

Palliative Care and Pulmonary Hypertension

Guest editors Christopher Barnett, MD, and Hunter Groninger, MD, conducted a roundtable discussion on March 23, 2018, with Keith Swetz, MD, Associate Professor of Medicine at the University of Alabama School of Medicine, Section Chief of Palliative Care at the Birmingham VA Medical Center and Medical Director of its Safe Harbor Palliative Care Unit; pulmonary hypertension patient Donna Hershey, RN, Children's National Medical Center, Washington, DC; and Anne Kinderman, MD, Associate Clinical Professor of Medicine at the University of California, San Francisco, and Director of the Supportive & Palliative Care Service at Zuckerberg San Francisco General. Their wide-ranging conversation about the role and status of palliative care for pulmonary hypertension patients follows.

Dr Barnett: By way of introductions, I'm Chris Barnett. I am the director of the pulmonary hypertension (PH) program at MedStar Washington Hospital Center.

Dr Groninger: I'm Hunter Groninger, physician. I'm the director of palliative care also at MedStar Washington Hospital Center.

Dr Swetz: I'm Keith Swetz. I'm a physician at University of Alabama, Birmingham. I do palliative care and internal medicine and work as Section Chief at the Birmingham VA Medical Center.

Ms Hershey: I'm Donna Hershey. I'm a pulmonary hypertension patient. I was diagnosed in 1989, so I've been a patient for a long time. And I am a patient of Dr Barnett's currently at Washington Hospital Center. I also am a nurse.

Dr Kinderman: I'm Anne Kinderman. I'm the director of the palliative care service at San Francisco General and I'm on faculty at UCSF.

Dr Groninger: We are interested in this conversation from the PH provider, from the palliative provider, and from the patient perspective. What are some strengths and opportunities for raising awareness about palliative care and palliative medicine in the area of pulmonary hypertension and what might be some opportunities that, from a provider/researcher perspective, might be things that we could be thinking about? And then really importantly, from a patient perspective, what have experiences been like through the trajectory of living with

PH? And what might be some opportunities that, from a patient's perspective, might align well with concepts of palliative care and where we might want to share with readers where these collaborative efforts might go?

Keith, you're someone who really has early experience in noticing this clinical opportunity for palliative care to work with pulmonary hypertension patients and their providers and have done some work at this. I'm wondering if you can just start off by giving us a background sense about what your observations have been so far.

Dr Swetz: Sure. Thanks for those kind words, Hunter. This certainly has been a population that I've been very interested in, mainly because early in my internal medicine residency, I would see folks with pulmonary hypertension to some degrees that had significant symptom burden, either from the disease process or from the treatment itself. And part of the challenge early on was really separating out hospice and palliative care as two distinct entities, because it is very important that within the pulmonary hypertension world, we wanted to be as positive and as encouraging with our folks. We'll hear Donna's story, dealing with this disease for a long period of time and being able to have a good, functional life. But a lot of folks have real issues with quality of life and high symptom burden, again from the disease or the treatment itself. So, what I really wanted to try to do was figure out what the barriers were from getting folks to work on a symptom management strategy, work on early but iterative goals of care discussions, because I

knew that when things got advanced for many patients, there wasn't a whole lot of preparedness and there were a lot of misperceptions about what palliative care was versus hospice. And I think in the past 10 years, we've seen that that's gotten a little bit better. But I'm grateful to see that Chris and Hunter are co-editing this specific issue because I think there's still a lot of stigma and stereotype that needs to be better understood by providers and patients and caregivers.

Dr Groninger: So, Keith, maybe just to elaborate on that a little bit for the readers, can you give a sense about how you'd characterize the role of palliative in the PH experience?

Dr Swetz: I think when it comes down to it, again, I try to practice palliative care by the philosophy of: I want to do things that are going to either help you live longer or feel better. And I think we know that prostacyclin and ET blockers and the many drugs that have come out are tremendously helpful in prolonging survival, but they come with their side effects of neuropathy, leg pain, jaw pain, diarrhea, nausea—really difficult symptoms that the patient in a way feels as though they need to suffer with often because they want the medicine to work. But I really like to try to make sure that we're doing all we can to address those symptoms, as well as when it's appropriate to address symptoms related to dyspnea and fatigue, that might be due to advancing disease process and not necessarily remediable with PH-directed therapy, but that might respond well to low-dose opioids or other modalities for managing the dyspnea. So, I think

early on, understanding that palliative care can be a longitudinal partner with the PH team to provide symptom and patient-directed focus is a good thought. But then as the disease progresses, and particularly if there are more complications, palliative care is someone who is there to be able to bridge some of the gaps between restorative and palliative treatments and be able to provide quality of life, particularly with the challenges of end-of-life care and hospice, which are often challenging because of some of the costs of the PH medications and other factors that are present.

