



Redefining Cancer Palliative Care

Palliative care is the active holistic care of people across all ages living with a life-limiting illness to live as well as possible, for as long as possible — supporting their physical, emotional, spiritual and social needs. It also aims to improve the lives of the patient's families and their caregivers. Palliative care initially and historically focused on alleviating the relief of suffering at the end of life. However, it is now considered best practice and is increasingly implemented earlier in the trajectory of life-threatening health conditions.. Existing research suggests that palliative care is both effective in reducing symptom burden and improving quality of life, cost-effective and is synonymous with quality of care. We are talking to director of the Symptom Management Service at the UCSF Helen Diller Family Comprehensive Cancer Center and associate director of the UCSF Palliative Care Leadership Center Dr. Mike Rabow about the evolution of cancer palliative care, misconceptions, symptoms management and the multidisciplinary approach that it entails today.

Full Transcript:

Priya Menon: Good morning, everyone and welcome to CureTalks. I'm Priya Menon, your host. Today on CureTalks we are discussing Palliative Care with Dr. Michael Rabow from UCSF Helen Diller Family Comprehensive Cancer Center. Talking to Dr. Rabow on the patient panel, are our Patient Advocates Jeremy Pivor and Dr. Grace Cordovano. And as I was just mentioning we have with us the director of the Symptom Management Service at the UCSF Helen Diller Family Comprehensive Cancer Center and Associate Director of the UCSF Palliative Care Leadership Center, Dr. Michael Rabow. Its such a pleasure to have you with us today Dr. Rabow.

Dr. Michael Rabow: Thank you so much for having me.

Priya Menon: I'm going to jump right into the questions Dr. Rabow. First of all, I would like you to define Palliative Care and then talk about misconceptions, symptoms management and hospice fit into Palliative Care.

Dr. Michael Rabow: Of course. So, the definition of Palliative Care is important because I think across the world there's lots of misunderstanding about what Palliative Care really is and correcting that misunderstanding is one of the first steps for providing good clinical care to people facing serious illness. So, I would define Palliative Care as simply care that's focused on maximizing the quality of life. And important in that definition is the fact that focus of Palliative Care doesn't exclude other things that people might focus on. So, Palliative Care doesn't exclude a focus on attempting to cure an illness. It doesn't exclude a focus on trying to control an illness. It's really that part of care though that is focused on maximizing the quality of life for as long as someone is dealing with the distress of a serious illness. So, it's really a theme of care along with other things, that may be going on things like, compassion or safety or other focuses. The relationship between Palliative Care and other things is important as well. If you can imagine a Venn diagram with the big circle being Palliative Care, care focused on quality of life and dealing with distress. Within that big circle of Palliative Care includes some other particular areas. So, within Palliative Care, some people are actually facing the end of their lives and that, we might call end-of-life care. And that can be a part of Palliative Care but isn't the entirety of Palliative Care. There's lots to Palliative Care that's needed by people who aren't facing the end-of-life. Within the smaller circle of end-of-life care, there is hospice care, which is a type of care for people who are at the end-of-life. Hospice care, I think is the best way to care for people who are facing their dying but it's not the only kind of care that people receive and only a portion of people in the United States for example receive Hospice Care at the end of their life. So, Hospice Care is a very specific type of care for people of end-of-life. Typically, defined as people who are expected to die within six months. There's end-of-life care that might not be through the hospice mechanism. And then there is the



very broad field of Palliative Care that can include care for people facing the end-of-life, but also the mass of people who are facing serious illness and other illnesses that are creating distress.

Priya Menon: So, how does a person get a palliative team together and like even if it's just temporarily for a recovery period of some major treatment modalities?

