EQUITABLE CARE AT END OF LIFE

Martha L. Twaddle, MD, FACP, FAAHPM, HMDC: I'm Dr. Martha Twaddle, The Waud Family Medical Director of Palliative Medicine & Supportive Care at Northwestern Medicines – North and Northwest Region. And I'm really honored today to bring to you some very important information in the care of our patients, particularly at the end of life, ensuring that care is accessible and equitable as we look at serving really everyone who we are honored to serve throughout their trajectory of care, and particularly at end of life.

A little bit of housekeeping. I have no conflicts of interests or anything to disclose or confess; and, I am, however, one of the folks who writes questions for the LKA and approves those questions, so, there'll be nothing in this presentation that has to do with the exam.

This picture, quite colorful, is not my needlepoint. This is actually what's called a mortality map. And I put it up here really as it is an amazing visual showing incidence of mortality and how it changes over age 0 to typically 100 years or older than 100 years and breaks down for female and male sex and also some of the ethnicities.

What's interesting and important in this slide is, not to spend a lot of time on all the detail, but just to remember always that 100% of our people are going to die. 100% of the patients that we care for are at some point going to be at end of life. And the challenge for many of us, particularly those who do primary care, is we often don't have really the skillset to care for people throughout that entire trajectory; and we feel a lack of confidence as we get to the end of life, and we need help and we do know that care at the end of life is best managed by an interdisciplinary team. But we also know how important it is to engage primary care and treating specialists in that interdisciplinary team, not to lose them in the care of patients.

So, what we're going to talk today about is specialty and generalist level palliative care, why and how? How do we learn? How do we stay engaged irrespective of our degree of training in palliative care? We want to look at ways to create an environment in which there is truly equitable care all the way to the end of life. Describe some of the disparities in the management of pain and symptoms, particularly for those in underserved and rural communities. Look at how these barriers may interfere with access to care, access to pain and symptom management for the patients, and also for those who are providing the care. And some of the evidence-based approaches to facilitate access to care for our patients. There is a very robust bibliography that supports this presentation. And if you're interested in reading more, we can provide you with that bibliography.

So, some folks feel that what's important is that everyone gets the same support, so really equality. So irrespective of what you need, everybody gets the same that's "fair." So that first image on the left shows the visual of equality; and, obviously, giving everyone the same amount sometimes doesn't really provide the benefits needed because some folks need more than others. So, the second little visual is equity, giving folks what they need in order to be able to access. And the third, and this is where we really want to engage all of us in finding solutions, are what are some of the systematic, systemic barriers that exist that really prevent people from accessing the ideal support that they need, the amount that they need, and also at the time that they need it?

Mr. G

So, let's put this in the context of a person, first and foremost. This is a story of, details changed for HIPAA. Mr. G, a 77-year-old Hispanic male. He's been brought to see you by his son Gabriel, and Gabriel has brought his father up from rural Mexico, given concerns around his health and lack of access to effective medical care. Mr. G lived in the States for a number of years. He still has insurance in the US, which can sometimes be an obstacle, but has been living in Mexico with extended family for recent years. What Gabriel has discovered is his dad has lost about 15 pounds over the past three months, and he's been complaining a lot about nausea and pain when he eats. He's bloated. He just feels like he's full all the time, even though he's not taking very much, and especially not enough nutrition.

When you see Mr. G, you're immediately struck that he appears quite chronically ill, and he's got pale conjunctiva, nail beds. His blood pressure is low at 108/60. His pulse is somewhat high for him at 90. His lungs are dull at the bases. His abdomen is tender, not really guarding per se, but it's distended and clearly uncomfortable. And he has some fullness and shifting dullness, and his umbilicus is protuberant. His labs show anemia, elevated liver enzymes. The albumin is only 2.8, and a CT reveals a mass in the tail of the pancreas with ascites, multiple lesions in the liver and lungs.

And as you prepare to sit down with the family to go through this, Gabriel says to you quite emphatically, "Do not talk to my father. Do not tell my dad anything. Talk only with me."

National Consensus Project

So, as we look at these seriously ill scenarios, and I'm using Gabriel's father, Mr. G, as an example, we're going to use the *Clinical Practice Guidelines*, *4th Edition*. They're published on the Web. This is a really rich compendium blueprint, a framework to approach patients and families with advanced serious illness and how best to care for them. And I'll be highlighting several of the domains that this publication describes.

A Tiered Approach to Integration of Palliative Care Support

Now the publication is not intended just for specialty level palliative care. If one is a specialist, like I am, then, of course, we need to be in adherence as much as possible with every aspect of the *Clinical Practice Guidelines*. But these guidelines were actually published with an eye towards improving not just specialty level, not just laying out this blueprint, but really looking at the generalist. All physicians, clinicians will provide care for seriously ill patients and their families, so how do we make sure that they are equipped, and how do we encourage them to create interdisciplinary team models?

I, somewhat ad hoc at times, but integrating different perspectives as generalists because all of us should be engaged in this work and some of us might find it so incredibly fulfilling that they become champions, that they spend extra time, that a significant amount of their work is in caring for those who are seriously ill.

