

Dr. Elizabeth Wulff-Burchfield:

Well, thank you all so much. I really appreciate all of your time and attention, and I'm so glad to be able to build on what we just all heard, which is really profound and so important, so, so important to the human experience. So I'm a palliative care physician and a genitourinary medical oncologist at the University of Kansas. For complete disclosure, I am an assistant professor and I aspire to be a full professor one day, but I don't have any... Let's see, don't have any disclosures particularly relevant to this program today.

But first I'd like to just talk about the idea... I'm going to spend some time talking about living well with cancer, and what that means for all parties involved, how to collaborate in achieving that outcome, and why I believe it should be the standard of care. Included in that, we're going to talk about the ways that palliative care as a discipline can help promote that worldview and that approach to care. So first, for context, something that I've reflected on, given that I wear both the hat of palliative care and medical oncologist, are that for most of the human history when medicine was a profession, there were only a couple of outcomes that could come from cancer. And one of those outcomes was that the cancer went away, all the way, and stayed away, and one of them was that the cancer was rapidly fatal. And it really is a very modern experience to be able to live with cancer.

A Very Modern Challenge

- For most of the last century, there were two possible outcomes after a cancer diagnosis, including bladder cancer. Cancer was either
 - ▣ Cured
 - ▣ Rapidly fatal
- Modern treatment techniques have significantly impacted outcomes, but for many cancers, the greatest proportional improvements have been among patients with advanced disease.
- This has created a third outcome in addition to those above:
 - ▣ Living **with** cancer.

Dr. Elizabeth Wulff-Burchfield:

So treatments, there's been such incredible innovation, and continues to be, and will continue to be, incredible innovation with systemic therapies that I have the privilege of prescribing. And a lot of that has happened for persons who have advanced cancer. We do suspect that a lot of those are going to be translated earlier into care. But for right now, a lot of that is happening for individuals whose cancer is not expected to go all the way away. And what this means is that people are able to live with cancer. But this is new, this is really new. And, as many people participating in this webinar could attest to, I think the broader culture, at least in North America, really understands the old, outdated paradigm that people either were cured of their cancer or died from it rapidly.

And I think the idea of living with cancer is not well understood. And while, even though we know that folks who are living with cancer are growing, thankfully, I see that in my clinic every year, that I get to spend more time with my patients, it's clear that we don't really understand as a field, a medical field, and in terms of our resources and research, what people need who are living with cancer, compared to folks who have the other needs. However, one conclusion does seem pretty clear, and that's supposed to be a crystal at the bottom, but it's not the clearest crystal. But what I will say, what is crystal clear, to use this phrase, the quality of individual survivorship when they're living with cancer must be elevated as a co-primary goal with all of their cancer outcomes. So we must consider people living well to be as important as living as long as possible.

So when I think about communication, when it comes to advanced cancer, unpleasant symptoms can go along with cancer, and that's a very common experience for many people. We know from research that a majority of folks who are living with cancer have at least one unpleasant symptom to deal with, and a large minority have more than five that they're carrying with them. Folks who have to be hospitalized have more burden from their symptoms, and generally younger adults tend to report more symptoms than older adults. I can't speak to pediatric patients as well, because I'm an adult oncologist. And even though some younger adults do seem to have a greater symptom burden than older adults, we don't

Modern Challenge, cont.

- The broader culture (including laypeople and many medical professionals) still largely acknowledges the outdated two-outcome paradigm.
- Individuals living with cancer are a large and growing cohort, yet their specific needs are poorly understood relative to those who experience the other two outcomes.
- One thing is clear:
 - ▣ The quality of survivorship among people living with cancer needs to be a shared primary goal with the aim of cancer control.



Cancer, Symptoms, and Quality of Life (QOL)

- Unpleasant symptoms are common in patients diagnosed with cancer, particularly advanced or metastatic cancer.
 - ▣ Up to 61% of patients experience more than 1 unpleasant symptom, and up to 30% experience more than 5
 - ▣ Hospitalized patients with cancer typically experience worse symptoms
 - ▣ Younger adults report more symptom distress than older adults
 - ▣ No clear differences between men and women in symptom reporting

think that there are any clear demonstrated differences between people who identify as women and people who identify as men.

