProjectBigLife (Canada): <https://www.projectbiglife.ca>

- Health calculators for assorted disease states, including the End of Life (RESPECT) tool

Respecting Choices: <https://respectingchoices.org>

- Professional and client-focused resources, guidance on this evidence-based model of advanced care planning

Note. LGBTQ = lesbian, gay, bisexual, transgender, queer/questioning; POLST = physician orders for life-sustaining treatment.

4. have the right to refuse mental health treatment in your instructions.

(Colorado General Assembly, 2019; National Resource Center on Psychiatric Advance Directives, n.d.).

New Jersey is one of a number of states that has launched an online registry for PADs. The goal of the registry is to offer health care providers more immediate and streamlined access to these documents that detail mental health care, while enhancing consumer rights.

Federal and state laws provide persons with mental illnesses the right to indicate their health care choices in situations where their illness might prevent them from directly expressing their preferences. Consumers have the option to choose whether to participate in the secure online registry, will all information treated as confidential protected health information (New Jersey Department of Human Services, 2019).

Ensuring Comfort Amid the Opioid Epidemic

Attaining relief for any persons in pain can be challenging. Those individuals receiving palliative or hospice care have long dealt with misunderstandings of how to best address the pain and discomfort associated with their disease process, understanding cultural perspectives of suffering, and medication management. There is considerable stigma around appropriate use and often misuse of narcotics and how they factor into normal treatment paradigms for clients seeking relief from pain or discomfort when dealing with chronic and life-limiting illnesses.

Current client populations seeking comfort as opposed to cure in the opioid age and their practitioners are wrestling with new rules around medication administration and use. Societal and provider mandates speak to decreased reliance on opioid prescriptions, lower doses of narcotics, and for shorter time periods. The scrutiny is validated in light of the still overwhelming numbers: 282 million opioid prescriptions written by physicians at the height of the epidemic in 2012—enough for 8 of every 10 Americans (Karlin-Smith & Ehley, 2019). The greater monitoring and oversight of opioid prescriptions have led to an unintended consequence: increased suffering for persons experiencing pain, including those who are near the end of their lives.

The literature has focused on the assorted challenges faced by health care stakeholders as they adjust to a society now fixated on minimizing further opioid casualties. However, taking a reactive stance to an epidemic that was years in the making is leading to further problems. Dosing limits and misunderstandings of policies make it problematic for hospice and palliative care

practitioners to obtain frequently used medications (e.g., morphine), resulting in less than optimal pain control for clients. These shortages obstruct the care and comfort of a range of client-related circumstances: from persons who could be post a traumatic accident, complex surgical procedure, or actively receiving cancer treatment (Karlin-Smith & Ehley, 2019).

The Centers for Disease Control and Prevention prescribing guidelines and state laws restricting prescriptions generally do not restrict opioids for particular client populations. However, limited availability is becoming an unwelcome norm for practitioners to contend with. The guidelines affirm that doctors should discuss the (personal, physical, and emotional) costs of a high-dose regimen for any person engaged in these treatments and strongly encourage a prudent taper when appropriate. Doctors have been put on notice to prescribe opioids to new clients for a limited time frame and at low daily doses, (e.g., below 90 morphine milligram equivalents). That recommendation has prompted many states and monitoring systems to impose a hard stop at that level for all patients, except those who have a diagnosis of cancer or are receiving end-of-life care (Hoffman & Goodnough, 2019).

Persons who are unable to have their pain management properly tapered can experience other more severe challenges. They may be forced to seek illegal substances to manage their pain (e.g., heroin). They may engage in more desperate behaviors or actions if unable to tolerate the extreme physical and mental discomfort experienced from being incorrectly weaned from their pain management regime. Inappropriate pain management, improper opioid weaning, and suicide have become intertwined in a dysfunctional and concerning relationship. The increased incidence of suicidal ideation and intent can be the result.

Decision-Making of Children and Adolescents

Decision-making laws in the scope of health care and treatment are specific for children and adolescents. Although competent adults have the legal right to make decisions about their own medical care, it is

The greater monitoring and oversight of opioid prescriptions have led to an unintended consequence: increased suffering for persons experiencing pain, including those who are near the end of their lives. ... Dosing limits and misunderstandings of policies make it problematic for hospice and palliative care practitioners to obtain frequently used medications (e.g., morphine), resulting in less than optimal pain control for clients. These shortages obstruct the care and comfort of a range of client-related circumstances: from persons who could be post a traumatic accident, complex surgical procedure, or actively receiving cancer treatment.

not same for children. Individuals younger than the age of 18 years who live independently without the support of parents and make their own day-to-day decisions are allowed to petition the court for emancipation. If this petition is granted, the minor is provided the same legal rights as an adult, including the right to consent to (and refuse) medical treatment (McNary, 2014).

Children and adolescents may have the capacity to take part in medical decision making and are usually encouraged to do. Yet, the formal authority to make any final treatment decisions usually falls to the child's parents. All mentally competent people who are 18 years of age or older are permitted by law to consent or refuse medical treatment (McNary, 2014). A number of cases have been referred to hospital ethics committees and the courts in recent years. The question beckons: At what age do adolescents have the maturity to make their own decisions about health or behavioral health care? These situations can become precarious when the timing puts the decision making immediately prior to the birthday for the person to attain legal adulthood. The case of Cassandra Callender is example of this predicament and appears in Box 5.

