5 Things You Need to Know about Hospice and Palliative Care

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Welcome and Introduction
Hello, and thank you for joining this Learning and Action Network presentation on the five things you need to know about hospice and palliative care. My name is Tammy Geltmaker and I am with a Quality Innovation Network, five-state initiative, focused on igniting powerful and sustainable change in healthcare quality. We welcome participants from Alabama, Indiana, Kentucky, Mississippi and Tennessee, as well as other states that may be participating.

We are honored today to have Lori Earnshaw here as our speaker. Dr. Earnshaw attended St. Louis University where she obtained her BA in English, completed Medical School at Southern Illinois University and completed her Residencies in Internal and Palliative Medicine at the University of Louisville. Dr. Earnshaw has been at Hosparus Health since April 2016 and currently serves as Medical Director. In this role, she provides community-based palliative care for patients enrolled in hospice care and in an organization innovative pilot program for home-based palliative and advanced-illness care. She has held leadership positions within the American Academy of Hospice and Palliative Medicine, on the Academic Palliative Medicine committee and served as a chair as the Fellowship Director Special Interest group. She has been active as a volunteer for the American Cancer Society® Action NetworkSM and passionate about improving access to high-quality palliative care. At this time, I would like to turn it over to our speaker, Dr. Lori Earnshaw.

Thank you so much, Tammy. I am really happy to be joining you all today to talk about five things you need to know about hospice and palliative care. I am joining today from Louisville, Kentucky, Home of the Kentucky Derby. Wherever you are, I hope that you find this time together that we are spending very valuable in enhancing your knowledge and awareness of hospice and palliative care.

I wanted to acknowledge there are four kinds of people. I think we all fit in one of these categories: those who have been a caregiver, those who are a caregiver, those who will be a caregiver and those who will need a caregiver. Depending on which kind of person you are and where you are in your lives, despite the difficult topic, I hope whatever you get out of this will empower you in your role as a caregiver or someone who will eventually need to be cared for.

Our objectives today and the five things we need to know are how to define hospice and palliative care. I also want to empower you with the tools to be able to address common misconceptions about hospice and palliative care and the benefits of hospice and palliative care. I think we all need to know how to introduce hospice and palliative care and where to go for more information, so these are things that we will cover today.
The Origins of Hospice
To understand hospice and palliative care the best, we need to talk about the history of hospice and the origins of hospice. Modern hospice started with our founding mother, Dame Cicely Saunders. She spent time with the Irish Sisters of Charity at the St. Joseph's Hospice of the dying. That is where she learned a lot about hospice care and she founded Saint Christopher's Hospice in London in 1967. She developed the practice of pain management that acknowledged that pain is not only physical, that patients who have serious illness and people at the end of their lives actually have total pain. She advocated for an interdisciplinary team approach to patient care.

What is Total Pain?
What is total pain that Dame Cicely was advocating for us to address? Total pain is a holistic view of pain. I think the way we can view it is more than pain, but suffering. Pain cannot only be physical, and that is oftentimes for the medical community hones in on and we have the tools to address pain. Pain is spiritual and emotional and psychosocial. There are financial concerns that arise when someone is seriously ill. Palliative care and hospice care, more specifically, was designed to address the suffering and all of its domains.

Dame Cecily advocated for a change in our philosophy of end-of-life care from the old a view where there is nothing more we can do, to the new view that there is so much more we can do. We have an obligation to serve this patient population and their family.

Hospice in the U.S.
How did hospice come to the United States? The first inpatient hospice program opened in New Haven, Connecticut in 1974 and it was the Dean of the Yale Nursing School, Florence Wald, who proposed to start Hospice, which is still in existence today. Here in Kentucky, Hesperus Health was founded in 1976 and the first hospice in Kentucky and the first pediatric hospice program was the Kourageous Kids program in 1980. Kourageous Kids is still serving patients today.

What is Hospice Care?
If I can give you a definition of hospice care, I think the best definition is hospice care relieves suffering when a cure for an illness is not expected. The focus of hospice is to give treatments and provide treatments and enhance a patient's comfort and their quality of life. Not just the patient, but the patient's family. Care is provided often with physician supervision, but the physician is usually in the background of care.