And in my early years, that was true of me. I started off as a primary care internist. I did that for 12 years, and right away I was doing some hospice work at that time. But as palliative care began to grow in the United States, I became engaged in that, even though at that time there was no specialty, actually. I had the joy of helping to create what is now the specialty. So there's this opportunity, if we find that we are particularly fulfilled, find particular meaning in caring for seriously ill people, to improve our understanding, our knowledge, and to have these guidelines work for us.

Palliative Care Practice Guidelines

So, the guidelines are divided into these domains, and we're going to focus especially today on the cultural aspects of care, to start the physical aspects of care as far as symptom management, and some of the issues that arise as patients near the end of life. So, all of these are playing a role in this presentation, but those are areas I'm going to particularly highlight.

DOMAIN 6: Cultural Aspects of Care

And in this case, and as we start off, and thinking about equity, access, and being culturally sensitive. So the Guideline 6 talks about how we seek to respect patients' and families' cultural beliefs, values, their traditional practices, their language, and how they prefer to communicate and build upon this to really create a culture between us of trust and respect and being mindful of our own culture that we bring to the chairside or bedside and how it influences us, what we feel is "the correct way" to be sharing information.

And our Western ethic is that patients should know, and patient autonomy rules the day. But that ethic and that cultural approach is not the same for everyone. There are cultures where family decision-making is really the most important approach. So, first we need to better understand what is family and what is the preferred way that this family – and it may be biologic, it may be chosen – makes decisions when faced with serious news. And how do we best support them, all of them, as we navigate serious illness and all the different ramifications of that, including end of life? There's an aspect of cultural humility. We don't have all the answers, and we are there to learn, and I really look at myself as the student of these situations.

For your patient....

Very important to know and to always remember is that you cannot use retrospective population data, to apply it prospectively to predict the behaviors or outcomes of the person who's sitting in front of you for anything – for response to a medication, for their prognosis. And particularly as we see more and more information being published around cultural diversity and how certain groups of patients may or may not choose to use support, such as hospice, we can't make an assumption just because Mr. G is Hispanic that he is going to do certain things or this is going to be his preference. We can't do that. It's flawed. So, we never assume we know that folks of this culture may more likely choose certain ways of approaching serious illness, but we need to ask.

We need to engage and be humble and really be curious as to how this person and family prefer to make decisions, prefer to understand what's unfolding; and in so doing, taking that really empathetic, humble approach, we are part of the treatment. We are building trust. We are establishing rapport. We are demonstrating that person matters, and how they see their illness and how they live with their illness is really important to us, and respect carries a lot of caring within it.

What must happen first? "How much information do you find helpful?..."

So, the first thing we want to know, we're not sharing anything yet. We aren't talking about the results. We need to understand how Mr. G and his family prefer to make health care decisions. So, the response to Gabriel, as he says, "Don't talk to my dad," is, "You know, I am not compelled to disclose this information to your father. But what I do need is your father's permission to speak with you in exclusion of him. I need his blessing in that." Can even use that word. So sitting down, engaging a professional interpreter, preferably to a language line, particularly for serious illness discussions, and asking what type of information? How do you prefer to make health care decisions? How do you prefer to hear about information from testing, etc.? What is your preference?

"Bad News" "Serious News"

So, the sharing of, some folks call it bad news, other people call it serious news, the definition of that would be anything that alters one's expectations for the future. Changes, what I'd planned for, kind of the neutron bomb effect. Things might look the same, but many things have changed because there is now this very serious connotation or context to my life.

So obviously, the sharing of this information and the information itself will evoke strong emotions. How those emotions manifest will vary. Certain groups of physicians and clinicians have to do this more than others, and we see this also in the emergency departments. And in general, these are not conversations that any clinician really feels enthused about having, and I will share with you that these aren't conversations that I find comfortable. The goal is not that one would be comfortable having these conversations, but one would be confident that you have the tools, you have some of the techniques and verbiage to facilitate these conversations, which are inherently uncomfortable.

So again, the sharing of serious illness, and this will vary greatly, with different cultures and ethnicities, in terms of what might be the emotional response that we would see. When I did overseas work, I was always somewhat taken aback, even a bit rattled by the wailing that would accompany the share. It was not something I was used to; it wasn't part of my cultural upbringing to kind of tear at clothing or to wail and have this real demonstrative response to what this family system was experiencing, this really serious information.

Stop talking....

So, being prepared that there will likely be an emotional response, and that emotional response might not be loud at all. It might be kind of a glazed look that comes over the face of the individual. What's critically important is asking permission to share serious information and finding out, like in Mr. G's case, how much information do you find helpful? How do you want to have that information shared? And in his case, he said. "You know, don't. Don't share that information with me. I don't want to know. Talk to my son, and don't whisper in the hallway."

So, he was very explicit. Some people will tell you that they want to know, but we still need to pace the information because the impact of this information as it sifts through their consciousness and also hits their amygdala may evoke all sorts of responses and really artfully using quiet during this time, which again, is not necessarily comfortable; but one must be confident to don't just do something, sit there. Don't just jump in with, "It's going to be okay," because it may not be, and allowing that person, by watching their face and are they ready? Or perhaps they ask you a question, because if you start to overtalk their emotional response, they will not integrate what it is you're saying to them.