But we also know that these unpleasant symptoms are associated with undesirable outcomes, like worse quality of life, people who are so burdened by their symptoms that they can't get up and do things for themselves and live their life fully, as well as more distress and fear from the people who love them. So essentially, the more symptoms people have, the worse their quality of life is, and the worse it is for the people who love them. And also fear of these symptoms sometimes can be a barrier to people, can prevent people from seeking care for their cancer due to fear that this could happen to them, and kind of that avoidant tendency can take over. So I do feel really compelled to say that everyone who's diagnosed with cancer deserves to live well with cancer. And a really important way to help accomplish that is to avoid symptoms, to mitigate symptoms that might go along with the cancer or the treatment.

Dr. Elizabeth Wulff-Burchfield:

So in terms of us thinking about quality of life, when it comes to research, and even, to some degree, clinical practice, clinicians and researchers have some more technical ways to go about assessing quality of life for the people on the other side of our stethoscope. However, for the person who's receiving the care, they don't need to follow... Someone in that circumstance, most of the time, is not going to need to complete a questionnaire to understand how their quality of life is every day. But it's a nebulous concept. Some people feel really comfortable assessing themselves and trying to take their own temperature and think, "Well, how is my life?" But I think sometimes that's challenging for folks, especially those who have lived their life in such a way that they were taught to, and praised for, and have succeeded by pushing through things, forcing their way through pain or sickness and things like that in the past. It can be really uncomfortable for folks who've lived that way to stop, and pause, and take an inventory.

So a few questions that I think are important to consider when assessing one's quality of life are things like, "Are you having more good days than bad days? Or do the bad outnumber the good?" And furthermore, "Is there a trend? Did you start with more good than bad, and now it's the converse?" I think that's an important question. Another set of questions I like to learn about folks is what sort of activities, interactions, what sort of ways bring you joy, fill your cup? And are there things getting in the way of you doing those things? So if someone really likes to work on model trains, does pain get in the way with that? Does fatigue get in the way with that? Same thing could be if someone has friends or family they want to spend time with, do they have the energy to be doing that? Or are there factors that are getting in the way of them living that joy?

Assessing QOL

- Many scientific questionnaires/instruments help clinicians and research measure QOL, but none are needed to do this oneself.
- Questions to ponder (or spark conversation):
 - ▣ Are you having more good days than bad, or is it the converse?
 - Is there a trend in this split?

Another set of questions would be, "Are there essential activities or functions that you, as an individual, must have to think that you're living well?" So for example, for some people, I've had folks say, "If I can't go out for a run in the morning, my life would not be a good quality to me." And I've had some folks who said, "Even if I never got out of bed again, as long as I could interact with the people I love, that's okay with me." It really varies, and needs to be defined individually. And then also when it comes to people who are in the midst of struggle, who are dealing with symptoms, and a really important question that I try to prompt people to ask, and many times people come in to me having answered for themselves, "If things never got better, if this was the best that things got, would that be okay? Should we be promoting your current quality of life to last as long as possible?"

So in thinking about quality of life, as a clinician, while I do interact with my patients very closely, and dozens of people a week, I know that I must start from my own authentic perspective, which is that in adult medicine, most of us clinicians are going to operate under the assumption that things are fine unless we hear from somebody, or unless we hear or observe things to the contrary. We can always check labs and do imaging, but in terms of how someone's living, if they're not calling me between visits, if they're not sending me messages between visits, or if, when we are talking, they don't indicate that things aren't going well, if they physically look the same and they're exam and labs look the same, I may not know. I may not know they're struggling or even suffering.

So I think the truth of the matter is that all of the technology that we use in clinic really isn't very successful at showing us the real patient experience. And a lot of times I think barriers that come about, with regard to my patients communicating quality of life concerns, relates to fear that I will take away the treatment entirely, something perhaps that they are very invested in because they want to live as long as possible. Most of the time that's not indicated. In most circumstances, we can mitigate toxicities, sometimes with other medicines or procedures, sometimes by adjusting the doses of treatment, sometimes by adjusting the schedule of treatment, or even just taking a break. And that doesn't mean that we're closing the door on longevity, or closing the door even on that individual treatment.

Assessing QOL, cont.

- ▣ What sort of activities, interactions, or moments allow you to feel like yourself or bring you joy?
 - Are there barriers to you having these moments or experiences?
- ▣ Are there any activities or abilities that are key to you living a life that you think is good?
- ▣ If your life never got better than it was right now, would it still feel acceptable?