In keeping with the holistic approach and the attention to total pain that Dame Cecily advocated for, the hospice team is comprised of many different members. It is not just a physician, nurse or nurse practitioner. We work every day with chaplains, social workers, CNAs and volunteers who make up a big part of our care team. Beyond the patient staff, we have bereavement counselors who help the family cope with the loss of their loved ones.
Medicare Hospice Benefit

In 1983, the government said this is a wonderful model of care and we should create a funding mechanism and they developed the Medicare hospice benefit. They were the ones who said we need to pay for this and what patient population are we going to target? They decided they would pay for those who are terminally ill with a prognosis of six months or less. The physician would determine the prognosis. Instead of the usual outpatient hospital skilled nursing facility benefit, the patient would choose their Medicare Hospice benefit.

To empower you to talk about the benefits of hospice, I brought up these bullet points because they address some of the common misconceptions. Patients have the choice to enter or leave hospice care at any time. We need to remember that patients choose this type of care. Patients can choose their existing primary physician or their hospice medical director as their primary physician. Patients don't have to give up the physicians they have already have a relationship with. I think that is another misconception that sometimes prevents patients from wanting hospice care.

Hospice care can be provided anywhere the patient calls some. The hospice can go into homeless shelters to care for patients. The hospice team is more focused on the outpatient setting and not the hospital setting, but hospice team have arrangements with hospitals where the hospice team can be part of the team in a hospital. Hospice care can be provided anywhere. A lot of times I hear, it is not time for hospice, because I still want to be resuscitated when the time comes. That's okay. You don't have to be a DNR or focused entirely on comfort care to receive hospice care. Another thing I mentioned previously was the care for the patient's family extends beyond the patient’s death and there are free bereavement services available for the patient’s family members for 13 months after the patient's death.

Hospice Care is Underutilized

Unfortunately, hospice care is underutilized. Even though it is available for patients to have a prognosis of six months or less, as a physician oftentimes it is difficult to determine if someone has six months or less to live. We aren’t surprised that patients have a short length of stay with hospice. The median length of stay for hospice is unfortunately 11 days and sometimes admissions occur within hours of a patient's death. We aren't giving patients the full impact of what hospice can offer to them and their families.

Here are some statistics. Forty percent of hospice patients die within a week of enrolling. Fifty percent, half of hospice patients, die within 19 days of admission, but they are entitled to six months of hospice care. While 70% of Americans say they preferred to die in home, 70% die in a hospital, nursing home or long-term care facility. While hospice serves a valuable need, we aren't reaching patients soon enough and we aren't reaching enough patients.

Barriers to Hospice Care

I think we have addressed a lot of the barriers. Maybe there are others you have encountered and I'm going to recap some I already mentioned. We talked about the difficulty of physicians
determining life expectancy. Oftentimes this isn't addressed in medical education. I think with palliative care physicians being more involved in curriculum development, in American Medical schools, hopefully we will see this improve. You wouldn't be surprised physician attitudes about death and hospice and societal attitudes are barriers to hospice care. Some treatments are very expensive and hospice is paid a daily rate. That daily rate doesn't always encompass palliative chemotherapy for example. Not all hospice is able to afford treatments that are very expensive. Even as much as they would like to.

**SUPPORT Trial**

How do you serve patients sooner? How do we improve access to this holistic model of care focused on relief Dame Cecily advocated for? There was a study in United States call the support trial and it was a study to understand prognosis and preferences for outcomes and treatment. It investigated the care of seriously ill hospitalized patients. Serious illnesses that showed had about 50% mortality. It was done at five different teaching hospitals. The results were really startling. I'm wondering what you all are surprised about in this next slide.

Of conscious patients who died in the hospital, what percentage would you think has moderate to severe pain at least half of the time? Would it be 5, 15, 25, 50, or 75? Some of you may have chosen 50%, and you would be right. This was one of the many needs the SUPPORT trial uncovered for patients who are seriously ill in the hospital.