Dr. Michael Rabow: Yeah, I think that there's two important ways to think about that issue. One is the idea that Palliative Care specialist can be really important, and that care is offered through an interdisciplinary team, a team of providers from different disciplines who are really able to provide comprehensive care. Traditionally in palliative care, those disciplines have included physician, a nurse, a social worker and a chaplain. The four of those folks, plus of course others as needed and relevant would get together to create a team caring for a particular patient in their family. Those folks maybe already part of a Palliative Care service, an existing service that works in the hospital or in clinics or nursing people at home or nursing homes, wherever people are living and that's absolutely the easiest way to get Palliative Care services. It's the way that we have developed and the challenge with that is that there are different levels of penetration of Palliative Care, specialty Palliative Care services across the United States and across the world. And even within specific areas there may be really great access to palliative care. But unfortunately, we know the reality that vast numbers of patients probably the majority of patients in almost every area around the world don't actually have ready access to Specialty Palliative Care. So, the other answer to the question, how do you get a Palliative Care team together, is that you get a team of providers who are focused on quality of life, who are focused on dealing with distress, who are focused on Advanced Care Planning. From The routine processes of care that we have from clinicians who are available to help with this idea that specialty Palliative Care is important and especially important for patients with very complex issues, recalcitrant problems, but that the vast majority of people will be getting kind of care from their routine care providers who are providing some of the most basic elements of Palliative Care Direct symptom management with focus on pain management for instance. And I think that the other big element to Palliative Care is Advanced Care planning the idea of making sure that we all can work with patients and their families, to make sure that their values are able to be respected and their priorities, so that the care that they get is consistent with their wishes. So, I think specialty Palliative Care it is available. We know it's not available in lots of locations in which case primary Palliative Care or basic type of care provided by routine providers who aren't necessarily specialist in palliative care. It's going to be a key for the vast majority of people.

Priya Menon: So, who is responsible for coordinating this Palliative Care team?

Dr. Michael Rabow: Yeah, thank you. It's an important question. I think that if we stay within the sort of formal medical model, it becomes clear that Palliative Care should be orchestrated, coordinated by the routine processes of care that we have, so that if in the care of a particular patient, the primary care of physician is the main person organizing the patient's care and coordinating with consultations and referrals and specialists, that person would be the person who coordinates the care. I think there are situations when Palliative Care becomes the main source of care. I think for much of people's lives Palliative Care is part of their overarching care. But at the end-of-life, in particular, there may be routine providers who step away from the patient's care. Although I don't support that or think that that's a good idea, that maybe the reality in terms of what access people have to various types of care. When end-of-life care and comfort becomes the only focus of care, it may be appropriate for Palliative Care to really be in charge of coordinating the clinical care than patient gets. I think that we have to be flexible and recognize that the right care for any particular patient may be coming from the clinicians who know the patient's best and who the patient's trust most deeply and in many cases that will be long-standing relationships with oncologist or with primary care clinicians and those might be the appropriate people to coordinate care, especially if there are lots of other goals of care being attended to in addition to quality of life and symptom management.

Priya Menon: Before I hand over to Jeremy for his questions. Dr. Rabow, could you talk a little bit and specifically outline what services are offered as part of Palliative Care?

Dr. Michael Rabow: Yeah. So, in some ways I would say not to do a flippancy, but I would say that Palliative



Care services are anything that are necessary or appropriate to help people live better. So, I often say to patients anything that's causing trouble for you is a concern for me. Specifically, and informally in the field of Palliative Care we can think of that two main areas that Palliative Care focuses on; the first one is symptom management essentially just helping people feel better, feel better physically, feel better emotionally, feel better spiritually. So, when we think about symptom management very commonly, we are focused on pain management and other major symptoms including shortness of breath, nausea, insomnia, fatigue. In addition, the approaches biopsychosocial-spiritual ones, so we're focused on all sorts of other symptoms besides just sort of the obvious and visible physical symptomatology, but we're thinking about emotional symptoms like anxiety and depression and we're thinking about spiritual distress, we're thinking about relationship issues. So, symptom management includes all those areas and those are all kind of bread and butter of Palliative Care.