Communicating about QOL



- From the clinician side of the stethoscope:
 - ▣ In adult medicine, most clinicians (including really excellent ones!) will work under the assumption that every patient's quality of life is good unless there are visible signs or open communication to the contrary.
 - ▣ "Review of systems" forms, imaging results, and laboratory values only go so far – doctors and providers rely on patients and/or caregivers to raise concerns about symptoms and QOL
 - ▣ Most often, QOL concerns can be addressed without stopping treatment, so try not to let that fear silence you.
- Don't rely on telepathic medicine:
If it needs to be heard, it will need to be said

Dr. Elizabeth Wulff-Burchfield:

But what I would just say is we have not perfected telepathy. And I sometimes joke with this about my patients and just saying, "I can practice telemedicine, but I can't practice telepathic medicine." So if someone is struggling, when I'm meeting the folks in my clinic, one of the first things that I try to emphasize is that I genuinely want to know, and need to know, how things are going to help them in the best way possible. And so, if it's something that I need to know, then it probably needs to be told to me, just in case I don't pick it up otherwise.

I have a couple of thoughts about what I have observed, again, on my side of the stethoscope, in terms of what I think helps communication about quality of life for my patients and their loved ones and their support people. So I think it's important for people to take some time and space to think about what they think about their daily life, and how their overall wellbeing is, before coming to a conversation, because it can feel really uncomfortable to be put on the spot. I would also say having time for a face-to-face visit with their treating clinician is really high value. I think, again, the telephone is a really important invention, we use it quite a lot. Same thing with MyChart and other modes of communication, but it's hard to beat some sort of way for me to look into my patient's eyes and for them to look in mine when we're having these important human moments. And that could be through telehealth. I think either of those options are often better than just trying to piece it together with MyChart or other patient portal messages and things like that.

The other thing that I've observed sometimes is helpful is occasionally I'll have folks who will send me a message before a visit and will say, "Hey, in case I get swept up in the moment, or in case I get stressed

out from traffic tomorrow, there are a few topics that I want to talk about." To bring up quality of life things, to make sure that I'm aware we need to make space and I don't run the risk of moving the visit along, and ignoring, failing to make space and time for something important. And I would also just say having a support person there goes a long way, and I would strongly recommend considering that.

A few other thoughts that I think are worth considering are that when my patients and their loved ones communicate with me that they have quality of life concerns, some of the things I think help that communication are to keep it really simple. And it's not that people don't want detail, it's just that I think in clinician-directed communication, we are often taught to start with a warning shot and then a headline. And I think because, as we were hearing before I started talking, physicians, providers, nurses, social workers, and other clinicians have their own journey along with the people they're treating, their own grief or sadness of someone struggling. And so I think assuming that the person on the other side of the stethoscope from you is going to need the same courtesy and the same preparation that we give, I think, is a great starting place.

Communicating, cont.

- A few tips for successful discussions about quality of life:
 - ▣ Take your time thinking about QOL before the day and time of the conversation.
 - ▣ Make time with your doctor or provider for a face-to-face visit to discuss the topic (even via telehealth).
 - ▣ Consider notifying your doctor or provider ahead of time that you want to discuss QOL concerns.
 - Consider leaving a simple message through the patient portal or voicemail ahead of your visit
 - ▣ Consider bringing a support person for the visit

So I think starting with a warning shot by saying something like, "My main concern I wanted to talk about today is my quality of life or my overall wellbeing. I've been feeling worse, and I want to know what can happen to help me feel better." And then giving that person a moment to take it in, and then ask questions, because they will ask questions. They're not just going to say, "Okay, thank you," and walk out the door. Anyone you're working with will be invested in you.

And other options would be to say, "I've been struggling with side effects since I was here last, I don't want to stop treatment, but I want to see what's possible to make them better." Again, I think giving that kind of warning shot, "I've been struggling," and follow with a concise summary, that can be enough to spark a rich, and important, and successful conversation. So I would just say treating clinicians, we need all relevant information to do a good job, and most of us are people who want nothing more than to help others live well. So I think quality of life is always relevant to this, there's always a place to talk about that.