Some of the other results that were uncovered in the SUPPORT trial: 38% of patients spent their final ten days of life in the ICU on mechanical ventilation; 49% of patients who had requested a DNR order prior to being admitted to the ICU did not have one at the time of death. This is something that I don’t think that we always include in our decision-making and it is important. Thirty percent of families lost all of their life savings secondary to the high cost of treatment at the end-of-life. If this is treatment patients don't want—and what I hear from many of my patients is that they want to leave a legacy for their families and they want their families to be cared for after they die—then we aren't serving our seriously ill hospitalized patients well and there is a lot of room to improve their care.

What emerged from this SUPPORT trial, and had been brewing for a while—recognizing the barriers to hospice care and the gaps in care that patients were receiving not only in the hospital, but outside the hospital—came along palliative care. Palliative care is specialized medical care for people with serious illness. It focuses on symptomatic relief. It doesn't matter what the diagnosis is. Sometimes people think hospice or palliative care are for patients with cancer for example, but it is for any patient with any serious illness. The goal is to improve quality of life for the patient and the family. It is provided by a team that doesn't replace the patient's existing care team. Palliative care is appropriate at any age and stage in a serious illness. It can be provided together with curative treatment. Those expensive treatments that the patients don't want to forgo, that may actually be focused on improving their quality of life, they don't have to forgo to receive palliative care, because palliative care doesn't have the same restrictions that hospice has under the hospice Medicare benefit.
**Concurrent Palliative Care**
For those of you who are visual learners, this might be helpful in terms of how we frame palliative care versus hospice care. The time is diagnosis of the serious illness, curative intervention and palliative care may be proportionate and may not. Curative interventions might be the purpose of most the care the patient is receiving, but palliative care can be involved, so people can tolerate the side effects of these treatments and they are informed about what to expect and they can help with care planning, for example. Patients move further along as their illness advance, palliative care might be more the focus of care. It doesn't always replace curative care as you can see. Hospice care is care in the last six months of life, and that is ideal. As we know patients don't always get their six months. Hospice is focused on purely palliative treatments, without the expectation of care. After death, the bereavement care happens for survivors.

I think to sum up the difference between hospice and palliative care, I would like to quote the words of Dr. Diane Meier, who is the Director of the Center for Advanced Palliative Care, she sums it up as, “Palliative care is needs-driven. Hospice care is prognosis-driven.”

**Palliative Care Eligibility**
How do you know when someone can benefit from hospice or palliative care? We may intuitively know this, but sometimes it is nice to have a framework to go through a checklist of when your loved one or patient or family member could be eligible.

What are some of the signs that a patient is eligible for palliative care? Increased symptom burden should tip you off to the possibility of palliative care being helpful in improving quality of life. We often see increase in pain, nausea, anxiety, shortness of breath, and fatigue. Fatigue is a symptom that often goes unrecognized in cancer patients but is the number one symptom that cancer patients experience. Decreased appetite and weight loss, as well as cognitive decline are all clues that someone is eligible for palliative care.

When you see more frequent encounters with the healthcare system without a return to baseline, then you should think about palliative care. We see this a lot in patients who have heart failure or COPD. They may go into the hospital more and more frequently because they are having COPD exacerbations or the need for IV diuretics because of heart failure—those are patients that we should think could use palliative care.

A decrease in function is another tip off that someone may be eligible for palliative care, they’re not able to do things that they’re used to, if they need assistive devices to maneuver in their homes, or they need help with meal preparation, those are signs that you may consider palliative care as a need. Lastly, when suffering is not being addressed or not being optimally addressed, and when it negatively impacts their quality of life, those are patients who are eligible for palliative care.
Benefits of Palliative Care
What are the benefits of palliative care? We talked about the definition of hospice care and palliative care and the common misconceptions, as well is the difference between the two. There is a lot of evidence that palliative care has a positive impact on patients and families.

Palliative Care Is What People Want
There was a survey commissioned here in 2011, and they asked the general public what they knew of palliative care. Many people didn't know what palliative care was. When they were told what palliative care was, 95% said we should be educated about that. Ninety-two percent said they would consider palliative care for loved ones if they had a serious illness. Ninety-two percent say it was important for palliative care services to be available at all hospitals. Palliative care was very well received and the people who conducted the survey were amazed at the results in how well received palliative care was.