The other major element in addition to symptom management is the issue of Advanced Care Planning. And again, really the goal there being making sure we can as Healthcare Providers to a patient understand what their values are, what their priorities are so that we can help them plan their care to make it consistent with what their wishes are, with what their preferences are. We really want to align care with what patients want. One of the big challenges in the development of Palliative Care has been the reality that much of the time we give patients, the care that we have arranged for them rather than the care that they want and if we actually slow down and stop and find out from patients what's important to them? They may want something very different than what we routinely offer. The best example of that being that at the end-of-life, most patients don't want to die in hospitals or in institutions, but that's where the majority of patients die. So, we are giving people care that they don't necessarily want. And as it turns out there is another important element to this which is that the care that the people want isn't necessarily the most expensive care. A lot of times people want less aggressive curative intervention attempts or management intervention attempts and they want things that maybe even less expensive to provide than what we typically do in terms of hospitalizing patients, putting patients in the ICU and things like that. So, there's every reason to make sure that we're all aligned with what patients preferences are, what their needs are. So, the two major elements of Palliative Care are symptom management and Advanced Care planning.

Priya Menon: Thank you, Dr. Rabow. I'm going to pass it over to our first panelist Jeremy Pivor. Jeremy is a patient Ambassador on Palliative Care for the EndWell Foundation. He also co-moderates in a monthly brain tumor social media Twitter chat and is a regular contributor for CURE magazine. Jeremy was originally diagnosed with brain tumor at the age of 12. So, Jeremy, please ask questions.

Jeremy Pivor: Thank you Priya for having me on the call today. And thank you Dr. Rabow for being here and participate in this discussion. So, I appreciate everything you said and you went a little bit into this but from my experience of being an Advocate as well as a brain tumor patient since I was 12 years old and I spent a couple of years as a medical student actually based at a joint program between UC Berkeley and UCSF. I have seen a lot of times Palliative Care having a lot of stigma because people often associate it as synonymous with hospice and end-of-life and both happening/seeing this with patience, but similarly to the same extent and maybe the reason patients experience this is because of healthcare workers as well, they don't see the distinction between Palliative Care and hospice. So, I'm wondering from your experience how do you shift the language and understanding of Palliative Care away from just hospice and end-of-life among both patients and healthcare workers?

Dr. Michael Rabow: Thank you Jeremy. I really appreciate that question and obviously your perspective on things. I think it is exactly what you just said, which is that you shift the language. The service that I run, the Palliative Care service at the cancer center at UCSF that I developed is Symptom Management Service, and we called it that specifically because we wanted to try to avoid the stigma that people have around hospice and its association that people have between Palliative Care and hospice, but also the stigma that people have around palliative care. So, for many years, I went sort of under the radar in a Cancer Center providing symptom management, essentially a core element of Palliative Care without ever announcing that what we were doing was palliative care. So, in some ways if we could step away from the terminology and really focus on the actual activity or the goal, we will be in much better place to avoid the stigma and allow people to



access the services without getting turned away by a bad name or a difficult terminology.

So, really important way we are sort of stuck with some stigma, we're stuck with misunderstanding and if we can get back to the core and talk about activities, talk about goals, I think that people and Health Care clinicians of patients and families all will be able to agree on the activities that will pursue, for instance, rather than talking about Palliative Care specifically talking about quality of life something that almost everybody can get behind and in a way we need to normalize the goal of quality of life as part of the care that we provide. I think certainly in Cancer Care that has been an unfortunate tradition of suggesting that quality of life and quantity of life are in opposition and that you get to have one or the other. So, you have to take heavy duty chemotherapy that's going to make you feel horrible if you're going to get some benefit treatment in terms of living as long as possible. And the reality is fascinating and super important for us to all recognize which is that in fact, this is a situation of both and rather than either or.

That is what we learned specifically in 2010 from a study done by Jennifer S. Temel was that people actually do the best in the setting of metastatic cancer. Jennifer said in metastatic lung cancer, patients actually do the best in terms of the quality of their life, the control of their symptoms and how long they live when they get a combination of good oncologic care and treatment as well as good Palliative Care. So, we used to sort of think you had to make a decision, a choice between quantity of life and quality of life and in fact, the opposite is true. Is that the best care we can provide for ourselves, for our loved ones, for our patients is a combination of good oncologic care and good Palliative Care. That is having symptoms well controlled, having care consistent with your wishes actually ends up allowing people to live as long as possible. So, in trying to avoid stigma, I think if we can focus on what people's goals are? We can help them achieve that with lots of different services including palliative care.