Dr. Elizabeth Wulff-Burchfield:

Knowing that we're all human, we all bring our own experiences, baggage, attachment issues, all those sorts of things, sometimes those conversations are tough, and emotions can run high, and don't always feel great. And this can be the same if my patient were to bring up to me that they're struggling, it's not impossible that I could have an emotional response. That happens sometimes, and I think it's important to be prepared that, no matter how much someone cares for you, they could have their own experience that could lead them to have difficult emotions. So I also think it's important to recognize that when talking about quality of life, and particularly if we're not meeting the standard we need to

in terms of quality of life, everybody in the conversation can have difficult feelings about that. But clinicians can feel that they're failing their patient by not knowing about it, by not being aware, and they can feel sad sometimes, even defensive. And I think, often, my patients and people undergoing treatment and their loved ones can feel a sense of failure or fear abandonment.

I would say also it's important, I have one observation that I feel strongly about, that a lot of the field of oncology in modern years has revolved around a culture of non-abandonment, and emphasizing not giving up or giving in and those sorts of narratives that can lead to, sometimes, an oppositional response. When people express, "I would like to know what can happen to make my symptoms better." Sometimes an immediate response from a clinician is, "Well, we can't stop treatment." I think it's because of that cultural underpinning.

I would also say that, and this is my personal opinion, and I want to make sure everyone who's listening feels respected, but I don't always think that the fight or battle narrative for cancer, I don't think that's always productive. Sometimes I think it leads people to feel like they're losing a battle, losing a fight. And I certainly feel strongly that none of my patients are losers. And again, that can make for difficult

Stormy Weather



- High-stakes discussions are sometimes difficult and can stir up strong emotions.
 - When discussing quality of life, all parties are at risk for feelings of failure, disappointment, or fear.
 - The field of oncology has a strong cultural undercurrent of non-abandonment, therefore considering reductions or discontinuations of treatment sometimes triggers an oppositional response.
 - The "fight" or "battle" narrative regarding cancer treatment isn't always helpful, and sometimes one party will feel like they are "losing."
- If at first you don't succeed . . .

conversations sometimes. But it's always, again, knowing all of that, I do think it's important to be willing to try again if possible, because these are important topics that need to be addressed.

Sometimes we do reach an impasse in communication. And what I do want to emphasize is that I actually think that that clinical relationship, it can still be successful, it can still be therapeutic if you get in additional help in fostering that communication in a more successful and fulfilling way. And I believe that palliative care is the ideal resource to provide another perspective, and another mode of communication. One way to start about that, and in addition to working with palliative care, talking to a nurse on your team or a social worker can help as well.

Dr. Elizabeth Wulff-Burchfield:

In talking about palliative care, palliative care also is sometimes called palliative medicine, is specialized medical care for folks who are living with a serious illness. Cancer is always serious, and so this is appropriate for people across the trajectory; at new diagnosis, getting curative intent treatment, dealing with symptoms, or advanced illness. And palliative care focuses on providing relief from symptoms and the stress of illness, regardless of what that serious illness is, and in this case, we're talking about bladder cancer, of course, but this exists with other things like heart disease, neurologic disease, et cetera. And the goal of palliative care is to improve and maintain a great quality of life for patient and their loved ones.

Palliative care is conducted with an interdisciplinary team, including doctors like me, nurses, social workers, chaplains, child life specialists, advanced practice providers, and so much more. And I would emphasize that in palliative care, we say that it is for any age and any stage in a serious illness, and it can, and should, be provided along with curative intent treatment when it's needed. That may not be the focus of this webinar, but it still is important to know.

At an Impasse?

- Sometimes barriers persist for QOL and/or communication about QOL
- In almost all instances, the care and clinical relationship *can* continue successfully, but sometimes needs additional support.
- **Palliative Care** is the ideal resource to provide another perspective and layer of support in these circumstances.
 - ▣ Speaking to your team's nurse or social worker can also get the ball rolling



