

# *Palliative Care and Hospice:* **How Can We Overcome Barriers to Their Use?**

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**W**hen treating older adults in the U.S., especially those nearing end-of-life, palliative and hospice care are some of the best options available — yet they remain underused.<sup>1</sup>

We have roughly 73 million baby boomers in the U.S. today, and many of them have chronic health issues.<sup>2</sup> Yet most patients, and even some clinicians, are seemingly unfamiliar with palliative care and what it could do for them.<sup>3</sup>

And while the general public is relatively more familiar with hospice, that familiarity is often intertwined with falsehoods. In fact, a recent research survey found that 30% of participants thought (albeit incorrectly) that hospice “intentionally hastens death and the dying process.”<sup>4</sup>

In her book *Extreme Measures: Finding A Better Path to the End of Life*, Jessica Nutik Zitter, MD, sums it up nicely: Hospice has a “serious marketing problem.”<sup>5</sup> Indeed it does, and that marketing problem has real-world consequences. People are afraid of what they don’t understand, and this unfamiliarity has led to an avoidance of hospice and palliative care.

Most Americans are generally aware of hospice care, and the majority of them have a positive impression of it. Seven in ten U.S. residents say they have some familiarity regarding hospice care, including about a third who say they know “a lot.” Among those who say they hold some knowledge about hospice, a large majority (85%) say

they have a positive opinion of it, with almost half (47%) saying their opinion is very positive.<sup>6</sup>

Nevertheless, for those Americans who are either uninformed, or misinformed, about hospice and palliative care, the root cause of this issue points to five major factors.

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## **CHALLENGES AND MISPERCEPTIONS**

### **1. Everyone Avoids Addressing Death**

Individuals, families and physicians can all agree on at least one thing: They do not want to discuss death. The reality of death is so daunting, it’s hard to think about or even discuss, and our collective inability to address it only makes embracing palliative and hospice care more difficult because these treatment options require us to face, or at least acknowledge, our own inevitable end. There are efforts to raise public awareness of the importance of planning for these difficult decisions, such as the Conversation Project,<sup>7</sup> and the addition of an advance care planning benefit in Medicare.<sup>8</sup> Unfortunately, the U.S. health care system



hardly makes use of these valuable resources.

In addition, the insurance requirement for two physicians to “certify” that a patient will die in six months is absurd.<sup>9</sup> There is no clinical evidence to support the idea that a physician can accurately predict death six months out. Furthermore, neither physicians nor patients are comfortable with a definitive statement that they will die in six months. Allowing any patient with a terminal diagnosis, regardless of life expectancy, access to hospice would go a long way to addressing this problem.

Unfortunately, Medicare is set up for the six-month requirement because the system deems stays of more than six months as too expensive. Therefore, it targets these stays as fraudulent and an abuse of government funds. But the irony is that the longer a patient stays in hospice, the more money it saves the government. A recent study from the University of Chicago documented that hospice saves Medicare more than \$3.5 billion annually. The longer a patient stays in hospice, the more Medicare saves.<sup>10</sup>

Through new frameworks developed by its piloted Medicare Care Choices Model, the Center for Medicare & Medicaid Innovation is implementing some of the changes to the hospice benefit. The demonstration, which ended in 2021, showed strong results regarding cost savings and patient and family satisfaction among the multiple payment models and demonstrations.<sup>11</sup> However, these compelling results have not yet yielded meaningful Medicare policy changes.

## 2. The Words We Use

Kevin Haselhorst, MD, a retired emergency room physician turned advocate for better end-of-life care, believes the language we use around this care contributes to this misunderstanding. For example, the difference between hospice and palliative care is confusing. Likewise, the terms curative care and comfort care add to the confusion. At a foundational level, curative care aims

to promote recovery from an illness or injury and to cure disease. Comfort care is provided to control pain, alleviate other symptoms and can include greater focus on emotional and spiritual support.<sup>12</sup>

Here’s a straightforward distinction: Hospice is comfort care without curative intent — the patient no longer has curative options or has chosen not to pursue treatment because the side effects outweigh the benefits. Palliative care is comfort care with or without curative intent.

In an attempt to clarify matters, the Center to Advance Palliative Care conducted a survey in 2019 to demonstrate how specific messages and talking points can improve perceptions around palliative care. Some of the statements that scored well focused on improving life expectancy and providing the best quality of life. Similarly, statements about care that is appropriate for any age or provided as an extra layer of support alongside curative treatment were popular with participants.<sup>13</sup>

## 3. Insurance Rules Don’t Align With End-of-Life Care

Generally, insurers do not reimburse for palliative care provided by nonphysicians (the palliative care team consists of several nonphysicians such as nurses, social workers, chaplains and pharmacists). Adding insult to injury, insurers are also stingy in terms of reimbursing the palliative care physicians themselves. Not surprisingly, the outcome of these payment practices is a shortage of palliative care physicians in the U.S.<sup>14</sup>

Insurance rules hurt hospice because patients are required to give up other Medicare-covered treatments for their terminal illness and related conditions in order to access the hospice benefit. Patients are, of course, afraid of death and are reluctant to give up their options for curative treatment. As a result, patients and physicians avoid pursuing hospice until it’s too late — often delaying until a week or two before death — which significantly diminishes the value of



For CHA’s palliative care resources, visit <https://www.chausa.org/palliative/palliative-care>.