I do appreciate your point though because one of the things that I hear very often in my Palliative Care practice personally is that people come in to see me for the first time they sort of force themselves to go to Palliative Care even though it carries some stigma in their mind and once they've their first meeting with me, they usually say something like wow, I was really scared about coming here and I wasn't sure about coming here, but actually now that we've met, I really like you you're a nice guy and it seems like this is going to be helpful to me. What most people say once they've gotten into Palliative Care is that they wish they had started it earlier. And so, I think if we can really focus on the actual work that we do symptom management and Advanced Care planning that will do a better job at sort of pulling down some of that stigma. That being said, I want to really put a lot of this responsibility on healthcare workers.

I think that we as healthcare workers really need to force ourselves and our colleagues to educate ourselves, to really not be misunderstood about what Palliative Care is and in our Healthcare Systems we need to normalize Palliative Care. So, I think one of my long-range goals is making Palliative Care something that everybody with serious illness received, meaning not necessarily an extra visit with a Palliative Care specialist but that we build Palliative Care into the routing fabric of hair. We shouldn't have to have a special referral or a special clinic that people go to, to maximize the quality of their life when they're dealing with a serious illness. So, really building in these elements, these routine or primary elements of Palliative Care into the system, I think is the way to normalize this process and really routinize it and make it available to every patient who's dealing with illness. So, everyone needs to know, every healthcare worker needs to know the basics of health, to provide some decent pain management, the basics of having basic Advanced Care planning discussions. And in some ways the real tool of Palliative Care is clear and deep communication and I think that improving communication skills for all providers, for all people who touch patients in some way during their time in Health Care would be really key.

Jeremy Pivor: Yeah, I really appreciate that. And when you're talking about the realization that comes after that first nerve-wracking appointment with Palliative Care and realizing, it's not just hospice it is more than that. I experienced that two years ago when I had my first Palliative Care appointment for my second recurrence of brain tumor and I realized that I had actually been, well my mom and I had been actually doing Palliative Care for me since my first recurrence when I was 12 years old without even realizing that it was Palliative Care. So, transitioning to that, away from just adults what does Palliative Care look like for kids and



then also a bit differently for when you reach that young adult stage of your life.

Dr. Michael Rabow: Yeah. I think that's a really important question and I love your mom's realization that you were doing Palliative Care. I think if we can remember that Palliative Care is sort of what your mom would want for you. Meaning I care is that no one wants people to have undue unnecessary suffering and no one wants their child to experience unnecessary pain. And so, if you focus it from that perspective, I think that's a wonderful way to sort of start to break the stigma. In getting to your question about pediatric Palliative Care and Palliative Care for young adults is really important. I think that Pediatric Palliative Care is more complex and more difficult in many ways and perhaps more important in some ways than adult Palliative Care. Different because there's a recognition of the complexity of developmental issues for children. So, children as they grow obviously understand the world in different ways and in growing ways and adult providers may forget to really pay attention to how someone is understanding their illness, how understanding their symptoms and their goals.

This is not limited to Pediatrics, but I think it's most start in the Pediatric world where you have adult providers who may or may not be aware about where a child is developmenting and how they are understanding their illness. So, I think that the developmental aspect is really key and there's a specialist in the field of pediatric Palliative Care that isn't super common in adult palliative care, which is the child life specialist. A therapist who is specifically expert at helping to understand a child's developmental stage and really helping communicate with them and providing care consistent with their understanding and ability to understand the palliative care. So, I think that child life is an important addition to Pediatric Palliative Care, again when in adult Palliative Care involve child life, it is typically to help the children of adult patients who have serious illness, manage that news and those relationships. I think that in pediatric palliative care, there may be different goals than in some situations of Adult Palliative Care partly because of where kids are at and partly because we recognize the role of family in a different way than we do often with adult patients.