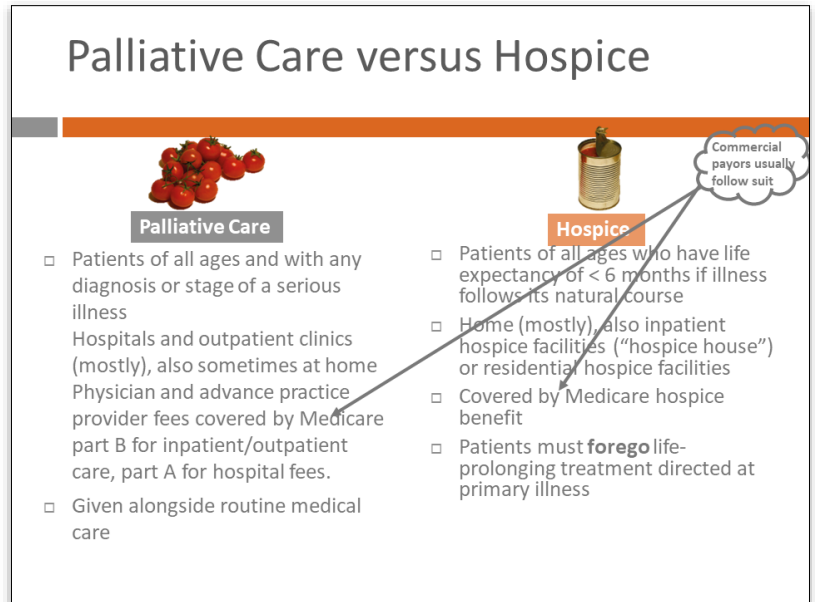
Palliative Care Defined

- Palliative care, also known as palliative medicine, is specialized medical care for people living with a serious illness.
- Focuses on providing relief from the symptoms and stress of a serious illness—whatever the diagnosis.
- The goal is to improve quality of life for both the patient and the family.

Palliative Care Defined, cont.

- Palliative care is provided by a specialized interdisciplinary team:
 - ▣ Doctors
 - ▣ Nurses
 - ▣ Social workers
 - ▣ Chaplains
 - ▣ Child life specialists
 - ▣ And so much more, depending on the setting
- Palliative care is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.

I do think, often, folks conflate palliative care and hospice. I know many, many, many clinicians who continue to struggle with some of this, and have a lot of fear about palliative care because of some associations they have with hospice and not, and wanting to make sure that hospice is introduced at an appropriate time. So some things, there are a lot of similarities between palliative care and hospice. Again, any age and any stage for palliative care, and hospice is for any age of person, but it's really intended for folks who have a limited life expectancy, and aren't pursuing treatment of the underlying medical problem.



Dr. Elizabeth Wulff-Burchfield:

Palliative care is largely conducted inpatient and in clinic. There is some home palliative care available, that's really variable. Gosh, that could be a whole other webinar unto itself, because it's kind of complex. But hospice is actually primarily undertaken at home, wherever that person's home is. If they live in a facility, or if they live in a private home, or with other people, then that's where hospice is primarily conducted, although there are inpatient hospice or hospice houses sometimes where people need to get care. And then outpatient or palliative care is paid for by insurance, just like any specialist, like if you see a dermatologist or a cardiologist, versus hospice is a comprehensive benefit that includes all medical care, equipment, medicines, and care at the home or in a hospice house in order to help someone live well.

And the other things that are important to remember are that palliative care can and should be given alongside routine medical care, even for the illness that the person is dealing with. But in hospice, individuals need to focus... Hospice is meant to be someone's entire medical team, and it's really intended for people who don't have conventional treatment options, or don't want them. So it's important to differentiate. I think of them as being opposite ends of the same spectrum.

And palliative care in advanced cancer has a lot of benefits, including improving symptom control and quality of life. And these benefits are preserved whether folks are getting this in person or through telehealth. Also, the benefits are there whether someone's seeing a physician, advanced practice provider, or a nurse. And I would say that communication is a central piece of palliative medicine. And that's actually, in truth, in my own training, I can tell you, most of my training was really in communication. The medication part was much

Palliative Care in Advanced Cancer, cont.

- In addition to improved symptom control, early palliative care has been shown to improve global QOL for patients with advanced cancer
- These benefits from palliative care have been shown to occur with in-person visits AND telehealth visits
- Benefits are consistent regardless of whether palliative care visits are with physicians, nurses, or advanced practice providers
- Communication is a key component of palliative care, and can benefit the whole team
- **Palliative care is the ultimate resource in pursuit of living well with cancer.**

easier for managing symptoms, but communication is really, really the thing that takes the most time to learn, and the most expertise to master. So for all of these reasons, I would say that palliative care is the ultimate resource in pursuing a life with a good quality when dealing with an advanced cancer.