Communicating Serious News

Most patients do want information, and what's interesting is in studies they prefer that bad news is delivered in a positive way. So, what does that mean? Oftentimes that means that serious news is carefully delivered, it's thoughtfully and compassionately delivered, with many reassurance of the engagement of those clinicians that they are there to help. And what I typically say to my patients is, "Look, you're going to write your own story. And I'm not sure what this journey's going to look like, but what I can assure you is you're going to have a team of people around you that care about you and that we will work together for you to live well in the midst of this very serious diagnosis and stay in very tight communication as to how things are going." That sometimes, that reassurance that one is not alone, that people care about them, is really what you want them to walk out of that appointment holding close to understanding.

Cultural Competence & Humility

So, culture impacts decision-making; and again, how we share information is also influenced by our culture and understanding how to best approach folks in this regard is really important. In many cultures, family members make decisions as a group; and in many cultures, interestingly, the patient is not the primary decision-maker. And in Western cultures they are; and if we're not cognizant of that, we can inflict great harm by not respecting how people prefer to have this information shared. So, in our documentation in palliative care, as specialists, we always document the goals of care – what the person's hoping for, what gives life meaning, and we document communication preferences. How much information is helpful? Do they want to engage in truly shared decision-making? Do they prefer not to, and do they want someone with them? And it is not appropriate by any means to inflict information on people if it's not in the way and in the timing that they would like.

Language Barriers

When we are working with folks whose primary language is not ours, it is best practice always to use a professional interpreter or a language line. Family can be used to give us information to a degree when it's not serious news, and sometimes family will interpret for me when it's about symptoms. How are you doing? What's a day like in your life? How is the nausea? That type of thing. Even then, I think periodically, to use a language learner, use an interpreter is really important.

A professional interpreter should always be used when sharing serious news with a family. Family may be quite eloquent in English, if that's how you would be speaking to them. However, they may not think in English; and particularly when confronted with serious illnesses, they're trying to process what's being said, and they're doing translations in their own head. It can be really helpful and much less stressful if one uses an interpreter.

And where I find interpreters particularly helpful is also giving me feedback as to what can be said. Perhaps the way I'm choosing to phrase something is really not culturally appropriate, and they can then adjust to make it more culturally acceptable. So, I really love working with an actual interpreter. It's so much better.

What are the FIRST questions asked?

And the questions asked, first and foremost, is how do you prefer to make decisions about your health care? How much information is helpful for you? Do you like discussion? Do you like articles? Would you just like the Cliffs Notes? How much do you want your family to know? Everyone in your family, or are there spokespeople for your family who should know? Is there anyone you wish to have with you when we're discussing your treatments and results?

And in the event where you are impaired or incapacitated and can't make decisions on your own behalf, who's your champion? Who do you want to speak for you? And that helps you establish a health care power of attorney and get that documented.

Mr. G

So, as I alluded to, Mr. G confirmed that he did not want information, and he was decisional, and he did not want to hear anything about his condition. This is not what he wanted to hear. He wanted me to speak to his son. He wanted his son to understand and make choices on his behalf, and we were not to whisper outside his area of hearing. No whispering in the hallway, which I thought was an interesting directive as well.

Physical Aspects of Care: Symptom Management

So very important as we share information that's a big part of our care, as we communicate and we have these exchanges and to be culturally sensitive, that's a big part of equitable care is tailoring the way we communicate so that it is very much harmonious with the way people want to receive information about their health.

The next aspect is we're going to focus on our physical aspects of care and, in particular, symptom management. And the guidelines speak to how the interdisciplinary team is really involved in symptom management because symptom management isn't just the physical symptoms. It's also the psychological and spiritual existential distress that can arise as a result of a serious illness.

And the goal is to improve physical well-being. The goal is very much to improve the functionality of the person. Are they able to do more? Are they able to participate more in their life and not just report to you that they have no pain but that their quality of life and symptom management is greatly enhanced? And symptoms are associated with a serious illness, but symptoms are also caused by the treatments that we provide. So how do we balance, particularly if care is not going to cure but is truly palliative, how do we balance the symptom burden of some of the treatments that we're recommending so that people can enjoy high function and quality of life?

We are paying attention to the physical, and we're also paying attention to the emotional, spiritual, and cultural aspect and the social determinants around care delivery that will influence how well they can access some of the supports they need with their serious illness.

Effective Symptom Management

Because this this is a challenge. Effective symptom management is very much challenged by health disparities, and these get worse as people get closer to end of life. We've seen very much, like in nursing homes in particular, where they're depending on a racial and ethnic makeup there, maybe less completion of advanced care planning, less discussions and documentation as to what people want. In general, Black patients are less likely to use hospice care. If we look again, these are population studies. We can't predict for your patient of color what's going to happen, but you can know that culturally and ethnically there is a propensity for less access of hospice care; and these folks are more likely then to be hospitalized at end of life. And that may not be fully consistent with what they would prefer. They might want to be home, or it may be what they prefer is to be in the hospital.