Palliative Care Improves Quality of Life
There are numerous studies that show patients who receive palliative care have a better quality of life. They have fewer symptoms or less intensity of their symptoms. They don't have as much depression and they have better pain control, and they are more satisfied with their care.

Palliative Care May Increases Life Expectancy
To many people's surprise, there are studies that show that palliative care may actually increase and not shorten life expectancy in certain patients. There was a retrospective review of almost 4,500 Medicare patients. Many had lung cancer or pancreatic cancer. Those with palliative care live longer than those without palliative care. Another study that came out in the New England Journal of Medicine in 2010 showed that palliative care given to patients with metastatic lung cancer in an outpatient clinic had a survival advantage of 2.7 months when compared with standard oncologic care. If palliative care were a pill, we would see ads all over the television for it, like many of our chemotherapies. ENABLE III trial showed improved survival in patients who enrolled earlier in palliative care. We have seen that hospice care usually happens in the last few days or weeks of life, and we have seen that most of these advantages appear when patients enroll earlier, like months earlier.

I think it is summed up beautifully in this quote by Dr. Diane Meier, “perhaps unsurprisingly, reducing patients’ misery may help them live longer”. I think that we often equate palliative care with dying sooner, or maybe those of us in healthcare actually do, but that is not what the evidence suggests and we need to dispel that myth that helping people live better might actually help them live longer.

Having the Conversation
How do you have a conversation about serious illness and end-of-life? This is not something you usually bring up in casual conversation. I wanted to give you some tools about how to discuss topics that will help you understand better what people want as their ending situation.
I don’t know how much you know about advanced care planning and the American population, and I'm wondering what percentage of Americans you think have had discussions about their end-of-life wishes? Ninety-four percent of Americans agree that having a conversation is important, but only one-third of Americans have had that discussion. That discussion is what matters and prepares our loved ones to make decisions when we may not be able to speak for ourselves.

Why don't we have the conversation? I'm sure some of you are thinking about the times you have been in a situation with, perhaps your loved one or in your work. I don't think you would be too surprised about these results. The Conversation Project wanted to figure out the reason why Americans hadn't done advanced care planning. A quarter didn't think it was necessary—I am not sick yet, so why do I need to do that? Twenty percent thought it would upset their loved ones and that it wasn't the right time to have the discussion. Seventeen percent just didn't know how to start that conversation. I think we would all agree, it is never too early to have a conversation, but we are just not having these because of various reasons, and then it is often too late. That is when you're left trying to figure out what a patient would want at the end-of-life or in a situation where there aren't any clear answers.

Why don't we have the conversation? Another Department of Health and Human Services report shows it was difficult to predict the many future scenarios, and then there is also the perception that executing an advanced directive is difficult. They are right. It is just hard and none of us can know how we are going to die, some of us with chronic illness may have a better idea than others, and advanced directive laws vary from state to state. Palliative care serves a vital role in helping people through this process.

Why should we have the conversation? We might think our loved ones know us very well and they know how we would make decisions if something happened, but the evidence suggests otherwise. There was a study in the Archives of Internal Medicine that shows healthcare proxies correctly predicted the end-of-life treatment preferences of their loved ones with only 68% accuracy, so there is the need to have these conversations. Sometimes we think it is not the right time, or I don't want to upset them. The evidence suggests otherwise. Cancer patients who had end-of-life conversations with their physicians were more likely to receive end-of-life care consistent with their preferences and they experienced less physical distress.

Along those same lines, when you look at surrogates of ICU patients, 93% felt that avoiding end-of-life and prognostic discussions was an unacceptable way to maintain hope, and families want to be prepared emotionally and logistically for death. If we don't talk about it, we are depriving them of the opportunity to have discussions and make plans. Having end-of-life conversations does improve the bereavement adjustment of families, so it's not only good for patients, but it is also good for their loved ones.