Inclusion and the LGBTQ Community

At this current historical juncture, case managers are experiencing a new generation of ethical considerations involving respect for cultural sensitivity, client individuality, and treatment choices. Intervening with the rapidly shifting faces of populations at risk for the Social Determinants of Health (SDoH) has prompted robust industry response, particularly in the context of treatment adherence. Among the largest of these SDoH faces is the LBGTQ community,

who experience countless barriers and challenges to accessing quality health and behavioral health care. Their experiences run the gamut from general stigma and discrimination to provision of substandard care and denial of care by providers contributing to overall poor health outcomes (Fink-Samnack, 2019a, 2019b).

In the context of palliative care and hospice, this community deals with major barriers when receiving care for chronic and life-limiting illnesses. A number of case managers might recall the earliest generations of the AIDS crisis, when persons who were hospitalized endured care that reflected high levels of stigma. They were often placed in isolation rooms, where it presented that despite the ravages of their disease states, they were left to fend for themselves; food trays and other treatment supplies frequently left outside of the room, limited to no visitation.

A litany of issues are faced by health care consumers of the LGBTQ community, including clients not being called by their preferred name, failure to respect their gender identity, or acknowledge their marital partners or family members. When these issues present during the end of life, the emotional punch is intensified—the client and support system's coping and adjustment capacity hampered by unnecessary factors. Clinical themes around lack of empowerment and loss of control by the person can further evoke trauma or other more pervasive behavioral health responses. Acquaviva (2017) identifies three types of barriers for consideration of LGBTQ inclusion in palliative care and hospice, which are further detailed in Table 2:

- Perceptual
- Financial
- Institutional

BOX 5

The Case of Cassandra Callender

September 2014: 17-year-old Cassandra underwent surgery to remove a lymph node. She was given a diagnosis of Hodgkin's lymphoma and chose not to receive further treatment. Cassandra left the hospital with her mother to allegedly seek a second opinion, out of state.

Cassandra believed that chemotherapy would be toxic to the body and had long-term negative effects that would impact her fertility, damage her organs, and cause great harm. She was also aware that not receiving treatment would most likely lead to her death.

Connecticut Children's Medical Center contacted the state Department of Children and Families (DCF). DCF went to state Superior Court where doctors testified that Cassandra needed treatment. DCF was granted temporary custody of Cassandra and the Court ordered her and her mother to cooperate with the agency.

After two court-ordered chemotherapy treatments, Cassandra ran away from home and refused to return for treatment. Another court hearing led to DCF removing her from home. The court also gave DCF authority to make all of Cassandra's medical decisions. The case centered on whether Cassandra was mature enough to determine how to treat her cancer. Several states recognize the "mature minor doctrine," which refers to the statutory, regulatory, or common law policy accepting that an unemancipated minor patient may possess the maturity to choose or reject a particular health care treatment, sometimes without the knowledge or agreement of parents, and should be permitted to do so.

Cassandra's attorney filed an appeal to the Connecticut Supreme Court asking the state recognize her as a "mature minor" who can refuse therapy. The family claimed that being forced into treatment was a violation of Cassandra's rights.

Cassandra's cancer returned by 2016, with her lungs full of masses along with her surrounding lung, chest, heart, and neck. By this point, she was older than 18 years and able to refuse treatment, though continued using alternative treatments.

Note. Adapted from Firger (2017).

TABLE 2
LGBTQ Barriers to Care

| Barrier | Elaboration | Example |
|---------------|---|---|
| Perceptual | <p>A. Persons have traditional misperceptions about palliative care and hospice.</p> <p>B. Persons have fears/concerns specific to gender identity, gender expression, or sexual orientation.</p> | <ul style="list-style-type: none"> • If I receive palliative care, my pharmacy benefit will change and I can't have chemotherapy or surgery. • Palliative care is just another term for hospice care. • Hospice is for people with cancer, not people with other illnesses or conditions. • Hospice is a physical facility like a nursing home. • If I'm admitted to hospice, it means I've given up hope. • I will be refused care because of my gender identity, gender expression, or sexual orientation. • I will have to spend my limited time and energy educating my health care providers. • I'll be treated like a pariah or a freak. • I will have to hide evidence of my gender identity or sexual orientation (e.g., photos, books) in my home so that my health care providers won't figure out I'm LGBTQ. • I'll run the risk of being "outed" to my family members. • I will be treated politely enough, but the care I receive won't be the same quality received by others. |
| Financial | <ul style="list-style-type: none"> • The complexity of health care costs, co-pays, and insurance coverage may have lesbian, gay, bisexual, transgender, queer/questioning (LGBTQ) individuals (like their cisgender and heterosexual counterparts) unsure how much out-of-pocket cost would be, or what costs are covered. • For LGBTQ individuals who lack health care insurance, financial concerns will be even more pressing. | <ul style="list-style-type: none"> • Transgender patients receiving hormone therapy may worry that a hospice admission would cause them to lose pharmacy coverage for their hormones. • They may also fear that the hospice wouldn't understand that it's essential that patients remain on hormones for the rest of their life if that's their preference. |
| Institutional | Hospice and palliative care programs may unintentionally erect barriers that prevent LGBTQ individuals from accessing their services. | <p>Realities include:</p> <ul style="list-style-type: none"> • Discriminatory admission and employment policies; • Noninclusive marketing and outreach materials; and • Inadequate orientation and training for health care providers, staff, and volunteers. • Institution's nondiscrimination statement does not include gender identity, gender expression, and sexual orientation. |

Note. Adapted from Acquaviva (2017).