...and social determinants

Racial and ethnic minority residents are more likely to experience poor pain and symptom management. The opioid epidemic has very much impacted this in terms of access to good symptom management, and rural communities and communities where the majority of folks are African American or Hispanic may not even have pharmacies that stock adequate opioids or symptom management medications.

So, access to these meds in certain communities, particularly marginalized communities, can be less. I practice in an extremely diverse area of Illinois that has both urban and suburban and rural areas and, interestingly, two suburbs that actually abut one another. There is a 15-year difference in life expectancy, depending on which suburb you're living in – one being an affluent, highly educated area called Lake Forest, and the other right next to it, Waukegan. You'll see a drop-off in life expectancy of 15 years. And then also looking at access to medications and treatments and pharmacies and groceries is absolutely jaw-dropping.

But there are other things that we do within our system of care. Again, it it's not just about giving people what they need. It's there are systemic issues within health care delivery systems that aren't just the health centers but the communities in which those health centers sit and how they engage with their community partners.

And insurance, prior auths put a significant delay on access to these medications. We might prescribe a pain medication for our patient and find that it's either not in the pharmacy or it gets kicked into a prior auth and delays access to the med for several days for a person who is symptomatic. This makes me absolutely enraged. Pharmacies may not stock adequate amounts. We try to kind of send out a test prescription early and say, "Hey, could you get this for our patient? And by the way, they're going to need it and likely more quantity as time goes on." We try to really encourage pharmacies to stock this. Sometimes they reluctantly do so, but the more communication there is, and if we are abiding by guidelines and using one pharmacy, then things can sometimes go a bit smoother.

For family systems, there can be worries if families have individuals within the family system that have substance use disorder that may be actively misusing substances or diverting. There can be tremendous apprehension, fear of regulatory interventions, of police interventions and of misuse, or having meds in the home that could have their family member be further at risk. So, we have to take stock of this. Be engaged in conversations. Is there anything that would make it difficult for you to have these medications? Do you understand what these medications are for and how they are used? And there's always talk with pretty much every patient, <u>don't</u> see the difference between dependence and addiction because that seems to be a common issue that people don't fully understand.

Prognosis

In the back of our mind, as we are caring for our people with serious illness, we're always thinking about what is the prognosis, the prognosis that they might recover, the prognosis that they might live well, the prognosis in terms of time. We're thinking that we're kind of the prophet or sage of what's to come; whether or not we disclose this information is another question.

The Integration of Palliative Care in the entire trajectory of serious illness....

In the ideal model of palliative care support, we are caring for people throughout this trajectory. We're meeting them early enough in their care trajectory that relationships can be established. Communication can be optimized. The sharing of information can really be exemplary versus less so.

And what we're looking to then is this really seamless transition to full support in a hospice-like care setting when things are appropriate. How we navigate this from a communication standpoint varies tremendously. And there are folks who will say, you know, I just am not comfortable with sharing information and certainly sharing information around prognosis.

I love this slide from *The New Yorker* because it really is kind of the slide for palliative care. "There's no easy way I can tell you this, so I'm sending you to someone who can," because information sharing, prognostication are a big part of what we do in our work; but we try to do this within the context of other caring professionals who might have a long-standing relationship with patients and families.

Prognosis

So, prognosis can give a framework around decision-making and help people prioritize how to use their time. It helps with life planning. It helps with prioritizing relationships. I just recently had a very poignant situation with a patient where he had been estranged from his three sons after a divorce more than 50 years prior. He had not spoken to his sons, and when we sat down and talked about his widespread liver cancer, I asked him what's most important. And he said peace and reconciliation, and what was amazing is within a couple of days he was able to connect with his sons, have those conversations. How sad, 50 years, and it was hugely important to him for his life closure. He lived only about a week more after this event.

Not everybody, though, does have that goal. Not everybody wants to talk about it. I think of the Woody Allen quote, "I'm not afraid to die. I just don't want to be there when it happens." So, some people don't want to engage in this information; and, in general, we're not really good at prognostication.

This is a study I actually was a participant in back when Nick Christakis was at University of Chicago, and he looked at 326 patients with cancer who were in hospices in Chicago. And he found that really about 20% of the time accurate in predicting prognosis. Most of the time we overpredicted prognosis.

And, interestingly, even when patients ask, less than 50% would actually provide frank disclosure what they thought the prognosis to be. But one of the really repeated findings of this study, and it's shown up in other research, is that the longer we've had a relationship with a patient, the more likely we are to overestimate their prognosis. So, the closer the relationship, the more likely we are to err on prognostication and typically to overestimate life expectancy versus underestimate.

Prognostication – Hospital PC teams

We get really good when a person's like in the active dying stages and the prognosis is anywhere from less than a day to three days. We're about 85% accurate to say, oh, they're going to die, which is pathetic in many ways. For most of the time, it's almost a 50/50; and that's why it's important not to tell people they have three months or two months. And in large part, because again, those numbers come from retrospective population data that you cannot apply to the person sitting in front of you. You can't anticipate what their story is going to be, but you can give them an idea if they want to know of timing. And we will speak in terms of days to weeks, weeks to months, months to years.