Dr Groninger: That's super helpful. I think I'm just going to keep running with this. I know I want to definitely come back to just those last couple of phrases that you just said, Keith. Chris, could you comment on what Keith just said and what your experiences have been from the PH side, in terms of when have you engaged or wanted to engage palliative support, and what has that been like for you?

Dr Barnett: As Keith said, most of the PH medications do have significant adverse effects. There are lucky folks who have the good fortune of being able to tolerate the medications at treatment doses without having significant adverse effects, such as pain, headache, things that can be irritating, like nasal congestion, versus things that could be debilitating, like chronic severe joint pain. I think the experience of patients is sort of a spectrum. In my experience, it can be very challenging in the clinic to do the things that we need to do, to treat the right heart dysfunction as well as we can, while simultaneously managing the adverse effects of the therapies. I think it can oftentimes—given limited time that we get to spend with patients—be very hard to do both of those things at once. I also sometimes discover belatedly that patients have had symptoms, adverse effects of their therapies, because they haven't necessarily wanted to prioritize that discussion during clinic visits. I try to make an effort to probe every single clinic visit to discover adverse effects that I can treat or at least be aware of, and sometimes I find that I don't discover those until a

later time. I think that partnering with another provider to help in finding those symptoms and help manage those symptoms brings a lot of value, especially when patients are complex hemodynamically or in other ways. Also, no matter what we do with medications, most people may not live as long as they want and having somebody who can bring that perspective and start those discussions very early on is very helpful. Working with palliative care brings both of those things: someone to focus on the symptoms and someone who's not the PH provider to start that conversation about kinds of expectations very early on.

Dr Groninger: Thanks, Chris. Donna, I was going to turn it to you and get your reflections on what's been said so far.

Ms Hershey: I was diagnosed in the '80s, and then I was very sick in 2004. It was when I started on Flolan. It was assumed at that point that PH was a terminal illness. I guess, in some ways, that may have been an advantage to me, in the sense that I always thought of it as making the best of the time I had. Then, lucky for me, treatment has exploded, and I've been so lucky to be alive, living with the disease now for I guess almost 30 years, which is crazy to think about. I think it does help to—like Dr Barnett was just saying—know from the beginning that this is a life-limiting illness, or at least that's what it's expected to be, so that you do take advantage of the time that you have. I think I do that different ways, at different times. I might view that as I want to take advantage of these moments, this year, this month. But other times, I feel optimistic and say, you know, I'm going to live for 20, 30, 40 more years. I think it's kind of good to have both possibilities in your mind so that you can live for the now, but also plan for the future.

Dr Groninger: That's helpful, just to get some initial thoughts. Actually, I did want to ask if you, Donna, have had any experience with palliative providers in your experience so far.

Ms Hershey: Not with PH. But from a professional standpoint, I'm also a nurse

at Children's National Medical Center, and I happen to be on the palliative care team there, so I've worked on the other side with children that are dying. So, I do kind of know a little bit about the process. The support group that was started at Washington Hospital Center by one of the social workers is part of the palliative care program. And when they have the meetings, they'll introduce themselves as, "I'm part of the palliative care team." And then they do some activities that are related to relaxation and spiritual examination and things like that, which seems like it's definitely related to palliative care.

Dr Groninger: Anne, I wanted to give you a chance to comment. We were talking about the intersection between the two disciplines and opportunities. What is your experience in San Francisco when you found it beneficial to involve palliative services?

Dr Kinderman: I think that the reality for illnesses like pulmonary hypertension where there's kind of a trajectory that you may be unclear on the timeline, but you know that this is a serious illness that is progressive. I think what folks in my field have advocated for is incorporating palliative care principles for the team, the PH team, to start incorporating principles of symptom management, advanced care planning, patient support—all of that from the beginning. And then involving palliative care when the needs kind of feel like they're outstripping peoples' comfort level or expertise—so times where people think about that or they have particularly hard-to-manage symptoms or complex psychosocial issues, certainly during disease exacerbation, when people are hospitalized. And certainly, I would hope as people have significant functional decline and it just gets to be a lot, a lot for everyone to handle, it seems like that's a great time to bring in another supportive team.

Dr Groninger: Can you give a really specific or concrete example of when this worked really well or when the timing was right?