Professional Response to Inclusion and Conflicts of Interest

There has been much recent attention by society to enforce executive orders, state laws, and organizational policies that protect a professional's right to refuse intervention with populations based on conscience objection and choice. However, a majority of these efforts have been overturned and fought. Professional regulations and ethical codes across disciplines set clear guidelines and parameters for what may present as conflicts of interest practices, for example, when a case manager's values and beliefs are inconsistent with those of a client. The onus remains on each individual professional to be alert to and avoid conflicts of interest that interfere with the exercise of their professional discretion and impartial judgment. It becomes the responsibility of practitioners to not reject but rather,

“inform clients when a real or potential conflict of interest arise take reasonable steps to resolve the issue in a manner that makes the clients' interests primary, and protects clients' interests to the greatest extent possible. In some situations, protecting clients'

interests may require termination of the professional relationship with proper referral of the client.”

(National Association of Social Workers, 2017)

A large of body of work now addresses advancing and transforming professional perspectives to account for providing a more universal approach to ensuring empathy and respect for diverse populations, particularly for LGBTQ inclusive hospice and palliative care practices (Acquaviva, 2017). It is vital that health care professionals maintain the highest levels of self-awareness to foster objectivity in every client interaction, as well as minimize the risk(s) of implicit bias. It can become a cultural shift for case managers to acknowledge any presence of bias and strive to treat all persons with equity and fidelity. Fully incorporating inclusivity in one's practices becomes another vein entirely and an important opportunity for professional education and growth. Box 6 provides a seven-step process for hospice and palliative care professionals to use when striving to improve the provision of inclusive, nonjudgmental care when planning, engaging, and reflecting on any client interaction. Although the model was written for the LGBTQ community, there are global themes

BOX 6

Seven-Step Process for Providing Inclusive, Non-judgmental Care in Hospice and Palliative Care

Step 1: Know your clear purpose

Step 2: Know your attitudes and beliefs

Step 3: Know your mitigation plan

Step 4: Know the patient

Step 5: Know your emotions

Step 6: Know your reactions

Step 7: Know your strategy

Note. From Acquaviva (2017).

that make the elements applicable to other cultures and client communities.

The Impact of Value-Based Care

Value-based care has forced fresh conversations and considerations for population-based care, particularly specific to the quality of care rendered at end of life. The industry engages in regular debates to reconcile balancing the costs and value of care versus the volume of that care. Many professionals argue that although a mind-set of *more is better* works in some sectors, it is not always the case in the health care industry. Taking a page from the Triple (or Quadruple) Aim, emphasis should always be on making the best decisions that account for the most appropriate care for the populations at the right time. However, those right “costs” become a matter of individual interpretation. In VBC or any other payment model, practitioners want to provide clients the best chance to do well. But there is an ethical flip side that begs consideration—attention to that care which may not be not beneficial and in fact sometimes is harmful to patients (Schulman, 2019).

Palliative Care

Palliative care’s merit to the VBC equation has also become a strong theme in the literature. The key emphasis on each health care consumer’s treatment priorities, values, and quality of life, plus respecting the natural limits of care, makes palliative care align well with VBC’s goals. The SPARK Program serves as a prime example on why palliative care is viewed as a strong driver of VBC and appears in Box 7.

Palliative care remains an underutilized and often undervalued resource. Although 75% of the states have received a grade of A or B in the quality of their palliative care, the national U.S. grade remains at a concerning B. Quality and access in rural areas remain particularly troubling, with grades of C and D common across a majority of those areas. There

has been steady growth in the overall number of hospital palliative care teams in recent years, though far from the full complement of hospitals and health care organizations. More than 72% of hospitals with 50 or more beds have an active team. Historically, this number has risen significantly since 2001, as shown in Figure 4. The hospitals with facility-based palliative care teams serve approximately 87% of all hospitalized individuals in the United States (Center to Advance Palliative Care, National Palliative Care Research Center, 2019). An interactive map showing individual state rankings appears on the report reference website, which is in the resource list in Box 4.

Hospice

Experts have viewed hospice as the first proven integrated, coordinated care model. Hospice embodies the truest iteration of VBC by encompassing care that is:

- value-based,
- person-centered, and
- meets the unique needs of patients and their families by addressing all aspects of well-being:
 - physical,
 - emotional health,
 - spiritual needs,
 - family support, and
 - patient preferences.

(Banach, 2019)

Yet, despite the clear value of hospice to society, access obstacles abound. Limits to hospice access continue, with entry only during a person’s final 6 months. Pilots continue to explore the benefits of earlier access in ways to ensure more beneficiaries reap true advantage (e.g., Medicare Care Choices Model). Those persons and their support systems who face serious illness deserve care reflective of the program’s original intent, which incorporated value and volume as key attributes. When properly aligned, hospice can ensure a true client-centric care effort.