Certainly, in the United States, we are guilty of really thinking about adult patients as autonomous beings, sort of an out-of-context their family, even their culture, ethnicity, race, which of course makes very little sense and is wrong. With kids, I think there is a much more basic routine understanding that they are existing in the context of their family and much more attention to the family as a unit. With young adults obviously, there's this really important transition going on between being a child and being an older adult, where again it can be very different goals, very different understanding. I'll give you one brief story which was a patient on the adult Palliative Care service because he was 21 or 22 years old. So, he was technically an adult in our designation, and we hadn't really started making the distinction of young adults and identifying folks in that age group or developmental group as being different than adults. But when we approached him and described to him all the beautiful things that we had in our Palliative Care Suite in the hospital, we had a bureau that had religious text in it and helpful objects to promote meditation and helpful videos and quite... and sounds, all sort of things that we assumed might be helpful to someone facing serious illness.

He turned to us and said in his language, where is the remote control for the TV? That's all he wanted. Because he wanted to play X-box, he wanted to play video games and that's how he connected to his friends, that's what was meaningful to him, and that's how he spent his time and that's how he got pleasure and joy. For all of us older adults, in that room trying to be helpful it was a wake-up call that we really hadn't leant about who this person is and what he needed to live his life as well as possible. So, I think that is a generic role for people of all different ages but certainly as adult healthcare workers making an effort to provide good care for children and good care for young adults. We have to really go back and understand what it is that the people want and what they define as a high quality of life.

Jeremy Pivor: I appreciate that and my final question, it's broadening out a bit more and my challenge to you is to try to make it concise because I couldn't. But if you could shape the future of palliative care, what would it look like and why?

Dr. Michael Rabow: Sure. So, to make it ultimately concise, I will say it's Palliative Care 2.0. So, Palliative Care 1.0 has been the development of a specialty in Palliative Care, subspecialty in Palliative Care where we



have experts who can provide expert level, specialist level, symptom management and Advanced Care planning using the tools of communication that is specialty level Palliative Care. And as I said earlier, that's all well and good except there aren't enough people to do that. We don't have enough services across the world do that for everybody and clearly you could know that I believe that all patients with serious illness should be getting palliative care. And so, I think the future of Palliative Care is Palliative Care 2.0, which is as I said before really building Palliative Care into the routine processes of care. There should be no health care that does not include elements of Palliative Care as the routine. And in the same way that, we would never think about doing surgery without anesthesia. We should never think about treating people with a serious illness without the basic elements of palliative care, symptom management and Advanced Care planning.

And so that I would care to point out is going to be about having specialty Palliative Care be in the background, to help educate and to be referred to for particularly difficult or complex cases. But the vast majority of patients, I sort of think of this as a 10% 90% rule. So, specialty Palliative Care might do 10% of the care, but primary palliative care, the routine care that all clinicians provide is going to be necessary to provide care for the 90% percent for the vast majority of patients. And so, we're going to have to just build routine symptom management into our workflow. We're going to build all that into our EMR and really just make sure that's the routine that everyone gets a huge shift in many ways. But in other ways that's a little bit of a return back to the history and the origins of health care where in the battle days or the good old days, depending on how you conceive of them, all clinicians had was an effort and ability to try and relieve suffering, to relieve symptoms and to make sure that we understood who our patient was and what they needed. We didn't have all sorts of other treatments that can sort of distract us away from the primary need of making people feel as good as possible and relieve symptoms and make sure of care is consistent with what they want. So, in some ways we're going back to that very ancient element of healers and healing, which is really providing some bearing witness to serious illness and where we can to ameliorate some of the symptoms.

Jeremy Pivor: Well, thank you for that. It was great talking to you Dr. Rabow and thanks Priya for having me.

Dr. Michael Rabow: You as well Jeremy. Thank you for your questions.