Dr Kinderman: It's hard for me, unfortunately, because we are just opening up outpatient services for patients who have diagnoses other than cancer. So really, the ideal places when you want to get involved earlier on are to have more outpatient services. I think the thing that is tough is that a lot of people are confused by associating or thinking that palliative care and hospice care are synonymous. There's a real reluctance to involve palliative care because the feeling is, "Well, this person is still continuing on with treatment," so there's this false dichotomy that you have to choose one or the other and it's really only when people are thinking about transitioning to hospice or comfort care that palliative care is considered. So, during times where people are not necessarily dying during this admission, but this is a trajectory where we can see a kind of decline: that is a really good time to get us involved.

Dr Groninger: And Keith, you've done some research on this, from looking at the clinicians, at the physicians, the PH teams, kind of what their perceptions of palliative care and hospice care and things like that, and some potential barriers. I wonder if you could share a little bit about what you've found.

Dr Swetz: Absolutely. I think some of the findings were definitely expected. We saw some mistrust from clinicians, predicated often upon previous bad experiences. So, you'll sometimes hear comments or anecdotes, you know, "I don't want to call palliative care, they'll just give my patient morphine and they're not ready for that." Or those concerns about—and I know we'll come back to cost issues—that the palliative care providers may not have a real good understanding about what epoprostenol infusions are and that we don't stop them, as there are protocols to potentially wean. But as medical directors or palliative care providers, we need to be aware that patients and families have very clear expectations for how those drugs are managed throughout the course of their illness. It's a very different paradigm to think about possibly even considering discontinuing those. So, I think there's that concern, does the

palliative care provider really understand this very complex illness? Are they going to try to automatically go to hospice? I think that's some concern. But then I think one of the challenges that's true with most advanced diseases is there is this real concern that having a discussion that's going to be perceived negatively by a patient or caregiver or that it may be associated with taking away hope. I think there's just such wonderful work from Alexi Wright and Holly Prigerson and Tom Smith in cancer and other diseases that you can have open, honest discussions with patients without taking away hope. And that patients often want to have these discussions to some degrees, to fill in some of the uncertainties they may have about their own issues or how they're perceiving their own issues or their own symptom burdens. I think those are some traditional things. I encourage our palliative care providers to be humble and curious and understand that, just like left ventricular assist devices or pulmonary hypertension or certain types of rare malignancy, that the management and the trajectory of these entities is very, very different from the entity that we might see with solid tumor palliative care, which was what most people focused on. And even that's changed in the era of immunotherapy where prognosis is really uncertain.

Dr Groninger: Keith, so one of the things that I think was a question that Chris and I were musing about—and I'd be curious for peoples' thoughts in terms of the heart failure world—it feels like of late there has been much more—I wouldn't say open arms, totally open—but opening arms to collaborating with and even integrating with palliative consultative services. And some of that is in heart failure in general or in mechanical circulatory support or transplant. Has there been something that's prevented this kind of shift in the PH world? Do you think that's coming, as well? What are some of the differences maybe?

Dr Swetz: Well, I'll just say briefly—and I'd love to hear others' thoughts—when I've spoken at some opportunities someone said, "Well, what you're offering and what I potentially could offer my

patients is wonderful. I want that for my patient." And I asked, "Well, where are you?" And they said, "Prestigious academic medical center that has a high volume of PH." And I said, "Okay, so what about this?" And they said, "We don't have these services available." So, I think part of it has been there's been such a large focus on palliative care in the inpatient ICU-type setting that the bandwidth of palliative care providers to venture out into this area is very variable across institutions. So, when I mentioned this particular academic institution at a talk, I was shocked. I thought, "I know of colleagues there, but they weren't able to see these particular patients." So, I think the availability and the understanding is one of the real challenges. And hopefully, as there's more cardiac-specific palliative care, programs like the University of Michigan, programs like your own, Hunter, people are really emphasizing having providers who are interested in this. That's one thing. I think another historical barrier has been, and I share this with the group because the first time I was ever asked to give a talk was at a PHA meeting. I was so unbelievably delighted and excited to be chairing a panel, a medically led session for patients. And during that session, there were people outside the room who were actually saying, "Don't go in and listen to him. He's going to take away your hope. You need to fight. You need to stay positive." And that was not something that I had never encountered before. But as I understood it better, I think really it is such a broad spectrum of illness and there was such early misunderstanding of what palliative care could provide, particularly thinking that this is hospice and comfort care only, that that was perhaps even more pervasive than in other cardiac illnesses. Considering the demographics that this disease affects, younger folks like Donna that really have so much to live for and so much to want to live for. So, it's taken some time and that's what my work has tried to focus on, changing the perception and bringing those barriers down. I'm just absolutely delighted that there are so many folks from different institutions on this call that recognize there's a need. And I hope that this roundtable

really is going to help to break those barriers down.