LEGISLATION

Death with Dignity

The DWD movement has continued to play out across the media. A constant tug-of-war occurs across the U.S. where dedicated laws are passed and then often appealed. My initial article on the end-of-life topic (Fink-Samnick, 2016) was written soon after Brittany Maynard’s tragic story hit social media. The 27-year-old woman was diagnosed with a Stage 3 malignant brain tumor and made the decision to move with her husband from California to Oregon to end her life, under the latter state’s DWD legislation.

BOX 7

SPARK Program: Overview and Outcomes

Program overview

- Operated by the Visiting Nurse Service of New York.
- Established to integrate care management and palliative care to medically and psychosocially complex Medicare members.
- Employ patient-centered interdisciplinary care to
 - increase patient satisfaction and quality of life,
 - increase the completion of advance directives,
 - decrease hospitalizations and ED visits, and
 - offer hospice when appropriate and acceptable to the member.

Eligibility criteria

- Three or more admissions within the past 6 months and/or
- Advanced illness and less than 24 months' life expectancy based on the Palliative Performance Scale and/or
- High symptom burden based on the Edmonton Symptom Assessment Scale and inadequately controlled symptoms of patients who refused hospice
- Consent of member/proxy to enroll in SPARK
- Consent of the primary care physician

Outcomes

- The return on investment (ROI) was 5.1%
- During the 4 years of the program, the net savings exceeded net cost by more than \$350,000.
- As program participation continued, average months of participation per program year increased by an average of 11 months per year.
- With increased duration of participation, average savings per member per month increased by an average of \$216 between years 2 and 4.

Note. From Bernstein and Singh (2019).

Subsequently, Brittany's mother was instrumental in the 2015 passage and 2016 enactment of California's, End of Life Options Act. The law allows terminally ill patients to request aid in dying in certain clearly defined situations but has been the subject of major

scrutiny. Since enactment, the law has been appealed, discontinued, and reenacted, and remains in place at the time of this writing (Death with Dignity, 2019a).

Figure 5 shows the current legal landscape across the United States including those states with a DWD statute and those considering DWD legislation in 2020. Montana remains the only state where DWD is legal by court decision only, meaning the end-of-life option is legal in the state courtesy of a state Supreme Court ruling. When I wrote the initial article, four states had active legislation in place. That number is now at nine states, plus the District of Columbia, and rising. The website for DWD appears in the article resource list, Box 4. The site maintains an interactive map that is updated regularly and includes access to the individual laws.

REIMBURSEMENT CONSIDERATIONS

Medicare Advantage Hospice Carve-In

Through the Value-Based Insurance Design (VBID) Model, the CMS is able to test a variety of complementary Medicare Advantage (MA) health plan innovations. The goal of this effort is to reduce Medicare program expenditures, enhance the quality of care for Medicare beneficiaries, and enhance coordination and efficiency of health care service delivery. The VBID Model contributes to the modernization of MA and tests whether these model components improve health outcomes and lower costs for MA enrollees.

Starting in the 2021 plan year, the Centers for Medicare & Medicaid Innovation (CMMI) will test new waters by expanding their MA VBID model. A large percentage of those MA beneficiaries are dual-eligibles, many who are considered low income. These persons and the MA plans that cover them have

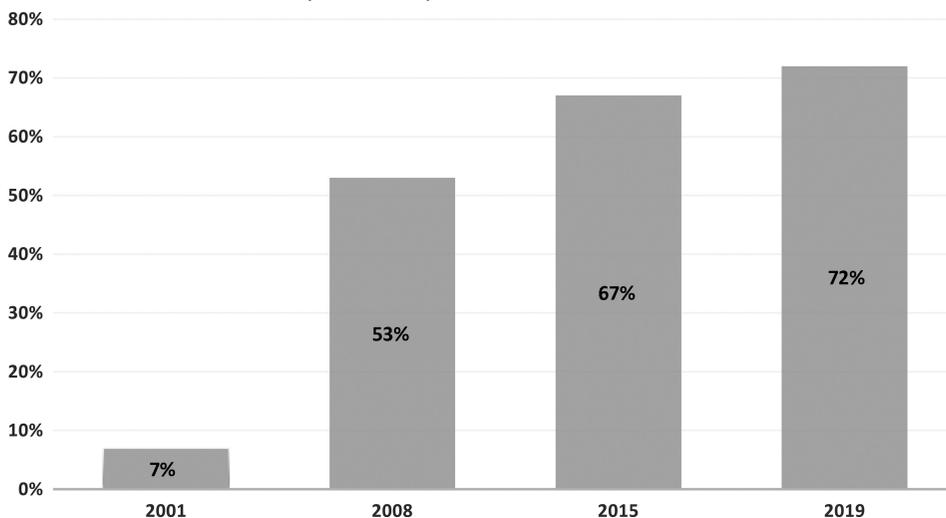


FIGURE 4

Rise in hospital-based palliative care teams in the United States. Data from Center to Advance Palliative Care, National Palliative Care Research Center (2019).