We often say, look, my role, it's difficult at this time to really get a sense of life expectancy. However, my role and the role of my team is to discuss with you when changes happen, what those changes mean, and what decisions might need to be prioritized given those changes and, again, negotiating whether or not that's the approach that a person would want to take.

Prognostication – Would you be surprised if your patient died within the next year?

So knowing that we tend to overestimate this question, Joanne Lynn offered, and has been often used by insurance companies to identify people who are at risk and might need more support, "Would you be surprised if your patient died in the next year?" If you wouldn't be surprised, they likely actually have a prognosis of less than six months, and they're probably eligible for hospice. But they certainly do need more support, and we need to do an assessment as to unmet needs and what the trajectory might look like so that we're making sure that we're aligning care with what is meaningful for that person and their family.

Trajectory - Cancer

So, let's take a look at just how do we prognosticate. Well we prognosticate based on published data around the typical trajectory of certain illnesses, and we use functional data as a big part of that is are they impaired as far as their activities of daily living, their independent activities of daily living? And then we also look at their cognition and, of course, their nutrition.

Cancer in which the hospice benefit was based, important to know, those, when they first define the hospice benefit and Dame Saunders original work in hospice was for cancer patients. And cancer, even today, has a fairly predictable trajectory. Most people remain functional for a period of time. Fairly stable functionality. And in solid tumors, when we see a deterioration in cognitive and nutritional and functional domains, and particularly for those individuals who are no longer receiving disease-altering treatment, their life expectancy is usually three to four months.

So I do a lot of work, probably 90% of my practice is oncology embedded in a cancer center at Northwestern. And what's really been wonderful is that this line, the horizontal line has gotten longer and longer. People live a lot longer with cancer diagnoses than they used to, and they maintain sometimes amazing functionality. But when those changes occur, again, cognitive, nutritional, and further functional deterioration, that's when we really need to be stepping up support, and very much to the degree wanted by this patient and family, planning for what is likely going to happen. And we're planning around death, do they want to be at home? Do they want to use hospice care? What would be worse than death? Some of those conversations absolutely need to happen.

Trajectory – Organ Failure

Most people don't die of cancer, and even with cancer patients, many times they have comorbidities that are as significant or place even more burden of illness on them than their cancer diagnosis. So multi-organ system failure is a huge reason that folks deteriorate and die, even internationally. So, this would be really the combination of cardiac and pulmonary, renal, liver dysfunction. And the care trajectory is that these folks fairly steadily, but really over a period of years become more and more functionally impaired, not over a period of weeks or months, but over years you see functional deterioration and a need for more supports.

And what happens within this too is they begin to be hospitalized, begin to utilize, they're in the emergency department because of an exacerbation of their chronic condition; and we get them back to cruise altitude, unfortunately, not quite as high as they were before until the next hospitalization. And sometimes prognostically, it's really seeing these frequent exacerbations and the fact that these individuals just do not have the resiliency to recover functionally, cognitively, or nutritionally in sufficient amounts in between these episodes of symptom exacerbations or deterioration in their condition. But again, this is spread out over years; and when death happens, it is often very sudden, particularly cardiac. These folks may be quite impaired, but not look much different the day before they died as the day they died. And they looked very much like they did a couple months ago. It's just when death happens, it is sudden; and that can create its own stresses.

Trajectory - Frailty

Frailty is the most robust of what we're seeing emerging as the number one syndrome around end of life, and this gets missed. These are often elderly women, frequently have a comorbidity of dementia, and these folks too have had year years of gradual functional deterioration needing more support, whether or not they have it. And again, with equity, can they get it? Often living within family systems where they're getting a lot of care, but no one can work full time because everybody's taking care of grandma part time.

They gradually deteriorate, and it's very difficult to identify for this group of people when they're terminally ill, and when would they best access hospice care? This is the group of patients who have a long length of stay in hospice and who also tend to be discharged from hospice for extended prognosis because it is so difficult, number one, to measure their decline when they are so impaired; and their decline can be over the context of years.

Proportion of population vs proportion of total preventable spend

What's important for us to recognize, if one of the ethics is justice and distributive justice, is that this population is accounting for a huge amount of utilization and what we call preventable spend within our health care systems. This population is not well-served by the emergency room and hospitalizations. They don't get better. So, we need to be talking and thinking and creating demonstration projects as to how to better support people and their caregivers when this is the issue for them because there really are not good supports within all communities and particularly communities that are marginalized, particularly communities that have less access to health care supports to care for these folks. A lot falls on family, which has tremendous impact for generations.

Prognosis

So, you know, as we as we think about our patient, the person in front of us, as we're thinking about their primary diagnosis of cancer, cardiac, interstitial lung disease. But we're also thinking about these buckets that I've mentioned – nutrition, cognition, function. Function's a big one, and I'll highlight some different tools that measure that, and that we can be using and that we can be documenting over and beyond their vital signs. Look at how many times they've had to go to the emergency department or how many times they've been hospitalized.