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hospice.<sup>15</sup>

Evidence suggests that if these insurance rules were changed, patient care would improve and costs would decline, as exhibited by the Medicare Care Choices Model demonstration mentioned earlier.

### 4. End-of-Life Care Reform Is Ignored

One of the most notable studies in end-of-life care comes from the Institute of Medicine's 2015 report *Dying in America*.<sup>16</sup> Developed by a panel of national experts, the report features one quote in particular that succinctly summarizes their recommendations:

“In the end-of-life arena, there are opportunities for savings by avoiding acute care services that patients and families do not want and that are unlikely to benefit them. The committee that produced this report believes these savings would free up funding for relevant supporting services ... that would ensure a better quality of life for people near the end of life and protect and support their families.”

Modern society has lost its fundamental understanding of death, according to a 2022 study in *The Lancet*.<sup>17</sup> A worldwide commission observed that we need to release ourselves from the expectation that in old age we are obligated to fight against death with all that medicine has to offer. They argue that dying today has become a clinical experience, when not too many decades ago it was a family experience. The commission argues that the dying process should be owned by individuals and families, with support from health professionals, instead of the other way around. They go so far as to suggest that medicine has hijacked the dying process.

Finding ways to implement these wise recommendations will require health system changes.<sup>18</sup>

### 5. Physicians and Their Roles: Rethinking the Care Approach

In my initial pursuit to discover reforms that would improve health care that led to my recent book, I discovered that transformation would

be best achieved by improving end-of-life care. I have spent five years researching why these end-of-life care reform recommendations are not being adopted, with a primary focus on trying to understand why end-of-life care is not improving. One reason is that modern medicine has a serious problem with physician role clarification. For example, what specialist is in charge of discussing end-of-life care with a patient? No one.

For example, if a patient needs to go on dialysis, shouldn't they have a palliative care consultation before the nephrology one? Or, if a patient has challenging cancer, shouldn't the patient have a palliative care consultation? Or, if a patient is in their late 70s or older and is recommended for heart surgery or a pacemaker, would they not benefit from palliative care consultation?

There are some palliative care consultations in inpatient settings. In my experience as a health care executive, these were mainly for patients in intensive care units. But outpatient consultations are rare. This, coupled with the issue of not wanting to address the reality that a patient is dying, results in patients not receiving the full picture of their care choices. It also contributes significantly to fragmented care for older adults.

### WE DON'T WANT TO GIVE UP HOPE

The entire health care system allows everyone to avoid facing the big issue: death.

Here are some examples:

- We train physicians to view death as failure. In his provocative book, *Uncaring*, Dr. Robert Pearl describes the physician culture as follows: “For physicians, saving a life is the highest virtue, while losing a patient is tantamount to failure (even when providing more care would have been futile).”<sup>20</sup>

- We pay physicians for treatments and procedures but do not pay them to talk with their patients or discuss with other physicians about their shared patients. The team approach to palliative care relies on care providers having conversations with patients and one another, but the



health systems' coding does not allow insurance payments for these critical conversations. Palliative care lacks appropriate reimbursement. Fee-for-service medicine poorly compensates non-procedural specialties like palliative care, resulting in poor access and fragmented care.<sup>21</sup>

■ Insurers focus on curative care because they believe health insurance is not intended for comfort care. Therefore, they deem comfort care as not medically necessary. Consequently, insurance companies spend billions of dollars on dialysis, intensive care, transplants and heart procedures, often without questioning whether these measures are considered necessary in cases where a person is near the end of life. However, they seem unwilling to pay for adequate home care, which is less expensive and often more important.

### The fear of death encourages unrealistic expectations — we don't want to give up hope. Yet, realism about the end of life is also important.

■ There are stiff legal penalties for undertreatment, but not for ignoring an advance directive, the legal document with instructions for medical care if a person becomes unable to communicate his or her choices. Accordingly, physicians err on the side of overtreatment.

One observer compared seeking most specialized care for a frail elderly patient as akin to buying a lottery ticket. The fear of death encourages unrealistic expectations — we don't want to give up hope. Yet, realism about the end of life is also important. Both individual initiative and systemic change will be needed to reduce the stigma against palliative and hospice care. This includes building better responses for how, where and when this kind of care is provided and reforming the payment systems behind them.

**MICHAEL CONNELLY** is CEO emeritus of Mercy Health and led the multistate organization from 1995 to 2017. His book *The Journey's End: An Investigation Into Death and Dying in Modern America* provides more analysis of these issues and offers solutions for reform.

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