Priya Menon: Thanks, Jeremy. Next in the panel we have Dr. Grace Cordovano. Dr. Grace is a champion for Palliative Care to be included earlier in cancer treatment planning paradigms. She amplifies the message that treatment planning must focus on treating the whole person and not just a clinical diagnosis. She's an advocate for leveraging digital technologies to enhance treatment of the whole person in the context of life altering diagnosis as well as for Palliative Care, to be meeting patients where they are. Grace, you can ask your questions.

Dr. Grace Cordovano: Great. Thank you Priya and thank you Dr. Rabow. So, I'm calling in from the northern New Jersey area about a half hour out of Manhattan, which was a Covid-19 hotspot area and I'd love to hear your thoughts on how Covid-19 and this pandemic have impacted palliative care.

Dr. Michael Rabow: Yeah, thank you. And I appreciate what your life has been as a clinician and as a person as well coming out of a hot spot you have been in. I think that one of the major impacts on specialty Palliative Care of the pandemic has been a recognition, that our role which has traditionally been as a consultant. We sort of wait around for a referral from another clinician to say Hey, I've got this patient with serious illness, can you help in terms of palliative care? That doesn't apply in the midst of a pandemic when things get really crazy. When things are overwhelming, we can't wait around for referrals to roll in. Because clinicians get way too busy to stop and think what help do I need, who can I call for help? People are really just trying to do the best they can with an overwhelming clinical situation with people stacked up in the halls and in streets, waiting to be seen for very serious and for some life-threatening conditions.

And so I think one of the recognitions that Palliative Care programs, specifically in the northeast of the United States had was this recognition that you can't wait for a referral, you have to actually go in to the ER and be



present there. It will be helpful to reach out to clinicians and not wait for them to ask for help to be present physically in the ICU and establish routine prophecies. So, you're not dependent on a referral. I think that the other big element is to really think about how we communicate with patients as well as possible and families remotely. And so, there's so much care, the vast majority of care is happening remotely via zoom or other technologies. And so, the question is how we communicate well? I'd said before, that communication is such a central skill of Palliative care. So, how do we adapt that skill to online communication?

Make sure that we're still able to communicate around serious issues with people, have them feel comfortable and have them understand the support that is available remotely. I think that sort of triaging the communication remotely is key and then of course thinking about adjusting Advance Care Planning to focus in on Covid specific Advance Care Planning. Most people don't understand what a ventilator looks like, what it means to be on the ventilator. They don't understand whether or not they'll be able to speak when they are ventilated. So, there's some really basic information that has been missed in our communication around Covid. So, there's lots and lots of new stories about Covid. But I think most people don't really have an understanding about the decisions that they might be asked to make around care in the ICU for instance. And many people don't understand and or are able to predict what it will feel like to be socially, physically distant from family members. If you were going to be in the hospital, but your family member couldn't join you. Will that influence the decisions you make about being in the hospital?

Dr. Grace Cordovano: Thank you. I wanted to ask you a question about how technology can be used? How can we leverage technology to enhance and improve access to palliative care? Are you seeing any improvements? Do you recommend technology? I know that Palliative Care is more of a human touch, high touch situation, but in light of what we're all living through right now, I do think that there could be a benefit to leveraging technology and I'd love to hear your thoughts.

Dr. Michael Rabow: Absolutely. Yeah, I think it's a great question. So, prior to Covid our practice, the Palliative Care practice in the cancer center, we were already doing 50% of our visits via zoom, via telemedicine. Because people come from far away. Some people are close but have to deal with traffic in San Francisco, which can be horrible, and people have to pay for parking. So, there are all sorts of reasons why telemedicine makes really good sense and has the huge benefit of improving access. So, allowing people from all sorts of places and all sorts of levels of resources to be able to access healthcare. So, there's a real advantage of telemedicine that we were starting to use in Palliative Care already. But now with Covid, we essentially switched over to nearly a 100 percent of our business happening remotely and the big advantage of telemedicine, in addition to access, really include an involvement of the family.

