

VALUE-BASED CARE

Enhancing Quality and Patient Engagement Through Hospice





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The benefits of hospice care are clear: By providing goal-concordant care at the end of life, hospice not only enhances the patient and family experience, but also reduces the provision of burdensome, costly medical treatments that will not extend life. Readmissions may also decrease. The percentage of Medicare beneficiaries who elect hospice care has been increasing gradually – from 44.2% in 2012 to 48.2% in 2017, according to statistics from the National Hospice and Palliative Care Organization. But many eligible patients do not elect hospice or they enroll too late to gain much benefit. In 2017, 28% of Medicare hospice patients died one to seven days after enrollment. This executive dialogue explores the cultural, operational and financial challenges facing hospitals and health systems as they help patients at the end of life choose and transition to the care settings that match their goals.

KEY FINDINGS

- Confusion exists around the type of care hospices will provide, which may contribute to a patient's decision not to elect hospice at the end of life. For instance, many think that patients will have to stop treatments that alleviate symptoms and side effects, such as ACE [angiotensin-converting enzyme] inhibitors for heart failure and radiation for cancer. But this is not necessarily true. It depends on the hospice provider. Medicare allows hospices to provide treatments that improve quality of life, which traditionally may be considered restorative (e.g., physical or occupational therapy, or the use of antibiotics for a infection). Hospices set their own formularies, which may be closed or open.
- The value equation for hospice can become muddled by business considerations under the traditional fee-for-service payment system. The clinical and financial rationales for hospice care are better aligned under value-based payment arrangements, particularly when providers take on financial risk for a patient population.
- A fix-it mentality, or focus on curative treatments over quality of life, may be interfering with providing goal-concordant care to patients at the end of life. One example is sepsis. Care pathways for sepsis emphasize rapid diagnosis and aggressive treatment. But research has revealed that many sepsis patients meet hospice-eligibility eligibility when they are admitted to the hospital. Care pathways need to allow for consideration of a patient's wishes and values based upon prognosis and care goals near the end of life.
- In many hospitals, the end-of-life pathway often begins with palliative care with the expectation that patients will transition to hospice if and when they choose. However, a number of bottlenecks exist in this system. One is helping patients and providers understand what palliative care is and how it can help them. Something as simple as rebranding "palliative care" to "supportive care" helped to increase referrals at MD Anderson Cancer Center.
- Hospice is often an afterthought and needs to be more strongly considered as an option.

 Health care research shows that many patients are dying outside of the Medicare hospice benefit. Often these same patients are contributing to 30-day hospital readmissions. Hospitals and hospice providers should work together to ensure continuation of treatments that can help manage the patients symptoms while keeping reducing likelihood of hospital readmissions. Studies have found that patients who receive hospice post-hospital discharge are less likely to be readmitted to the hospital withing 30 days.

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MODERATOR (Lindsey Dunn Burgstahler, American Hospital Association): **Can you sum up how hospice care improves value?**

BRANDON STOCK (VITAS Healthcare): Hospice increases patient and family satisfaction by helping patients achieve goals related to improving quality of life during the time they have left. There are also significant financial savings for the overall U.S. health care system. As providers in health systems know, really intensive and costly care at the end of life is not going to lead to the patient's desired outcome.

JOSEPH SHEGA, M.D. (VITAS Healthcare): In addition, hospice potentially has a substantial effect on patient and family finances. There are studies that investigate overall health care spend that can be translated into deductibles owned by patients families. But we know that when cancer, heart failure and other diseases reach the end stage, providing expensive, nonbeneficial treatments can substantially impact patient and family finances.

MODERATOR: The goal of providing the right care in the right place at the right time based on patient desires is critical. From the hospital C-suite perspective, what makes

this challenging with regard to hospice?

BRAD JOHNSON (American Association of Critical-Care Nurses): Hospital administrators understand how the acute and post-acute pieces fit together. I think they have understood the life journey of the patient for a long time, and believe in the importance of moving patients along that continuum. The problem lies in aligning the financial mechanics. I was working with a hospital system decades ago that was heavily invested in post-acute care. But the organization couldn't get the business model to work back then. Palliative and

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- Brandon Stock VITAS Healthcare



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post-acute care can be challenging businesses to run from a financial perspective. No matter how well you do, you're always watching the corners.