Prognostication data points

And other issues also play a role, whether or not they want to continue. What are their preferences and some of the psychological, emotional, and spiritual aspects of care? So, there are data that help us. We can look at different scales, such as their MELD score for liver disease or New York Heart Association. I use that for both pulmonary and heart. The Eastern Cooperative Oncology Group. We use what's called the PPS, the Palliative Performance Status, which also looks at cognition and nutrition.

We look at their BMI, their weight, not real helpful, but somewhat helpful. We look at their median arm circumference because that tells you, even if they're gaining weight, and they're losing muscle mass and that is important. And then capturing their ADLs. How much assistance do they need? Of course, cognition. Unfortunately, it's harder because these both have, the Mini-Mental status, and I think the Mini-Cog now too are copywritten, so, you can't easily just use those things. It's crazy. So how do you best measure cognition and capture that?

Prognosis

Patients don't come with just one problem, and particularly the older they are, the more they seem to accrue a lot of different diseases and diagnoses. And so, there's the additional burdens, not any one comorbidity may be serious in and of itself; but it's serious because it's occurring in combination with many other things. And then what we list are the secondary conditions, conditions that are related to these primary diagnoses, how they're manifesting. So, things like dysphasia and pressure ulcers and recurrent urinary tract infections and shortness of breath and all sorts of different aspects that are caused by the diagnoses that they have.

Prognostic Tools – Advanced Diseases

There are some tools that we can use that are even on the Web that can help us. With my patients with advanced dementia, I like to use the MRI or ADEPT. That's not medical like magnetic resonance imaging. That is the Mortality Risk Index and the ADEPT tool for giving a number. When I'm looking at patients who have advanced dementia, that gives you an idea of how likely they are to succumb to their illness in the next six months. It helps us if we're making referrals to our hospice partners in the community.

This is an area of interesting research. There's things coming out, but at this point, we again, we're still not that much more capable of identifying patients other than putting all this together in aggregate; and our best sense is they are more likely to die than not near ahead or in the next six months, and what supports do they need to have? And then, of course, what kind of supports can we get for them?

Depression and Social Isolation

Key issues as well have to do with depression and social isolation, and I see this obviously a lot. It's sad. COVID made this so much worse. Social isolation. People going literally, one of my patients said to me this week. "I think I go the whole week, and I don't talk to anyone else." So, they're not doing their own grocery shopping. If they're shopping online, they're not having conversations; and they're lonely, and then they don't eat well. And this just causes deterioration in their immune function, and this is an independent risk. Loneliness and social isolation are risk factors for death, and they can be worsened because of access to supports and whether or not those community centers or places to gather are available to certain folks.

Spiritual Beliefs and Prognosis

Spiritual beliefs can help in coping. They also can challenge those of us in health care, particularly patients who are expecting a "miracle." And we always say to them, you know, we hope for that too; and we'll be here to celebrate. And in the meantime, are we able to plan?

It's hard to find that comfortable spot in between our place to work, when folks are very much assuming there's going to be a miracle and they choose a more aggressive approach around their end-of-life care. Those folks, in particular, tend to utilize a great deal up until the very end.

Most studies do show, however, that when folks have rich spiritual life that they tend to navigate serious illness with healthier coping, their families do as well, and that their risk of depression may be reduced again. Just because someone is of a certain spiritual tradition or religious tradition doesn't necessarily say that this is what's going to happen. Same approach is with culture. Same approach as with physical is we need to be engaged and asking questions.

Domain 7: Care of the Patient Nearing the End of Life

So, these all become very, very important as patients near the end of life, and one of the domains of care within the palliative guidelines has to do with caring for patients at the end of life; and this is where we need to bring in our skilled colleagues who do this. That's why I love utilizing my hospice colleagues in the community because this is what they do in helping families navigate this and being there for families even after death.

History of Hospice Care in the US

Hospice started in the US around 1975 through a project at Yale, and it very quickly became a home-based model, a home care model similar to home health. It was piloted by Medicare in 1982 and became Medicare law in 1986, and then commercial insurance started to integrate hospice care in the '90s.

Medicare Hospice Benefit (MHB)

So, hospice is a philosophy and model of care. But what's important to remember is that hospice is also an insurance benefit. And currently there are some endeavors to bring hospice into, if one has Medicare Part C, usually what would happen is that people would then go into traditional Medicare when they chose hospice. What they're looking at is whether or not that provider of Medicare Part C would actually provide the hospice or oversee the hospice care as well. That's still pretty early.

But the conditions of a participation, what regulates and oversees how hospice is delivered is federal law. And so ideally, a hospice is certified by Medicare because that means then they can bill Medicare and receive reimbursement for care, and the how care is to be structured and delivered is laid out in the Code of Federal Regulations. And you can go read it; it's accessible to all of us.

Eligibility requirements § 418.20

And what it says is if one's going to use Medicare for hospice care, there's two things. You have to have Medicare Part A, and you have to be certified as terminally ill. And the definition that Medicare uses, it's not a medical definition. It's the definition that Medicare landed on is terminal illness is defined as a trajectory where a person is more likely to die in the next six months than not die, if this illness follows its typical course. So, it's this prognosis of six months or less if the illness follows its normal course; that's in the law. And again, we have to be able to prognosticate, to the best that we can, prospectively as to who can then be eligible to use this benefit.