So, I have been having the family meetings with 10 or 15 people, calling into a zoom account, to have a meeting in an ICU with a loved one. Whereas in the days prior to the use of technology or the recognition of the benefits of this technology, we used to wait for people to arrive from work who happened to be local, but otherwise we have much less involvement of the family. So, I think that there are some real advantages to technology and clearly having family members be able to zoom-in on an iPad, that ICU provides patients and that ICU doctor, ICU nurse holds up in front of the patient, so that they can see their loved one, is an important adjustment to the difficult realities of physical distancing. That being said for sure that the technology is hard, in the sense that Zoom still has not invented the ability for us to touch each other via zoom. And how we can get better at communicating deep emotions through Zoom, is really going to be key to the future of continuing to using zoom, which we will be using remote technologies and telemedicine over the rest of time. A big jump was Covid in us, realizing that it was possible and sort of outfitting many people with technology. But we have to pay attention to the reality that expressing, understanding, feeling emotion, all of those things are more difficult with zoom. You have to be careful to pay attention to that. And we also absolutely have to remember the digital divide. The fact that many people don't have access to technology or appropriate or sufficient broadband technology. I think that really making sure that equity in the use of telemedicine becomes a major commitment is also really important.

Dr. Grace Cordovano: And I guess one more question be, we talked about the importance of advance directives and this was something that was on high alert in our area with everyone essentially sheltering at



home and now starting to these conversations with loved ones about what their wishes are? And a challenge we found is what do we do with these Advanced directives once they're completed or they're filled out? So, families were being told leave it near your wallet, leave it your pocketbook, just in case. What do you recommend people do with the advance directive, when perhaps they haven't been a patient at the local hospital or they want to send it to their doctor, but their doctor says well, we don't have a place to put it just hang onto that.

Dr. Michael Rabow: Right. So, I do think that one of the ways to address this sort of access to advanced directives is through technology. So, having registries of advance directives within a state or a community, having a registry of post forms another version of a way that people can express their wishes for care at the end-of-life is key. Having access to the advance directive is key because if there's an advanced directive that exists but no one can find it, it's essentially of no use to anyone. And so making sure that our Healthcare Systems in general, are developing or have the ability to keep a repository of advance directives as a routine part of the electronic medical record, as a routine part of the patient's chart is absolutely key. I think that in the end even more important than the paper work is that people have had a chance to think about their wishes and had a chance to discuss it with their family and specifically had a chance to discuss it with someone who they would assign or point as a surrogate decision later.

We know that the written form is important but across the United States and in other places, the most important practical issue is that there is a surrogate decision maker, who could speak on behalf of a patient who loses their ability to communicate to the doctors and nurses in the Healthcare System, of what their wishes are? If the surrogate has had a chance to have those discussions and really understands what the patient's wishes are, they can stand in what's called substituted judgment for the patient. They can essentially stand up on behalf of the patient, even if a form doesn't exist or the format isn't available. So, we should definitely try to make our forms available and electronically is probably the keyway. But more important is that these discussions have been had, including with the surrogate. But then also including the patient's primary care doctor or specialist or nurse, practitioner, other clinicians, so that we can really be in a fiduciary responsibility with patients, as healthcare workers to say, we are going to do the best we can and we have this patient and we actually have some direction from the patient about what they might have wanted in this difficult situation.

Priya Menon: Thank you Grace for those questions. Dr. Rabow, we have some audience questions that we could try and answer before we wrap up for the day. One is, do all cancer centers have formal Palliative Care teams or some do, and some don't? Is it something like if I ask for it my cancer center, they would have?

Dr. Michael Rabow: So, great question. There's been a lot of growth of Palliative Care in Cancer Centers over the last decade. So, at this point most Cancer Centers not all, but most Cancer Centers do have a Palliative Care programs. Almost all large hospitals in the United States have in-patient Palliative Care services and increasingly out-patient Palliative Care services are being developed in Cancer Centers. To be certified by the commission on cancer, you actually do need to have the availability of Palliative Care for your patients, either in-house or by referral. So, essentially the answer to the question is yes, all Cancer Centers should have access to Palliative Care and most of them have it developed within their own systems and coordinated or integrated into their system.