MODERATOR: A number of hospitals and health systems are beginning to take on financial risk for patient populations. Will these types of value-based payment structures help the business model?

JOHNSON: As we move to a more value-based environment, we hope to better connect the different points of care along the life cycle and really take care of the patient's needs at each point on that continuum. Right now, hospice is too often an afterthought versus an integrated part of the patient's care continuum. I think the reason for that is the financial structures that have existed in health care.

Many current hospital administrators are used to thinking in terms of fee-for-service payments versus value-based population health. This gets in the way of their being able to see the value equation of hospice. They may need help to make that leap. This gets into the need for better partnerships across the continuum of care and across disciplines.

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> - Brad Johnson American Academy of Critical-Care Nurses



stock: Toward that partnership goal, we are evaluating a lot of the new value-based models that the Center for Medicare and Medicaid Innovation is testing to understand how hospice and palliative care can fit into these innovative approaches? We're asking questions such as: What do those models look like from an operational and business model perspective? How can hospice and palliative care align with hospitals, primary care and other providers? And what changes would we have to make to be successful under these models? At the same time, we are hoping to inform partnerships between hospice providers and hospitals by identifying performance metrics that are

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important to our referral sources and community partners. For example, hospice helps decrease hospital re-admissions and overall Medicare spend per beneficiary, while improving the patient and family experience. In addition, we are developing an enterprise data warehouse, which will be a single source of truth about our utilization patterns and other statistics. This is probably one of the largest clinical data sets that exists for patients at the end of life, and we will be able to use that information to glean important insights.

MODERATOR: Many patients – more than 50% of Medicare beneficiaries – don't take advantage of hospice at the end of life. Why is that? And how can we improve utilization?

AJITH NAIR (MD Anderson Cancer Center): I think most important is understanding where the patient is coming from. What is the deep desire, and what goals are the patient trying to achieve? Is he or she looking for a curative mode at the end of life or to improve the quality of life? Understanding the patients will help clinicians and organizations better meet the patients' needs. It also will help to ensure that the appropriate postacute settings can be selected for the patients, based on what they want to achieve.

SHEGA: I agree. But the utilization problem is partially due to patient and family confusion around whether or not to enroll in hospice. Eligibility requirements for Medicare hospice are clear. You can put a box around eligibility: prognosis of six months or less, if the illness runs its normal course. But many patients and families struggle with enrolling in hospice because they think they will have to give up a treatment that helps them. Now I need to distinguish between curative treatments and supportive treatments. To be covered under Medicare hospice benefits, patients have to sign a statement stating that they choose comfort care over care aimed at curing their illnesses.

Comfort care can include supportive treatments that aim to reduce disease symptoms or address short-term infections. These might include antibiotics, IV fluids, total parenteral nutrition, and ACE inhibitors or inotropes (a heart pump medication) for heart failure. From a cancer perspective, it might be hormonal therapy, chemotherapy or radiation intended solely for symptom relief. These treatments can improve quality of life in a patient's final months. Restorative treatments, such as physical and occupational therapy, also can be seen as supportive when they are intended to improve

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quality of life. But there's a lot of confusion because some hospices will not cover some or all supportive treatments. Hospices are paid a daily rate per patient by Medicare. We only get a predetermined amount of money and then we've got to make it work financially.

This is a big barrier. Patients may be on treatments that a hospice will not provide as part of that patient's care plan. Because of this, patients struggle with whether to enroll in hospice. Even a lot of clinicians think that hospices will stop all the supportive medications that patients are on and only give them morphine, etc.

MODERATOR: Can hospice providers decide what types of supportive treatments they provide to patients or does Medicare have regulations around that?