What's helpful is that in the 1990s, the benefit was expanded, and one could continue to use the benefit even if one lived longer than six months, so people could be recertified into an unlimited number of subsequent 60-day periods, as long as they are eligible, as long as they are still more likely to die in the months ahead than survive many months.

Since its inception in the late '80s and throughout the '90s and up till now, there has been an increasing utilization of hospice as a benefit beyond just the Caucasian patient cause early on it was primarily used by educated Caucasians. And people of color very rarely used hospice care, which has been a tremendous area of concern. And it's exciting in this data from 2021 to see significant growth in the utilization of the hospice benefit by different ethnicities.

Barriers to Access

Some of this has to do with misunderstanding around what is palliative, what is hospice, just health care literacy in general, a worry of discrimination, of limiting access to care, mistrust, health care coverage, whether or not they have it. What does it look like? Religious activities and how that then also, how does that background speak of palliative care and hospice? And as I mentioned earlier, in non-Hispanic Blacks, the completion of advanced care planning can be much, much less; and that's actually true in Hispanics as a population. And so if they haven't made plans around this, they may not plan for the utilization of hospice.

Lead the conversation with what it provides, not what it's called...

So, what I have found to be the most helpful in approaching people who come from all sorts of walks of life is when I talk about this benefit, if they're eligible and I'm thinking this would be of benefit to them, is I talk about what the benefits are and what the benefit provides before I give it a name. Because if I go in and start talking about hospice, or if I go in and talk about palliative care, people, the label can keep them from listening. So, I start off by explaining the difference between traditional home care, which focuses on rehab, and its short stay and if something happens on Saturday or after hours, you're going to go to the emergency department versus a different home care benefit that Medicare provides that allows 24-hour availability, a nurse who can come to you, provision of medications and oxygen, and durable medical equipment, and how I then feel that that may really benefit them at this stage of their illness that we need this level of support. And it's called hospice care. Have you ever heard of hospice? But starting off with what the benefit is and how it will benefit them before providing the label can be very helpful to the conversation.

Correcting Myths and Misinformation

I have people ask me, could you please make them hospice? Well, no, I don't make people hospice. I can bake cookies, but I can't make somebody hospice.

The other thing that a lot of people don't understand, including providers, is a patient can go in and out of hospice care; and I've had patients get significantly better because of great hospice care, to then be discharged for extended prognosis and actually go back into active treatment modalities if they've gotten that much better. Patients can revoke the benefit. Patients can be discharged during the benefit. That influences how much of each benefit period they have, but remember, hospice is not limited to six months. That people can use the benefit longer.

Proportion of Patients by Length of Service - 2012

When we made this slide, the color went away; but I just want to say that 75% or more of patients use hospice for six months or less and, unfortunately, more than 30% of people still are in hospice less than a month. And for many, it's less than seven days. See that little pie piece there in the upper right corner? That's less than seven days. That's a huge percentage of people still are in hospice just a few days.

Now that may not be a problem if they've had preceding time of support with palliative support. So my patients will say, family members have said to me, "You know, Martha, four years of palliative care and four days of hospice, that's great. It was seamless. I didn't want, I didn't need a whole bunch of hospice time because I had all this quality of life and symptom management and holistic support for literally years prior within interdisciplinary teams." So, I don't know as it's a downside, if indeed, it's preceded by really robust palliative care.

Integrated System of Care

And why this is important is, obviously, in palliative care we're focused on the sickest of the sick, those folks who do have a more limited prognosis or functional impairment, seriously ill. But what we're cognizant of is that they are cared for and loved by the well, or maybe the not so well, the chronically ill; and what happens to them in terms of outcomes very much will influence the health and well-being of those who love and care for them.

Caregiving Increases Mortality

And we just highlight a couple studies very briefly, is that caregiving increases mortality in and of itself in a study of nurses looking at 54,000 nurses. These folks who cared for a spouse, these are trained caregivers. They cared for a spouse more than 9 hours a week. Surprisingly, their risk of MI and death almost doubled for providing that kind of care, even though they were skilled and trained to do so. What's very sobering is irrespective of time spent, if a caregiver perceives that the caregiving is emotionally stressful, it doesn't matter how much time they spend. That in and of itself will increase their relative risk of heart attack and death by almost double.

What about the symptoms of the family members?

As we care for people in this, particularly as end of life looms large, we are thinking of that person; and we're also very much thinking of the family system and the impact of impending loss, anticipatory grief, real grief. Grief doesn't just begin when we lose someone or when we die. Grief occurs throughout as life changes and as we hear serious news and as we change the sense of what the future's going to bring.

And what we do know is that grief and the response to loss and pending and realized has significant impact on caregivers in terms of depression, immune suppression, depression of the caregiver, which could then lead to more morbidity. And sometimes we lose our caregivers before we lose our patients, which can be really stressful.