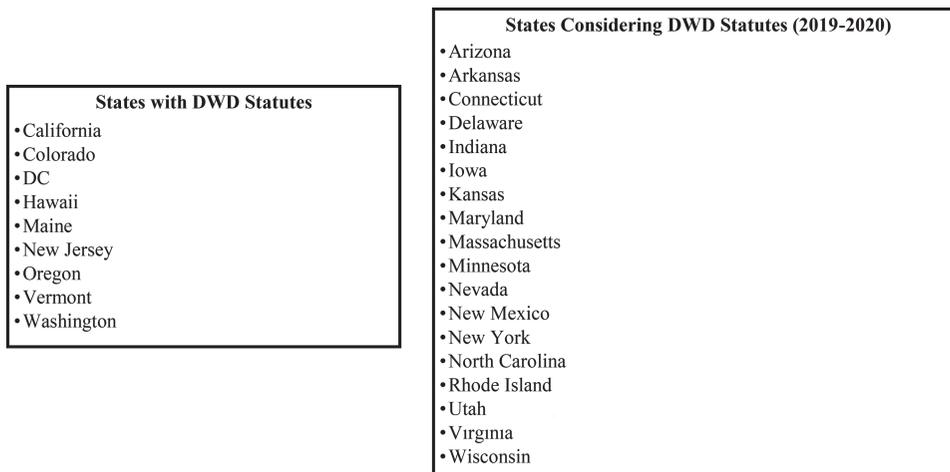


FIGURE 5
Death with Dignity (DWD) statutes across the United States. Data from Death with Dignity (2019b).

received much industry attention for the higher costs incurred for their care and poorer health and mental health outcomes from factors associated with the SDoH. Outcomes for these beneficiaries already reflect:

- increased rates of chronic illness;
- higher rates of hospitalization and hospital readmission;
- emergency department utilization;
- food insufficiency; and
- increased incidence of isolation and behavioral health challenges.

(Gooch, 2018; Thomas et al., 2019)

Currently, all persons using the Medicare hospice benefit are covered under traditional Medicare fee-for-service. Through the present MA model, the CMS contracts with and pays private insurance companies to cover its beneficiaries. When a person using an MA plan enters hospice, his or her coverage reverts to traditional Medicare. The new carve-in is intended to increase a beneficiary's access to hospice services, while facilitating a higher level of care coordination and integration between the person's hospice providers and other clinicians (Centers for Medicare & Medicaid Innovation, 2019a).

Response to the carve-in demonstration has been mixed, with split feedback on the merits of the new VBID hospice model. Reimbursement is a major worry for every health care stakeholder, with concerns on whether the MA plans will reimburse at rates

comparable with the current per diem plans received. Administrative burdens on plans and providers (e.g., paperwork, data collection, claim submission, and regulatory compliance) are another cost factor prompting uneasiness. Instead of current fee-for-service dealings where all stakeholders deal with one intermediary, hospice providers who work with MA plans will juggle with a series of insurers, each with their own processes and requirements. These processes can pose undue pressures on providers, plus costs they are challenging at best to mitigate, as in labor and time (Parker, 2019).

Data collection has become an even more critical mandate in the VBC generation. The CMS requires MA plans collect and submit data on a range of outcomes, among them utilization rates, quality measures, and client encounters. The insurance companies must collect these data from the hospice providers, with each entity having differing requirements. Although implementation details continue to unfold on the VBID Hospice Carve-in, ongoing information can be obtained from the reference source.

UPDATE ON THE MEDICARE CARE CHOICES MODEL

Rationale and History

Section 1115A of the Social Security Act allows CMMI to test innovative payment and service delivery models that have the potential to reduce Medicare, Medicaid, or Children's Health Insurance Program expenditures,

When a person using a Medicare Advantage Plan enters hospice, his or her coverage reverts to traditional Medicare. The new carve-in is intended to increase a beneficiary's access to hospice services, while facilitating a higher level of care coordination and integration between the person's hospice providers and other clinicians.

while maintaining or improving the quality of care for Medicare beneficiaries. With data revealing how less than 50% of all beneficiaries used hospice services, contributing factors were explored and a plan defined to review alternatives to the existing benefit.

The Medicare Care Choices Model (MCCM) was put into place through the CMS on January 1, 2016, and discussed at length in other publications (Fink-Samnack 2016, 2019a). The original 141 hospices participating in the model were randomly assigned to one of two phases. The first 1,000 eligible beneficiaries were enrolled in June of 2017 (Phase 1), with the second cohort (Phase 2) starting January 1, 2018 (Centers for Medicare & Medicaid Services, 2019b).

Target Population and Program Scope

The target population for the MCCM appears in Box 8. As of January 2019, some 85 hospices remained active in the model. The anticipated end date for the project is December 31, 2020. The CMS pays \$400 to participating hospices per beneficiary for each month the beneficiary is enrolled in the MCCM. There is a reduced fee of \$200 in the first month if enrollment is less than 15 days. Providers and any suppliers of services (e.g., durable medical equipment) continue to bill Medicare when furnishing reasonable and necessary services covered by Medicare that is also not covered by the MCCM. Medicare will continue to cover treatment of the beneficiary's terminal condition (Centers for Medicare & Medicaid Services, 2019b).

