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### **Stephanie Chisolm:**

And you both explained so much, in terms of the differences between palliative care and hospice, and identifying the emotional challenges. There are so many, as you pointed out, Daniela. A caregiver might be saying, "Come on, keep going, keep going!" And the patient is saying, "I'm sick and tired of being sick and tired, and I'm ready to just be at peace and enjoy what time I have left."

So from that perspective, you mentioned so many wonderful things. I hate to say, how do you bring that up again? Because so many people are like, "I just don't know." And you gave so many wonderful suggestions on how do you bring that up. And I can't even think of a question now specific to that. But Libby, you pointed out that palliative care can be at any time, it's not just for hospice. And thank you for providing those resources for how do you find it, because one of my questions is always, "How do you find it if you're being seen in a community practice, and that oncologist, medical oncologist, does not have a link to a palliative care expert?" So you gave the answer already, which is wonderful.

### **Dr. Elizabeth Wulff-Burchfield:**

To answer your prior question a little bit, I did just want to say that when folks are having... If there's conflict or just discomfort between the person with the illness and their loved ones, and not everybody is wanting to participate in the conversation, it's perfectly reasonable to ask a medical team to help with that. Or again, that could be a physician, nurse, advanced practice provider, social worker.

So any of us in practice would encourage, if I have patients whose loved ones are just not comfortable, and/or are saying, "No, I'm not willing to engage in that conversation, I can't go there," or something like that, it's okay. If my patient came to me and said, "My husband or my spouse is just not... He doesn't want to talk about it, and I need to talk about it." Then I would be very honored to either be the person to talk to that patient about it, or to say, "Can I try and help facilitate a conversation? Or we could have a conversation, then I could summarize it and present it to this person so that you don't feel like, quote, "the bad guy"." The bad guy is the cancer. Wanting to talk through things is a normal human need. So I think that's something that the medical team wants to help with, if we can.

### **Dr. Daniela Wittman:**

Okay, if I can just add to that, sometimes the members of the medical team, whoever they might be, can help the family member understand what the patient's going through. Because I think that as people are getting tired of their treatments, and of their fatigue, and of their pain, family members are focused on wanting to have that person around as much as possible, and so they want them to keep on going. I

think that the healthcare providers can provide some information about what happens inside of that person's body, and how that may make them feel, engage the family members' imagination in a way that the patient may not always be able to do, in the sense that they've already said many things about how they feel, but somehow they need a little bit of authentication from somebody else that that is really true. And it's not really about they're wanting to abandon their family members, but things may have become unbearable.

### **Stephanie Chisolm:**

Mm-hmm, absolutely. Well, there was one question in the Q&A box that I'm not quite sure of, because I've not heard this term before, but I know that you can use a doula to help guide through the birth process. But somebody asked a question about a death doula, or end-of-life doula. Do you have any information on that, Libby?

### **Dr. Elizabeth Wulff-Burchfield:**

Well, what I would say is that the terminology depends, it differs a little bit across the United States. And I will admit, I don't have a great deal of knowledge about this, and I really don't have a great deal of knowledge about this outside the United States, or at least North America. I would say that this is a little bit more nebulous than someone who's going through labor and delivery, because the dying process is often more protracted than how long it takes for a baby to come into the world. But what I have learned is that some of the folks who know the most about that are actually hospice agencies, and folks who work at hospice agencies, because if someone wants to work with either a volunteer, so sometimes these are volunteers, and sometimes they're private duty medical people, either a nurse or a social worker, and sometimes even, I think, chaplain type individuals, who can help physically be present with a family for additional support, and to help put things that are being observed into context, for example, symptoms.

I would also say that, in my opinion, the entire hospice team effectively accomplishes all of the tasks that a death doula would do. Now, one thing that's a little different is that sometimes in the hospital, for example, where I trained, I've spent some time at Vanderbilt, which is a wonderful medical center in Nashville, Tennessee, and we had volunteers who spent time at the bedside with folks who were going to die in the hospital if they didn't have loved ones. And so that's a little bit of a different role. But really in reality, the hospice medical team, because of the interdisciplinary nature and the varied expertise, really accomplishes all of the tasks. It's just sometimes if people want someone physically present, then arranging that, the people who know the most about it in a given area would come from a hospice agency.