Dr Barnett: I was going to ask, Hunter, about your thoughts about what Keith just said. I also want to hear Donna's thoughts specifically. But Hunter, you're at a growing palliative care hospital center, which has been unique. And I came quite late to this. I showed up and you had already achieved a lot. But how was it that you were able to grow palliative care inside heart failure? I came along and was doing more PH, then you were already here and already had a program, so it was really easy to integrate PH and palliative care because of all the work that you had done previously.

Dr Groninger: Well, thanks for that. I'll answer by reflecting on what Keith said, that I also had the opportunity to speak at a PH patient/family conference a couple of years ago. An amazing conference. I'd never been to one like it. And I sat as part of a panel to talk about issues like this, I met the physician colleagues on the panel. They were all PH clinicians. Some of them I knew. And they said to me beforehand, "Now, we're only going to limit this discussion to symptom management, okay?" And I thought, I said, "Well, why? I mean, you know, we're not prognosticating individual people today. We're talking about conversations." As Keith said, the perception, the misperception, if you have a conversation, that will be damaging to a patient. And then I'm reflecting on what Donna said, that patients are, to our minds, surprisingly interested to engage in these conversations. It's not surprising because this disease is affecting their entire life, 360 degrees, and to have a safe space to start to talk about what that's like, what one's goals might be, and how we can help to think about the future and what needs are here today is not as frightening to patients and families as we providers often think is the case. So, to answer your question, Chris, I think when we started out in the heart failure world, one thing that helped to move the ball forward here was a choice to sort of run with some relatively new regulations around LVADs and so on, about the role of palliative care and LVAD

destination therapy, and say, "Look, see, you have to do this. So, you know, you have to—you really need to let us be a part of this." Then I think what perpetuated that was really modeling that when we do have conversations with patients and families, when we are involved, it doesn't automatically mean that the goals are radically changing. It doesn't automatically mean end-of-life care. We can actually model ways of having conversations about advanced care planning, about preparedness planning, which are in a safe space, and that care continues no matter what. So, I think the kind of modeling and really working in a very collaborative way, like the palliative people are here to—we don't have our own agenda—we're here to serve the patients and families with the heart failure team. And Anne and Chris, you should speak to this. Having that approach, like Keith outlined, is something that would help to ease the concerns of others who aren't on the call, misperceptions about palliative care.

Dr Groninger: Donna, I was curious to know if, as someone familiar with palliative care and someone familiar personally with PH, what would you advise us in terms of next steps? What would you say is the design; what happens next?

Ms Hershey: I think the important thing to say about palliative care is: some people don't even know what palliative care is. I think the best quick answer is, "it's trying to make every day the best it can be." We don't know how many days are left, but we want them all to be the best they can be or, at least, what we can do under our power. For me, it's not really scary to think about palliative care, because to me palliative care is like making the most of your own life. And oddly enough for me, that's meant adopting two kids. I guess if I thought I was going to die next year, I probably wouldn't have done that. I guess it's kind of weighing—and obviously, not everyone's in this situation, too—to make decisions like that. The medical team also can help you to sort out realistic expectations for how you're doing. And for another patient that's significantly sicker, the conversation might have

been a little bit different. Whereas I was doing really well on therapy, the conversation was, "Well, do you think you can handle this?" and I said, "Yeah, you know, I feel good and I want to live my life, and this is something that's really important to me. And, I have a really supportive family." Of course, I thought it through that if in five years I'm not around—of course I don't want that scenario—but my parents are very involved. I have a sister that's very involved. My husband is an amazing dad. So those kind of conversations, even though it might not sound like palliative care—it actually sounds kind of opposite, but in some ways it could be palliative care in the sense of "What do you want out of your life?" Whether it's for the next few months, if that's what's appropriate for the patient, or is it realistic that you have a few years or whatever the timeline might be. Of course, we don't know about the timeline for sure; and in some ways, I'm kind of glad that no one ever really gave me a timeline. They said that this is a life-limiting illness; it's progressive. But they also said that we just don't know and especially with their being so many new medications and things like that.

Dr Groninger: Donna, that is super helpful. Do you have a sense about what is the right time for those conversations to happen?

Ms Hershey: I would say at diagnosis is really the best time. Because you don't want to go along thinking everything is hunky-dory and this is just a little nuisance illness and then a year later, somebody has a conversation with you about this is life-limiting. You want to know that from the beginning.

Dr Groninger: You were talking about the support group; can you give us a sense about psychosocial or spiritual concerns or needs or supportive benefits?