Family Support

And for those of us doing primary care, where this is particularly important, is we may care for multiple family members; and what we find is, more often than not, families want to know what is going to happen. And when they do know a bit about what's going to unfold, they have more confidence as it unfolds. Bereavement pamphlets, explanation pamphlets – going from my site – which is a little pamphlet, can be helpful. But I also find having these conversations, like I'll say to families, "Would it be helpful if I describe what you may be seeing in the days ahead?" And particularly around breathing, because the way people breathe, and the way they labor with their breath as they get closer to end of life can be very disconcerting to families. They can perceive that the person's short of breath. They can feel short of breath. So, by explaining to them what's happening, to explain to them what cues are that tell you that they're comfortable, that can be very, very helpful to a family.

As Expected Death Approaches

But this is predicated with lots of questions. Is it, would it be helpful if we talked about this? Would it be helpful if we planned for this because what I have discovered in my 30+ years of caring for people seriously ill and at end of life is that there are some family systems where you do not do this. You do not talk about this. Again, so it's not quite my culture or ethic. However, it's about them, so it's not proper to plan while they're alive for when they're dead.

Relief of Symptoms

And that makes it a little more challenging. So, we're creating a safety net even among our team as to how to help them knowing that things may happen more in a crisis state than we would like.

There's still a bit of the myth of the morphine drip, more so with families, I find, than providers of care. Morphine has to have an indication. We don't put everybody on morphine. Morphine doesn't mean you're going to die. And it is really interesting how, you know, do we put them on a drip now? Is it time for a drip? I hear from family even now. How that lives into perpetuity, I don't know. And we don't if there's not a symptom that would be relieved by morphine.

After death occurs...

And at the time of death, our engagement as providers may vary. For some of us in primary care who've cared for patients for a really long time, we might be right in the thick of it and be really a helpful mentor, director of how families navigate this, and just giving them time and space, encouraging them to take time, asking about rituals and things that would be beneficial to them.

Moving the Body

We might be even engaged, and depending on where the person dies and actually the disposition of the remains as it is referred to professionally and whether the body is moved, wrapped, anointed – all these things to be open and curious to lean in to ask, because this is where culturally many different things may influence how a family copes and creating space and opportunity to very much support them in their coping is about equity because if we don't pay attention to this, we could again cause great harm and loss.

Bereavement Care

What our team is actively engaged in always is letters, and whether or not you attend services, that's your choice. Whether you go to a wake, whether you go to a service. Obviously, assisting with the practical matters like death certificates. But what I love to do is to write people and say what their loved one taught me because these are our teachers. How people live and how they die inform us and add to really the group of professors that have influenced us.

Loss, grief for all those who care....

We have to be thoughtful about how this affects us. But if, depending on what kind of work we do, if we're oncologists, if we're cardiologists dealing just with heart failure, we have to realize that frequent loss can cling like bad perfume if we don't attend to and process this loss.

Mindfulness work, and that's a whole discussion in of itself, is very powerful in helping us mitigate compassion fatigue, really also help us process many things; and how we choose to practice mindfulness might be through gardening, might be through exercise, but simply being fully present and thinking about, you know, paying attention to our thoughts. What comes? What's intrusive? What is helpful? And working with that is really, really important to our development of metacognition and to our ability to be resilient in the work we do.

Conclusions

So, in conclusion, and I've kept you long, it's important to remember that everyone, every person we care for, they're going to write their own story and their stories informed on who they are, how they've lived, what they value, who their family is. And so we have an opportunity to be curious and ask open questions to learn more about what their story has been. And as we engage in that work, we become part of that story, which is deeply, deeply gratifying. Understanding, approaching cultural diversity with humility, curiosity, and celebration, it's really wonderful what we learn and grow to appreciate of how families and family systems and certain cultures work with this and support resiliency within it.

Care doesn't stop when direct treatments for diseases are no longer helpful. Care continues. We never stop caring for people. We never have nothing to offer. We always have something to offer people. It just may not be about treating a diagnosis directly but rather supporting and helping a person do well in symptom management and functionally. And that's really important as people get closer to end of life and then expands beyond just the person to their families.

And being tender with ourselves, recognizing that certain deaths, certain losses also really affect us and paying attention to that and how we need to take the time we can. How we choose to cope with really loss, illness, and sense sometimes of could I have done more? And what I tell my colleagues is asking those questions is why you're a really good clinician. It's important to say, could I have done this, could I have done that? But not to ruminate because you did the best you could in the time that you had in the place where you were. And that's what you want to be able to say is I did what I could for this person in a way that helped them. And what is frustrating in our world is seeing how certain systemic barriers prevent us sometimes from doing what we feel was the absolute best for people, and that's what we have to be committed to as health care professionals to always, always address.

Reflections...

So, take some time after this to think about what key areas you want to explore more, you want to learn about more. I encourage you to read the National Consensus Guidelines. It's a great read. It's got some really interesting, thought-provoking approaches; and within it are 45 practice examples of different teams across our country doing palliative care and how they've done it, how they've created teams, and how they've addressed the needs of their community, and it's quite inspiring. That's within the guidelines.

So, thank you very much for spending this time, and I hope that this has been beneficial.

END OF PRESENTATION