SHEGA: It's up to the hospices. For instance, hospices develop formularies, and then only the medications included in the formulary are provided to patients. In contrast, we have an open formulary. We recognize that supportive treatments can improve quality of life. So, we keep patients on these drugs while they are in hospice. We are a large

organization, providing care to around 19,000 patients every day across 14 states and the District of Columbia. Our size helps us achieve some economies of scale, which helps us cover the cost of an open formulary. As a result, we are able to help many patients that other hospices can't handle. This is something I'm passionate about, and we've worked across the organization to increase the number of patients with complex care plans.

From a financial perspective, this approach may not seem like a beneficial tactic for us. Again, we're paid a daily rate, and treating complex patients tends to cost us more than we are paid by Medicare. But we are approaching this from a value-based perspective. First and foremost, we want to ensure that our patients have the best possible quality of life. At the same time, we are positioning ourselves to be valuable partners to hospitals and health systems as they start to take on risk for patient populations. Under a value-based population health model, referring patients to hospice at the end of life, if that is what they want, can reduce costs of care for a health system. If we can partner with health systems to manage the care of patient populations, then it becomes a win-win for all involved.

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MODERATOR: What is the best way for hospitals to transition patients to hospice as they near the end of life?

NAIR: Many hospitals and health systems have a palliative care service, which provides comfort care and support to patients still receiving curative treatments. But the road between palliative and hospice care can be rough and filled with potholes. Sometimes palliative care doesn't make appropriate referrals to hospice. One challenge is that many patients confuse palliative and hospice care. Patients used to come to us asking: 'Why am I seeing a palliative care specialist? I still have a long way to go from a treatment perspective, right?'

To address this issue, MD Anderson changed the entire branding around palliative care. We now call it supportive care services. We built a clinical service line for supportive care and pulled together a multidisciplinary team, including physicians, nurses, social workers, pharmacists and dieticians. On campus, we have two clinics, designed with a calming ambience. Patients who are being treated for cancer can seek help with symptom management, get rehabilitation and obtain mental health counseling to ensure a strong quality of life and help them stabilize their lives. After we rebranded palliative care, we quickly saw an increase in referrals to supportive care.

MODERATOR: Could increasing the utilization of palliative care (or supportive care) feasibly help transition more patients to hospice at the right time?

NAIR: Our supportive care service helps patients with advance care planning, or thinking about how their disease might progress, so they can make informed choices and preparations. Patient education is critical. From a cancer standpoint, I think we need to offer education to patients before giving

them any treatments unless the patient is unstable. We need to help them understand the difference between treating their disease and managing their quality of life. Probably 85-90% of the fear and anxiety that patients face is tied to not knowing what to expect and then accepting the outcomes. Once that crossover happens, and patients accept that they may not have long to live, then it's a matter of understanding what the patient wants at the end of life and designing appropriate treatment protocols or clinical care pathways to facilitate those desires. Unfortunately, my wife was diagnosed with cancer and, as a caregiver, I was devastated. Everything changed overnight. My boss called me and said, 'More than your wife, it is you who needs to be strong. It is you who needs to be educated.' I had seen the side effects associated with chemotherapy, surgery

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and radiation. So, I started imagining the worst-case scenario and worrying about how I was going to deal with these things. But once I was educated on my wife's treatment regime and I knew what to expect and how to manage those adverse reactions, I felt I was in a better place. My fears were squelched. Now I am empowered to take care of the patient, my wife, rather than going through emotional distress and anxiety and putting my own health at risk.

MODERATOR: Do you think that a fix-it mentality in acute care hospitals might prevent some clinicians from recognizing when their patients would benefit from palliative or hospice care?

SHEGA: Sepsis is one area where hospice can provide great value. During the hospital stay, clinicians are focused on actively diagnosing sepsis and quickly implementing care pathways, which are all targeted toward treatment with a cure in mind. The assumption is that sepsis is fixable, when it is not always.

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A recent JAMA study found that sepsis was the immediate cause of death in 35% of hospital deaths over a two-year period. But most of these deaths were related to other chronic comorbidities and could not have been prevented. The researchers also found that 40% of sepsis patients had met hospice-eligibility guidelines when they arrived at the hospital, so they were already at the end of life.