Current Outcomes

When Cohort 1 approached the end of the Model's second year, approximately 1,325 beneficiaries were enrolled in the MCCM and offered more than 21,149 encounters. Ten percent of beneficiaries approached about the MCCM elected hospice immediately and nearly 80% of those who enrolled in MCCM elected

hospice upon leaving the model (Centers for Medicare & Medicaid Services, 2018).

LEVERAGING FURTHER OPPORTUNITIES

Artificial Intelligence and Algorithms

The Institute of Medicine study, *Dying in America* (2015), identified how a majority of health care consumers seek the guidance of their primary care physicians to know when end-of-life discussions and care are required, with current studies continuing to affirm this data point. This concept presents as antithetical to current care processes, often marked by more proactive efforts to ensure a cost-effective, timely, and quality-driven aim. Any person can be reluctant to bring up their wishes and goals, thinking they are usurping the role of their devoted practitioner, unless they are prompted by a concerned family member or a friend. In the current outpatient setting where the average duration of an appointment with a provider ranges from 13 to 16 minutes (Peckman, 2016, April 1), time becomes the enemy of proactive end-of-life discussions. This finite window leaves little opportunity to engage in any meaningful dialogue to address a topic as serious and multifaceted as care considerations at the end of life.

Although 99% of providers agreed that advance care and end-of-life planning were important to address, only 29% have had dedicated training in this area. Another 95% applaud the CMS reimbursement shift for providers to engage in these discussions, though a surprisingly small number—three out of 10 providers—indicated that their practice included a formal protocol to support their ability to determine patients' end-of-life care wishes (John A. Hartford Foundation, 2017). Several barriers have been identified for decreased utilization of such a critical intervention for sound patient-centered processes. These barriers range from policy-related factors that keep providers from engaging their advanced care planning conversations to technology limitations. Forty percent of providers indicated that their hospital's

BOX 8

Medicare Care Choices Model (MCCM): Target Population and Requirements

Having Medicare Part A and Part B as their primary health insurance for 12 months prior to enrollment in MCCM.

Being diagnosed with (1) advanced cancers; (2) chronic obstructive pulmonary disease; (3) congestive heart failure, or (4) human immunodeficiency virus/acquired immune deficiency syndrome.

Having at least one hospital-based encounter in the last 12 months (emergency department visit, observation stay or admission).

Having at least three office visits (with a Medicare-certified provider for any reason).

Being eligible for the Medicare or Medicaid hospice benefit.

Not having elected the Medicare or Medicaid hospice benefit within the last 30 days before enrolling in the MCCM.

Beneficiaries with hospital, SNF, or inpatient rehabilitation stays in facilities that are not their permanent residence, can be enrolled into the Model after discharge without waiting 30 days.

Note. Adapted from Centers for Medicare & Medicaid Services (2018, January 29)

electronic health record (EHR) system has no place to document whether or not a patient has informed a provider of his or her end-of-life care wishes. Of the 60% of providers who indicate that their EHR provides the advance care planning notes, less than half (31%) are unable to access that section of the record (John A. Hartford Foundation, 2017).

Electronic health record mortality prediction algorithms are viewed as a promising way to enhance care for patient care quality plus palliative and hospice access. A series of new algorithms have been developed to predict and identify better timing for these conversations with client populations. In Canada, studies show that only 15% of Canadians receive palliative care, with attention on developing tools to enhance awareness of the benefits of comfort care at the end of life. In direct response to these low numbers, Ottawa's National Centre for Individualized Health developed the Risk Evaluation for Support: Predictions for Elder-life in the Community Tool. Known by the acronym, RESPECT, the tool was developed and validated using routinely collected, population-level home care data from Ontario, Canada. This process encompassed review of 1.3 million home care assessments that were followed to 80,000 deaths, between the years 2007 and 2014. Some 25 questions were used to calculate survival, with the focus on what diseases the respondents were diagnosed with and how difficult it might be for them to care for themselves (Payne, 2018; ProjectBigLife Canada, 2019).

The PalliativeConnect platform from Penn Medicine has demonstrated success in increasing referrals for individuals to receive palliative care. Initially run as a pilot in 2017, the success of the program prompted expansion. Preliminary pilot results included:

- 51% of high-risk patients who would benefit from advance care planning, died within 6 months of the evaluation.
- 65% died within 18 months of evaluation.
- These numbers are compared with only 4% of low-risk patients—or those patients who would not benefit from or appreciate advance care planning—who died within 6 months of evaluation.

(Courtright et al., 2019; Heath, 2019).

The Dana-Farber Cancer Institute has also introduced a training guide to help doctors and nurses feel more comfortable engaging people in end-of-life care conversations. The guide specifically outlines how to assess a client's understanding of prognosis, values and individual goals, fears and sources of strength, capabilities that are essential to good quality of life, and the types of treatments individuals are willing to endure for more time. Following introduction to the guide, providers engage persons in advance care

planning far earlier than previously completed—on average of 2.4 months earlier than prior to the guide's implementation. Ninety percent of clients discussed their personal care goals and values for the end of life, which in turn improved quality of life and reduced anxiety (Heath, 2019).