**When Should We Talk?**

Here are some suggestions that come from the Institute of Medicine. Milestones are always a good time to talk. That might be a graduation, or a marriage, or death of a parent, or when a
loved one is relocated to a nursing home from home. Those are good opportunities, during these transitions, to have a conversation. There also might be specific situations that give you an opportunity to bring up these discussions. Part of routine health maintenance is the time when physicians or your primary care provider can bring these things up. If they don't, we should be empowered to mention we have an advanced directive or we want to know more about filling out the advanced directive and what physicians would recommend. We can be empowered to talk to our physicians about these things.

Another time is when you are initially diagnosed with serious illness. The American Society of Clinical Oncology’s position on comprehensive cancer care by 2020, is that all patients at the time of diagnosis of cancer have access to palliative care. I think they aligned themselves with this opportunity to have the discussion. The diagnosis is a good time to start the conversation.

When there is worsening health and turning points that I mentioned—when the patient with COPD in the hospital for the third or fourth time in a year, or the heart failure patients—those are opportunities to have a discussion. There is something called the surprise question that can help you step back and say, would I be surprised if this person died in the next year? That is a question some clinicians use to give them the opportunity to start these end-of-life conversations.

**How Do You Start?**

How do you start these introductions in bringing up this conversation? You need to reflect on what is motivating you and your goals. Sometimes bringing up a shared death experience is a good place to start, because it makes it more tangible and you can discuss more specifics. You can acknowledge that you are planning for the future, and if you are the one who is going to be making decisions on someone's behalf, it is going to help you and alleviate your stress and make sure that you know what your loved one wants. You can blame it on this talk. You can say I heard this talk from Qsource and it brought up these opportunities to have the conversations about how we want to be cared for at the end-of-life. There are some wonderful voices in popular culture these days. Paul Kalanithi who wrote When Breath Becomes Air, and his widow is speaking all over the country about his book and their experience with his death from cancer; Atul Gawande, who many of you are familiar with, wrote Being Mortal. There are a lot of books and art that can help you start the conversation. There is a Before I Die wall that has been disseminated all over the world and there are many exhibits in different cities in the United States. I would encourage you to use that as a springboard for these discussions.

What are some potential questions to ask to bring this up? These are questions I use for my patients. When you think about the last phase of your life, what do you think would be most important to you? What matters the most to you? What makes your life worth living? What makes you get out of bed in the morning? This gets to quality of life and it is different for every person. What does quality of life mean for you? When you think about your death, what do you hope it will be like? Who would you want to be there and where would you like to be? What concerns do you have about the end of your life? The key is making it open ended and approaching it with curiosity.
Conclusion and Resources

If you would like to look into some tools for how to have advanced care planning discussions, you can go to some of these resources listed—there are many more I’m sure, but these are some that I’m familiar with—The Conversation Starter Kit you can go to The Conversation Project dot Org. The Go-Wish cards are like a deck of playing cards that have different priorities and values that you put in order of priority. I have done that with my husband and we were both surprised of some of the things we learned about each other. The Joint Commission has Speak Up program materials available. There is a Values History or Five Wishes, those are advanced care documents. There is Respecting Choices out of Gundersen Health and they have a framework and an educational program; they talk about advanced care planning for different stages of illness. My Gift of Grace cards and Caring Conversations workbook are all tools you can look for to help you with these discussions.

In conclusion, all patients with serious illness and their families should have access to high-quality palliative care and hospice. I hope you have discovered tools you can use to describe hospice and describe palliative care to patients and their families. To overcome barriers to hospice and palliative care, we need knowledgeable champions and stakeholders that can articulate the definitions of hospice and palliative care benefits, so we can influence patient care, education and payment, as well as policy. Lastly, I think we can all contribute to the societal movement by taking time to have a conversation with our loved ones and we can start at home.

I have included some helpful resources to get more information about some of the things we discussed today. There is also a handout we disseminate at Hosparus Health that has facts about hospice care and they are also helpful as you engage in these discussions.

I want to thank you all for joining us today and thank you for giving me the opportunity to talk about one of my favorite topics, which is hospice and palliative care. Thank you all.

Thank you so much Dr. Earnshaw for this wonderful and very important presentation, and to everyone for joining us today. Please feel welcome to contact us at www.atomalliance.org if you have any questions about what you heard today or if you would like some additional information. Thank you again, and everyone have a great day.