Dr. Elizabeth Wulff-Burchfield:

I put this little bird here because, and we often think that, and what the research bears out, is that working with palliative care earlier really pays dividends. But some important tasks that palliative care accomplishes that I want everyone to know is that palliative care clinicians are experts in looking at goals of care with folks. Sitting down across from another person and saying, "What gives your life meaning? What makes your days sweet and joyful? How can we make that a reality for you?" That's looking at goals of care. Symptom management, dealing with unpleasant symptoms that people could have from cancer or treatment. In the setting of other illnesses, that would of course mean symptoms that might go along with that other illness. Advanced care planning, which is really important task that all of us should be doing without cancer diagnosis or with it, but palliative care clinicians are experts in helping with that. Communication, as I said.

And then finally, timing really does matter, because historically, palliative care was undertaken as an alternative to treatment of the underlying illness. But all of the research of the last decade tells us that working with palliative care in a concurrent fashion is really where the gold is. That's really what helps people for the longest amount of time, and building that relationship early really creates a foundation of trust and mutual respect that you can build on later when it comes time to undertake often difficult or challenging medical decisions as time passes.

Key Tasks in Palliative Care

- All palliative care clinicians have expertise in
 - ▣ Evaluating goals of care
 - ▣ Symptom management
 - ▣ Advance care planning
 - ▣ Communication
- Timing matters!
 - ▣ Building a relationship early will build the foundation necessary to tackle harder topics later (if needed).



Dr. Elizabeth Wulff-Burchfield:

Some things that palliative care does not do, that I want to emphasize; palliative care does not shorten how long people live. Not at all. In fact, multiple studies have shown that people can live longer if they work with palliative care. And we think a lot of times that's because people's symptoms are better controlled, so they can stay more active and strong. And also, if their symptoms are under better control and they're more active and robust, they can get more treatment, and then that treatment helps them more.

I would also say that, in spite of the fact that palliative care does not shorten how long people live at all, folks who do work with palliative care often receive less unhelpful care at the end of life. If someone is passing away from cancer and is in the dying phase, putting that person on machines will not, in any way, help them live longer, or at least not a quality of life that almost anybody would find meaningful. So avoiding overly aggressive and burdensome care at the end of life is really important, and it's considered an important marker of high-quality care. So much so that the American Society of Clinical Oncology has included it as a really essential quality metric that programs are evaluated on. And so I would say that when folks are working with palliative care concurrent with their medical care, they get additional support, so do their loved ones, and then, if and when they need hospice, they're able to get it with few barriers.

A few more words before I turn it back over to my colleague, how to connect with palliative care. This is a question that I get quite a lot, and I will admit to you that looks different depending on where people live, the setting in which they spend their days. But some general principles that I wanted to share, that asking a primary care doctor or oncologist for a referral to palliative care is a great step. And the reason I would recommend that is because what it can allow is for whatever resources go along, kind of are most closely partnered with, their treating clinicians are what they would likely refer to. And there are advantages there, because it can help foster communication between the different clinicians.

What Palliative Care Does Not Do

- Early palliative care is not associated with shortened life expectancy in patients with advanced cancer
 - ▣ Multiple studies have demonstrated better overall survival associated with early palliative care
 - ▣ Despite no loss of longevity, patients receiving early palliative care have less aggressive care at the end of life and longer time receiving hospice care
- Conclusion: Patients get support along with their oncology care when they need it, and then they get hospice care when they need it

How to Connect with Palliative Care

- Outpatient
 - ▣ Your primary care or oncology team are a great starting place – ask for a referral
 - ▣ Let your fingers do the walking and self-refer: <https://getpalliativecare.org>
- Inpatient
 - ▣ Typically, if someone is hospitalized their main medical team will need to request any/all consultations on their behalf, including palliative care.
 - ▣ However, if it's something you want or need, just ask your medical team



Dr. Elizabeth Wulff-Burchfield:

I would also say getpalliativecare.org is specifically designed to help people find palliative care near to them. And if there isn't palliative care very near to them in an outpatient setting, because of telehealth, that's more readily available now, although I know still a source of disparity, many of my patients who live in rural areas do not have Wi-Fi and can't actually do telehealth very easily. However, it does help. So if someone lives in Wichita, Kansas, and I'm in Kansas City, I have a license in the state, and it might be possible for them to see me for palliative care. Inpatient, if someone is hospitalized, talking to their inpatient team, they're sort of the gatekeepers for any consultations, whether it's with dermatology or palliative care, et cetera. But again, that's something that often a nurse on the team can help to facilitate, if the physicians or advanced practice providers aren't quite there.