ADVANCEMENT OF ETHICS COMMITTEES

Ethics and Bioethics Committees

It would seem that at this point in time, a majority of health care organizations have a functional ethics committee. This mandate of accreditation by The Joint Commission has been in place since 1992, specifically the inclusion of a mechanism to resolve ethical dilemmas in patient care (George & Grodin, 2016). These original "requirements were driven by several situations that involved a lack of clarity between the patient and family wishes, expectations for treatment, the provider's prognosis, and/or the treatment plan" (Fink-Samnack, 2019b, pp. 40). The precedents were set by several legal landmark cases (e.g., Karen Quinlan, Nancy Cruzan) that prompted health care organizations to establish and maintain processes that would acknowledge and support patients' rights in the most ethical manner, extending across all treatment, services, and business practices (McCabe, 2015). Although the exact details of that mechanism are left to the discretion of each organization, there are a series of best practice recommendations posed by experts, included in Table 3.

Despite the presence of industry-accepted guidelines for ethics committees, there is considerable variation on their operations from setting to setting. Among the distinctions include:

- varying perceptions of the right number and composition of members,
- preparation of each member and scope of each member's role, and
- the quality of the work expected.

It can be common to see ethics committees developed without any formal plan, which leads to unfilled expectations, inactivity, and a perception that the committee is not a valued resource (McCabe, 2015). Ethics committees continue to evolve, as does the nature of the situations and conflicts presented for their review and consideration.

A large misperception of the value of ethics committees to health care organizations often lies in understanding their function. It is not the role of an ethics committee to tell clients, caregivers, or colleagues what to do. The traditional (ethics) committee roles addressed the clinical nuances of particular situations, making sure the wishes of each person

TABLE 3**Functions, Scope, and Goals for Health Care Organization Ethics Committees**

| Functions and Scope | Goals |
|-------------------------------|--|
| Consultation | <ul style="list-style-type: none"> • Ensure training and support for committee members and consultants. • Provide consistent subject matter expertise for cases requiring formal ethics evaluation and recommendations. • Develop and implement evaluation metrics to ensure quality improvement and appropriate reports, publications, presentations for both internal personnel and external strategic partners. • Promote ethical leadership behaviors (e.g., explaining the values that underlie decisions, stress the importance of ethics, promote transparency in decision making). |
| Education | <ul style="list-style-type: none"> • Ensure knowledgeable ethics committee members. • Provide relevant education to organization (e.g., trainings, journal articles, reports, literature on professional resources, trainings, and conferences). |
| Policy review and development | <ul style="list-style-type: none"> • Work with organizational leadership to ensure ethics input in relevant situations that impact patient care. • Ensure development of appropriate policies to ensure systems and processes support and do not interfere with ethical practices. |

Note. Adapted from McCabe, M. (2015) and University of Washington School of Medicine (2013).

were acknowledged regarding end-of-life decisions. Particular emphasis was on recognizing the ethical principles of autonomy, beneficence, fidelity, justice, and nonmaleficence. Each of these principles aligned with the concepts of informed consent and the patient's right to refuse care, treatment, and services in accordance with all laws and regulations. In recent years, ethics committees, especially those affiliated with academic institutions and large health care systems have expanded beyond their traditional scope to become more comprehensive ethics programs. There has been expansion of how ethics committees are incorporated into care processes, as consultations in response to nonclinical ethics questions (e.g., ethical constructs around privacy and confidentiality of client information, attention to conflict of interest practices). Many organizations now actively integrate ethics throughout their health care institution operations (e.g., from bedside to the boardroom; University of Washington, 2013).

Ethical Disputes

George and Grodin (2016) discuss how the majority of what are originally perceived as ethical disputes, are more accurately understood as discrepancies in communication, or related group dynamics occurring between the identified patient, family, support system, and/or involved team members. There could be disparities in how the communications or consults by members of the clinical team (e.g., assorted specialists) are heard or understood by those persons involved. The use of standard conflict resolution process can be an asset in these situations, for example, ensuring that there is an opportunity to engage and listen to the patient and his or her family.

The accuracy of this observation is on target. Serving as the chair and cochair of several ethics committees provided this author a unique seat to many of these types of situations. What may have presented to

a practitioner as an ethical dilemma, quickly turned into a simple lack of addressing the client's questions, or an all too brief or unclear conversations among varied parties (e.g., specialists, family members). In the end, conflicting perspectives were usually resolved by an informal discussion involving direct dialogues with the identified parties or between the treatment team. This worked more effectively than needing a more rigorous, emotionally laden, and formal committee meeting.

AN EVER-EVOLVING LIST OF ETHICAL IMPLICATIONS FOR PROFESSIONAL CASE MANAGEMENT

The Four Cs of Care Considerations

The latest wave of trending topics in the end-of-life care realm validates one reality: there will always be potential gaps for case managers to mitigate in the ethical context of client autonomy and choice. Attention to the model, the Four Cs of Client Considerations (Fink-Samnack, 2019b) provides a template for case management professionals to follow. Independent of the situation at hand, primacy to these four key areas ensures proper attention by case managers to legal mandates and ethical requirements defined by the laws, regulations, codes, and standards that guide professional practice, inclusive of a client's:

The latest wave of trending topics in the end-of-life care realm validates one reality: there will always be potential gaps for case managers to mitigate in the ethical context of client autonomy and choice.