Care pathways typically don't make those distinctions. They focus on the treatment fixes. But maybe the fix sometimes needs to involve a conversation about what's really happening. 'Mom got sepsis because her COPD is so bad, and it's impacting her in this way and this way.'

There is also a post-sepsis syndrome that many clinicians don't always consider. In this syndrome, there's a marked increased risk of dementia, aspiration and myocardial dysfunction. Functional impairments also occur, making it difficult for patients to perform activities of daily living. The 90-day mortality of post-sepsis syndrome has been reported up to 40%. So, we have many patients who have multiple morbidities and are lucky to survive sepsis at the end of their lives. But then, by 90 days, many of them have passed away. Again, there's nobody really taking a step back at this post-acute care juncture and saying, 'Okay, where is Mom at? What really is the best thing that we can do for her at this point?'

MODERATOR: Do acute care clinicians need help to identify when patients might be hospice-eligible, or likely have six months or fewer to live?

SHEGA: In some cases, they may. Toward this end, we are spending a lot of time pointing out the different trajectories with sepsis: what a healthy person with sepsis looks like, what a person with multiple morbidities and sepsis looks like, and what an end-of-life patient with sepsis looks like. Then we try to tie that back to what the research shows about hospital and post-acute deaths from sepsis. We are trying to get everyone to think somewhat differently about the sepsis care pathway, to incorporate an understanding of the patient's overall medical condition and not simply focus on fixing sepsis.

NAIR: At MD Anderson, our mission is to eliminate cancer. We are partnering with other hospitals and programs nationwide and globally not only to spread our knowledge about cancer, but also to learn from them. At the same time, I have a true passion in understanding how cancer presents itself in advanced

stages so that we can communicate with patients about their prognosis and help them navigate this journey.

JOHNSON: We have to help the nursing staff understand when it's appropriate to help patients move to palliative care and hospice services. Nurses are entrenched in day-to-day care, and they become close to the patients they serve. So, I can understand how that can be a barrier to seeing that patients need services beyond their direct care. At the same time, nurses are fact-driven, research-driven. When we educate them about what the research has shown to work best, then they tend to buy in.

SHEGA: This is where a partnership with a hospice or palliative care provider can make a difference. Hospitals can leverage their partners as a resource to identify when patients would benefit from hospice and for initiating discussions with patients and families about these services. The hospice partner also can help clinicians and other staff to recognize when a hospice referral would be beneficial for patients. This might help to improve care team well-being. Studies show that nurses and physicians feel a lot moral distress when

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> - Joseph Shega, M.D. VITAS Healthcare



they think that patients are receiving care that they don't think is right, such as intensive curative treatments that won't improve their outcomes.

MODERATOR: In a hospital or health system, whose job is it to determine when a patient would benefit from hospice and then talk with the patient and family about hospice?

SHEGA: The approach is specific to the local culture of the health system. The hospice adapts to each local culture to meet the needs of the partner and the patient and family. These teams often feel comfortable engaging in what I'll call end-

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of-life discussions. They might say something like, 'I'm really concerned about how you're doing. I'm worried because you're not responding to these treatments anymore, and I feel as though we're in a different place now. We need to talk about a different type of care that can support you better.' Then the palliative care staff can talk about hospice benefits and provide a list of hospice providers. Some health systems aren't as adept at having these conversations. That's why I say that every health system does it differently and, in a system that has multiple hospitals, each hospital does it differently because it's related to the culture of that hospital. Even within a single hospital, the intensive care unit staff might handle these conversations differently from those in the oncology or pulmonary group.

NAIR: We probably need somebody on the care team who serves in the role of navigator – someone who can connect with the patient and who understands the patient from a cultural, social, emotional and financial standpoint. At the same time, the navigator needs to have enough knowledge of the science of medicine and a good understanding of the patient's medical history and prognosis to be able to

carry out conversations effectively with physicians and intervene on the patient's behalf.

Physicians are trained well from a biology standpoint, but may not be equipped to handle the range of nonmedical challenges that a patient may be facing, including financial and social challenges. In other words, there is the science and the art of medicine, and not all physicians are equipped in the latter.