And to finish at home, I would just say home palliative care resources are variable. And there isn't great home palliative care everywhere, and I'm sorry to say that. But a really wonderful website that's based in really high-quality medical data, and is used readily by palliative care clinicians of all stripes in all places in North America, is prepareforyourcare.org. It includes state-specific booklets that can help folks walk through an advanced care plan, and also videos that help coach people in both Spanish and English about how to go about raising the topic of advanced care planning, which can lead to other discussions.

Other things about how to connect, are that palliative care, if it doesn't feel right for you or for your loved one, you can still learn about it. You can learn about it getpalliativecare.org just to learn more about the field, so that when, if it might be appropriate at some future time, you would feel educated. Also, I do think that Gilda's Club sometimes has counseling and support, which is not the same as palliative care, but can be helpful. And I do think that CancerCare can be helpful. Certainly BCAN is one of my most revered recommendations and resources, and can provide incredible support to the patients who are dealing with bladder cancer and their loved ones. And while I didn't list that here, the only reason was because, to me, it feels so implicit that for me to want to partner with BCAN is because their mission is fully aligned with that of medical oncology and palliative care, and I completely emphasize that this is an essential resource.

How to Connect, cont.



□ At home

- Home palliative care is variable – some areas have great home palliative care and some do not
- However, if your area is lacking, you can always go to www.prepareforyourcare.org to begin educating yourself about some important conversations, and then discuss with your PCP or oncologist

How to Connect, cont.

- If Palliative Care does not feel right to you or is not available, consider some related resources that may be a good fit:
 - Learn more about palliative care: <https://getpalliativecare.org/howtoget/>
 - Gilda's Club
 - Counseling, support groups, fun activities
 - CancerCare
 - Counseling, support group, care navigation
 - <https://www.cancercare.org/helpinghand/>

Dr. Elizabeth Wulff-Burchfield:

Last warning I'll give is that there's, as I said, still a lot of misconceptions about palliative care, including among medical professionals. It can sometimes lead people to say, "Oh, it's not time for that, you don't need that, we still have treatment options." And I say, "Do not be discouraged." I might be discouraged if I encountered that from someone I trusted, and if I'd gotten up the courage to bring up palliative care, then I might feel discouraged. But what I would tell you is that that means that you actually get to educate that person who you're talking to, and it's okay to ask for a referral anyway. And also, one thing that I learned in my childhood as an avid Sesame Street listener and watcher, was over, under, around, and through. If this person is putting up a barrier to you, that's probably due to their own misconceptions or their own baggage, go over them, under them, around them, or through them.

You can self-refer, that's kind of going around or through. You can talk to their nurse, you can talk to another clinician that you work with. So I would just say we all need the support that we need. Palliative care is a great source of that. And if people meet resistance, it's not about them, it's about the person who's putting up the resistance.

So as I conclude, I thank you all so much and I really look forward to rounding out our discussion. But I would just say that everybody who lives with cancer deserves to live well. Everybody, everybody. And palliative care can often help that by managing symptoms and providing meaningful support, and getpalliativecare.org is a great starting place to help anyone get access to palliative care, at least in

Forewarned is Forearmed

- There are still many misconceptions about palliative care, including among medical professionals.
 - This sometimes leads to clinicians reacting by saying, "It's not time for that yet," or "You don't want palliative care, you still have treatment options available."
 - If this occurs, do not be discouraged.
 - If you think palliative care would help you, it's ok to ask for a referral anyway.
 - Can consider asking another physician or provider for a referral (e.g. if you asked your oncologist, you could ask your primary care physician).
 - Self-referral is almost always an option and rarely poses any problems with insurance reimbursement



Summary

- **Everyone who is impacted by cancer deserves to live well with cancer.**
- In the setting of advanced cancer, achieving a good quality of life for the patient can take work to achieve, but is worth the effort.
- Clinicians need to know if there is room for improvement in a patient's symptom control or QOL – speak up!
- Palliative care is an important resource for supportive care, communication, advance care planning, and medical decision-making.
- Check out getpalliativecare.org to find local palliative care resources

the United States. Thank you so much.