I would add just one point of advocacy which is, if you are in a location that does not have Palliative Care, you should demand it the same way, you would demand that your hospital system has a Coronary Care Unit, in case you have a heart attack. It is as important as other things that we've come to expect as normal and routine in Health Care system in the United States, at least. So increasingly, if you're not seeing Palliative Care or if you don't have easy access to it, you should demand it and I think most really good things in healthcare come actually from the demand of patients and their families.

Priya Menon: Thank you. The next question is what types of Palliative Care services can be offered to someone who's newly diagnosed with cancer. And how do we not make it scary to them the associate Palliative Care with hospice?



Dr. Michael Rabow: Yeah, so I love that question because it really points up the idea about Palliative Care should be starting right from the very beginning of diagnosis of a serious illness. I am really parting to emphasize that Palliative Care is part of routine care of serious illness. It's there from the very beginning and there continuously throughout, so that we don't have to make this big divide that we cross from cured of attempts to comfort only care or Hospice Care. To really recognize that Palliative Care is for the routine care of people with serious illness and as a regular part of care.

So, starting at right in the very beginning helps with that and the other thing that can be very helpful is to make sure that people have access to other people, who have walked this path before them, formal support groups or patient education around illness from other patients. There's no one more trustworthy around some of these most sensitive issues than other people who have gone through it or are facing it themselves. And so, books and videos, in person groups can be very helpful. I think that we all need and deserve a better orientation to what the Journey of serious illness might be for us. What it looks like commonly and that can include some recognition that 'yeah this is hard, It's terribly hard but people can do it, people can get through and people can get help to make it through as well as possible.'

Priya Menon: Thank you Doctor. The next question is how would Palliative Care help prevent infection and internal bleeds due to transplants and blood cancer patients?

Dr. Michael Rabow: So, well prevention of illness is definitely important and there's no better way to prove to control symptoms than to prevent them or to treat them at the source. Palliative Care definitely has to contribute to avoiding unnecessary infections and I think in a general way, although I'm not sure Palliative Care has a specific role around infection control, separate from other health care workers. I do think that Palliative Care has focused us on this idea of really paying attention to the overarching issues that patients face in really comprehensive care, so that we can't really dissect out infection control from symptom management, from cure of disease or attempts to manage disease. And really taking a much more holistic perspective and say, 'yeah, we can treat the disease but if someone has a horrible complication or dies from infection than we really haven't done our job'. So, I think paying attention to that holistic approach is now where palliative care's role lies.

Priya Menon: Doctor, one last question, are Palliative Care services covered by insurance?

Dr. Michael Rabow: So, most of the time they are. So, in the United States a lot of private insurance follows the lead of Medicare. And so what Medicare covers private insurances, often will cover and as a general rule Palliative Care services are covered. And so, that's a very encouraging element to the finances of this. Notably insurers are actually in the lead of wanting to develop comprehensive Palliative Care services because Palliative Care is part of the solution to providing care for populations of patients at reduced costs because Palliative Care helps people find the appropriate place for their goals within the health system. And so, if someone doesn't want to be in the ICU and actually wants to be at home, Palliative Care really can help us. We think that in from an insurance company perspective, if they have global responsibility for finances that actually can help save money. So, Insurers are one of the groups that are actually most supportive of promoting Palliative Care because it's good to care for people and it's good to care for our system.

Priya Menon: Thank you. Dr Rabow. Thank you for that very interesting session that we just had and all the information that you shared is very valuable for people who are listening. Jeremy and Grace, Thanks for participating and for asking all the questions that brought in the patient's perspective to this discussion. So, everybody we all just heard Palliative Care is active holistic care of people across all ages living with a life limiting illness to live as well as possible for as long as possible, supporting physical, emotional, spiritual and social needs. We thank UCSF Helen Diller Family Comprehensive Cancer Center. And the talk will be available on curetalks.com so please visit our website for details on upcoming talks. Thank you everyone. Have a great day.



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