Intervening with individual clients, their families, and all other involved stakeholders in the evolving end-of-life arena mandates a keen case management eye to a flurry of factors. Each of these issues intersects with professional case management's ethical principles of autonomy, beneficence, fidelity, justice, and nonmaleficence, as well as veracity. The moving parts of each situation involve opportunities for spirited dialogues among our interprofessional workforce, treatment teams, and other vested stakeholders.

- capacity,
- competence,
- coping, and
- choice.

Figure 6 provides a rendering of the 4 Cs model. Yet, despite this guidance, it can still be a grand challenge for any case manager to accept the lifestyle and treatment choices of every population they are assigned to. There are far too many unique contexts involved in actively assessing each client's situation.

Adherence to client self-determination is a delicate juggling act for the workforce. First comes balancing a client's ability to understand informed consent (capacity) and then fully engage in a decision-making process free of practitioner bias (competence). The client must then demonstrate understanding and adjustment to the information provided (coping) and finally participate in a treatment planning process

with all options presented (choice). There is no doubt that attention to self-determination for populations remains one of the most difficult ethical principles for professionals to reconcile, for it is about what the client wishes as opposed to the well-intended plans of the case manager. Imagine the differing perspectives that manifest across dealings with populations, perhaps altered viewpoints on treatment or discharge planning options, such as whether or not to trial a new medication and endure the side effects, or a person's readiness to define and accept a hospice plan. These events can present as more difficult to reconcile amid a client's poor judgment (e.g., the ability to manage independently at home when not possible or safe) or potentially what presents as an unrealistic view of prognosis.

The professional disciplines that comprise case management's workforce each include an ethical standard, guideline, or code that mandates placing

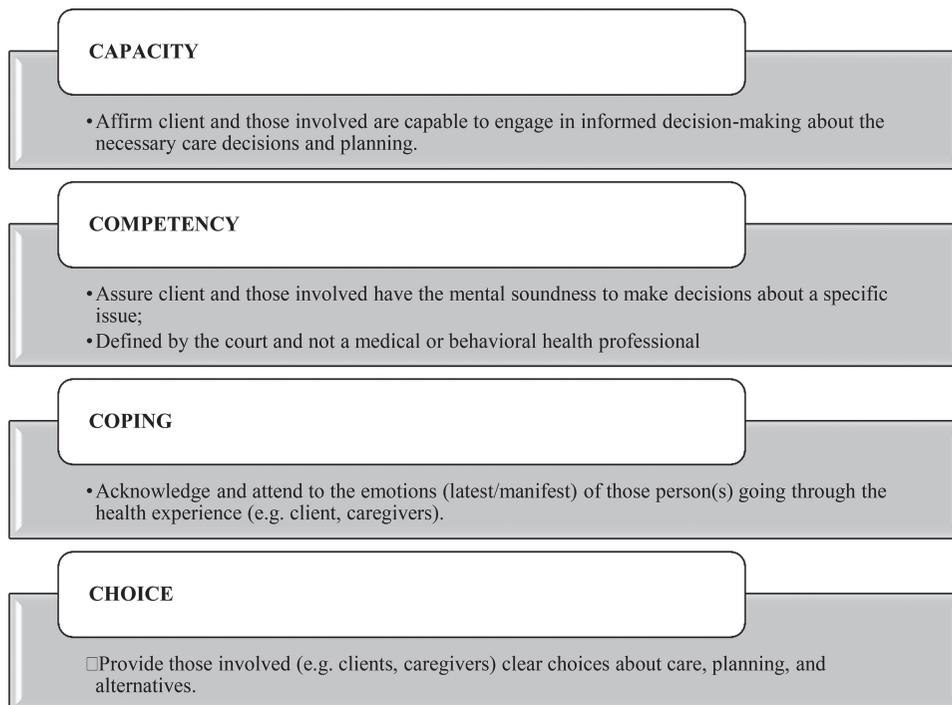


FIGURE 6
The Four Cs of care considerations. Adapted from Fink-Samnick (2019b).

public interests above their own, while equally accounting for integrity and worth of each person (American Medical Association, 2017; American Nurses Association, 2015; Commission for Case Manager Certification, 2015; National Association of Social Workers, 2017). The overriding theme of protecting the public interest is another enduring construct for regulatory, accrediting, and credentialing entities. However, at the end of the day, case managers are beholden to respect the rights and inherent dignity of all of their clients (Commission for Case Manager Certification, 2015).

CONCLUSION

Intervening with individual clients, their families, and all other involved stakeholders in the evolving end-of-life arena mandates a keen case management eye to a flurry of factors. Each of these issues intersects with professional case management's ethical principles of autonomy, beneficence, fidelity, justice, and nonmaleficence, as well as veracity. The moving parts of each situation involve opportunities for spirited dialogues among our interprofessional workforce, treatment teams, and other vested stakeholders. Although a number of issues have been detailed in both this and my original article (Fink-Samnack, 2016), others remain and new ones will unfold. A list of resources is provided in direct response to these changes and is provided in Box 4. "Change is the only constant" remains one of this industry's most reliable mantras. In the context of end-of-life and life-limiting care, the verbiage is especially accurate.

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