Dr. Daniela Wittman:

Okay, okay. So I just wanted to tell everybody who's listening that I looked up the definition of the word "palliative", and it means soothing, alleviating, calming, which means those are the interventions that will make life better, that will make life more livable. And that is something that everybody's entitled to, especially if they're dealing with cancer. And you just really heard a really nice summary of what you can access through that kind of care.

So one of the things that comes up every now and then, what do I do? What does a patient do when the family or the doctor won't talk about it? So there are things that can be done. First, it's really helpful to team up with somebody. Don't necessarily approach this by yourself. Team up with a friend, family member, a peer who has bladder cancer, social worker, counselor. Have a discussion and say, "Please support me in bringing it up to my family or bringing it up to my doctor."

And then once you decide to do that, let the family or the doctor know in advance that you want to have that discussion so that they can get psychologically prepared for it. You might want to write down what it is that you want to talk about, because in the heat of the conversation, you may not think of all the things that you want to cover. And expect to have feelings about it. And others will have feelings about it, and you can let them know that it's okay. That when people feel sad or defensive, it's usually the reacting to their own sense of loss in that situation. And all feelings, more or less, are acceptable, as long as people recognize that they are a reaction to a difficult subject. And it doesn't have to be only one conversation, it can be repeated as people get more uncomfortable with the topic.

I would say don't back down if others say, "Don't worry, you'll be okay," or, "This is not the time," or, "We'll talk about it at a later stage." If you feel like it's your time to talk about it, you have a right to talk about it. And so again, get support from whoever you trust and approach it again, you can disagree, you can stand up for what you think is right for you.

What can patients or family members do to start the conversation if their doctors or other family members won't?

- Team up with someone you trust (family member, peer who has bladder cancer, friend, social worker, counselor)
- Let family members or the doctor know ahead of time that you would like to have this conversation
- Write down what you want to talk about
- Expect to have feelings – and let the others know that they might also have feelings about and during the conversation
- Don't back down if others say "don't worry, you'll be ok," "this is not the time," etc., you have a right to have this conversation



So when people are coming to a place where treatment is no longer an option, there are many things that they can decide on, and that can make that period of life actually really rich. One would be to certainly allow one's feelings to flow, but the other thing would be to actively work with one's family, or with friends, on what one still wants to do, saying goodbye, even planning a funeral and memorial service. Sometimes when there are challenges in the family because people don't want to talk about it, don't want to plan it, but you do, a social worker can be helpful. And to the degree that it's possible, focus on the quality of life in the present, so that you can have as many good experiences and meaningful activities all the way to the end.

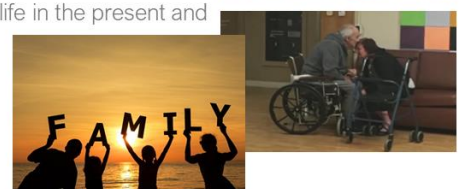
So I would say allow for grief to happen, it's a natural response. Definitely stay connected to your loved ones and to your healthcare team, and let everybody know what you need, and what you want to happen. And that would be a way to take advantage of palliative care, and of having as rich a life as possible all the way to the end.

Stephanie Chisolm:

Again, this has been a phenomenal program, and you both brought up something very important. The concept about a social worker is one, that people don't know how to find one. But I do want to just let everybody know that we started this month, with CancerCare, a special bladder cancer support line, and it is staffed by the social workers in New York that are really medical oncology social workers. And if you call 833-ASK-4-BCA, which is basically "Ask for Bladder Cancer Advocacy", then you are speaking up for yourself or for your loved one, and I encourage you to use that line. It's free of charge, and they're available during regular business hours in the New York time zone. So leave a message if you can't reach them, or if you're in a different time zone. But they can help with a lot of things, and some of it can be related to "What do you do when cure is not an option?" So thank you, Morgan, for putting up that slide.

Coping with loss, grief and mourning

- Work on coming to terms with the end of life – Anticipatory Grief
- Actively work on end-of-life planning with family and friends
 - ▣ Say goodbye
 - ▣ Plan funeral/memorial service
- Engage a social worker or counselor to help with personal or family relationship challenges
- Continue to focus on quality of life in the present and engaging in meaningful activity



Allow life to unfold until the end

Allow Allow grief to flow, it is natural

Stay Stay connected to your loved ones and to your healthcare team

Let Let everyone who needs to know what you want to happen



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