### **Stephanie Chisolm:**

Yeah, it's taking so long to just get people to think about palliative care as an option. So I'm sure this is going to grow if this becomes something that's really effective. So I think that that that might be something...

### **Dr. Daniela Wittman:**

Can I just...

### **Stephanie Chisolm:**

Mm-hmm?

**Dr. Daniela Wittman:**

Can I just add also the concept of a doula for childbirth is a wonderful, wonderful idea, and the people who do it often have some training, because one of the things that you want to make sure is that people are not imposing their own views on the person who is having the baby, that they're really there just to comfort them and support them, and that they understand the process and can assist the healthcare providers, whether it be a midwife or a physician who's birthing the child.

I think the same would have to be true for a death doula. It's probably a really terrific concept that is very novel, in a way, that could develop. But again, it'll be just important that that person understands what being a supportive person is, in the sense of not imposing, and being very comforting, and assisting the people who are providing healthcare, medical care, in the context of the family.

**Dr. Elizabeth Wulff-Burchfield:**

Mm-hmm, well said.

**Stephanie Chisolm:**

Mm-hmm, absolutely. Well, I don't really see a whole lot of questions that haven't been answered. When is a time for formal palliative care, not just an interaction with a primary doctor or specialist, but with a palliative care team? I think you covered that in your talk, if you have any other comments about that?

**Dr. Elizabeth Wulff-Burchfield:**

Well, a lot of times we think about it in terms of... Truthfully, primary palliative care is what oncologists and palliative care physicians and neurologists and other clinicians are doing to talk about goals, to manage symptoms. But I would say that those primary palliative care tasks are going to be a part of standard medical care. But if at any point someone feels like they could use a little bit extra support, symptoms could use a little bit more tweaking, or just the nature of conversations needs to be a little bit deeper or longer, then I think just my general experience has been that if someone asks themselves, "Is it time?" It's always time. Intuition is very, very helpful in a circumstance like that. And again, if someone meets with palliative care and it doesn't feel like a good fit, they could pull back and then circle back at another time. It's kind of a very low-risk endeavor.

**Stephanie Chisolm:**

Right. And I loved your idea earlier of getting an advocate to help with that process. If somebody, maybe the patient's saying, "I'm sick and tired of being sick and tired," or the caregiver is thinking, "I can't let them suffer anymore," but the patient's like, "No, no, no, keep going." Whatever. If they're not on the same page or not having that conversation, I loved your suggestion of enlisting somebody to help talk it through so that you can present this. And if it's not a friend or family member, then it's obviously bringing that doctor into the conversation to really talk about the goals for the time you have left, and how you want to spend your days. I think that's really critical. I think someone...

**Dr. Elizabeth Wulff-Burchfield:**

I agree. I think any discord between patients and loved ones is a really important time to involve palliative care. Sorry about that.

**Stephanie Chisolm:**

Absolutely. But what you have done is such a phenomenal program, that you literally anticipated every question that I have written down on my notebook, and there haven't been that many questions really submitted. So I want to thank you both for an absolutely useful, wonderful, warm... I feel really good that this information is now out there, because nobody talks about this, and it's just one of those things; yes, doctors may offer more treatments, but if it's not quality of life, if it's just prolonging misery, but it's not offering any cure, how do you make that time better? How do you give parents a chance to talk to their adult children or their small children, or give that grandparent time to talk to their grandchildren in a way that they're not in pain, and they're not medicated to the point where they can't talk the way that they feel? And that's such an important gift to be able to do that. So thank you both. Any last comments before we sign off?

**Dr. Elizabeth Wulff-Burchfield:**

Oh, I just want to thank you for hosting this important discussion. I think this can be difficult subjects to address, but they are an extremely important part of living, and to make sure that it's well, and to have a comprehensive picture. So thank you for being willing to host this important discussion, because I'm sure it's on many people's hearts.

**Dr. Daniela Wittman:**

And I want to say that this is really a quality that BCAN is famous for, which is that you bring up topics that other people are not talking about, and so patients can turn to BCAN for such a gamut of support, information that it becomes an incredibly important resource in bladder cancer. Thank you.

**Stephanie Chisolm:**

Thank you both. And I thank everybody for joining us.