Caregivers cannot assume the role of navigator because they are emotionally attached to the patient. If family members have differences of opinions about their loved one's care, it becomes a complex situation, creating a lot of emotional distress among those family members and the patient. A navigator-type of position would serve as a facilitator, helping everyone understand each other and remain attuned to the patient's wishes. Having a navigator on the team would allow physicians and nurses to focus on what they do best, and all the other disciplines to carry out their work. Again, a navigator would need to be clinically proficient, emotionally and culturally connected, and have solid communication skills to conduct those tough communications.

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JOHNSON: As we've talked about managing patients and helping them navigate, we've focused a lot on our ability to hand off patients to one another, for instance, handing off acute care patients to hospice care. I'm starting to think that we need to focus more on running the ball down the field together than on patient handoffs. I've been thinking a lot lately that we're not really moving as a team as much as we're tossing the ball to each other from our separate silos. The doctor gives the patient to the nurse for this part, and then the nurse gives the patient to somebody else. Coming back to the navigator idea, I'm wondering if that person needs to serve as a coach of sorts who pulls the team together, rather than pushing us into our own little boxes.

MODERATOR: The AHA Center for Health Innovation is involved in a project called Age-Friendly Health Systems in partnership with the Hartford Foundation. The project is encouraging providers to ask older adults what matters to them so that they can create care plans that reflect their patients' goals. Some providers are looking at having these conversations with patients upstream in the community before they become sick.

Do you think this could make end-of-life conversations easier when the time comes?

JOHNSON: I think it's important to help our entire society start thinking more in terms of true quality of life – which includes the end of a person's life. I know that's not a problem that is easy to solve. It's about trying to shift a norm in our culture.

NAIR: I think you touched on a significant topic: educating the public. When it comes to life-changing situations, including death, an individual's culture, ethnicity, social background and financial situation are relevant to his or her decision-making process. For example, when I reflect on my cultural background, we were told stories that made us think about what to do when faced with a situation in which we would lose our lives. These stories made us think about the critical steps we would need to undertake. I remember one story about a king who had a lot of material wealth. He was arrogant and his behavior invited a curse on him: He was told he was going to die in seven days. He spent the first day struggling with and finally accepting the fact that he would have to leave this plane of existence. Over the next six days, he worked on transforming his life so that he could make a graceful exit.

Death can happen at any time. That is a reality regardless of a person's stage of life. We have to find educational, cultural and other systematic ways to help people think about and accept this ultimate reality. Doing so will reduce the anxiety, depression, fatigue and other emotional reactions patients have when they are diagnosed with a serious medical illness and death is a real possibility.

Talking about and accepting death as a normal part of life is handled better by some families and some cultures than others. For instance, one of my colleagues came in late the other day. When I inquired about why she was late, she told me that she had gone with her family to select their final resting places. Death is a topic that many people fear. But my colleague had involved her young children – a kindergartner, second grader and fourth grader – in these decisions.

So, how can health care organizations educate the public about end-of-life issues and help them to think about what really matters to them throughout their lives, including at the end of life? The current emphasis on population health may help. Many hospitals are looking at improving the health and well-being of their patient populations and communities. Right now, most of this work is focused on preventing and managing chronic diseases like high blood pressure and obesity. But I wonder if these population health efforts also can be expanded to improving the well-being of people who are in the advanced stages of disease. We need to better prepare our communities to face this type of emotional crisis.

MODERATOR: In closing, what is the most important step that hospitals and health systems can take to start increasing appropriate utilization of hospice and palliative care?

SHEGA: Most important is a dedication to the patients – no matter where they are in their life journeys. Hospitals need to be committed to serving patients from birth to death. Setting that standard as the philosophy of your hospital or health system is a powerful message to communicate to patients and families as well as health care professionals. 'Life is a journey. We're never going to abandon you on that journey, and we'll help you through the whole process.' I think that's the way that health system leaders need to describe their relationships to their communities. And they need to develop necessary partnerships with hospice providers to ensure the right care to patients at the end of their lives.



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