Ms Hershey: The support group meetings that we've had have been really helpful. Just from talking about things that stress you out. Ways of dealing with that. Those kinds of things. And some

meditation. Also, I think just connecting with other patients: I cannot emphasize enough the benefits of that. When I first went to a PHA conference, I think it was 2008, it was like my whole world opened up. To meet other people that were struggling with the same things was so important. I try to do that in my work at Children's, too. Whenever I meet patients with a certain disease process, I ask them, "Have you met other people with your same disease? Have you been able to connect with people online?" Because to me, it just makes such a big difference for emotional support. And comparing ideas; even little things come up and you're like, "Oh, that happened to me before and here's what happened." You can't get medical advice from other patients, but it helps in a lot of different ways.

Dr Groninger: Other thoughts from people?

Dr Kinderman: I'm at UCSF and I work at the county hospital. So, I think one thing that is really striking in looking at a lot of the patient support resources online is just how much it takes to manage all of the medications and appointments and everything. A lot of our patients have really challenging life circumstances. So how do you address all of that and think about as providers what's the best treatment for people, what can they handle, how does that affect their prognosis, all of that. But I think, in incorporating palliative care, I have found that providers, when there are these automatic triggers from time of diagnosis, or things that were incorporated from the beginning, there are providers who are coming to recognize the benefits of that. And most people are in agreement that at the very end of life, having more support and symptom management and everything is helpful. It's the in between those two opposite ends of the trajectory that it is really hard for people to sometimes think about referring, because of this misperception that palliative care is hospice. So, I think that efforts to incorporate palliative care principles and to have triggered consults with particular events are really helpful.

Dr Barnett: Anne, are there things at UCSF that have helped develop the relationship between cardiology, heart failure specifically, and palliative care?

Dr Kinderman: At UCSF, over at the other campus where they do transplant and they do LVADs, I think there's been transition similar to what was already mentioned around the necessity for having palliative care consults. So, I think that that has helped to bring people together. And then when I think there are particular champions, either on the palliative care side or on the cardiology side who want to build something, I think that those are really the keys.

Dr Groninger: I wanted to follow up on something that, Anne, you were just talking about a little bit, and Keith you had mentioned early on: about transitions closer to end of life. And Keith, I think early in the conversation, you mentioned something that I found really important to address in the clinical setting about PH interventions, about the cost of medications, about what hospices are able to and not able to provide. Chris and Anne and Keith, do you have specific thoughts about when those transitions happen? How do you think about the sort of active disease-modifying therapies versus focusing on symptoms specifically related to medications and what is the role for disease-modifying therapies at end of life? What are thoughts that you might have about de-prescribing, things like that during those transitions?

Dr Kinderman: So, since most of my practice is in the hospital, when we've had people who are transitioning from really active disease-modifying therapy to hospice, which as has been mentioned, most hospices that I have worked with have not covered a lot of these medications when people transition to hospice care. That's really just a very clear cost issue, based on how hospice care is reimbursed, not necessarily because people don't think that it's helpful for symptom management. So, when we are aware that that transition needs to happen, we feel pretty strongly about making those transitions in the

hospital where we can monitor people for symptoms and make sure that things are under control before they transition back home or to a skilled nursing facility or inpatient hospice, so we can get a regimen that is going to help people feel comfortable.

Dr Barnett: I think this really represents a particularly difficult situation for a number of reasons. One was mentioned before: many of these patients are relatively young. And, it's not uncommon that there's few other medical problems. They may have had PH for some period of time or, even if it was diagnosed recently, often there are not a lot of other medical problems, and so there's always difficulty with the transition from aggressive care to more comfort care. And then the other thing is I think when folks are so sick that they require these sort of therapies—parenteral prostanoids in particular—that it's nearly impossible to stop those therapies, to titrate them off, and subsequently have someone leave the hospital to an outpatient setting, because usually they're so sick that they pass away in the hospital. I think, unfortunately, that's been the way that most of the PH patients that I've taken care of have passed away in the hospital, quite sick. It's challenging to find a better way to do that.

Dr Swetz: I just want to comment a little bit on my experience, which is similar in many ways, but just might add some different anecdotes. I think the inpatient end-of-life experience is something that most of us have been a part of. Dan Grinnan and Paul Fairman at Virginia Commonwealth did a nice study a few years back published in the *Journal of Palliative Medicine*, looking at some of the places of death and some of the challenges. And subsequent to that, I think there was a paper by Colin Wozencraft and then subsequently a full protocol by the University of Kansas group, Karen Williamson Porter and Lindy Landzaat, that talked about if someone was going to be de-escalated, It's important because sometimes it's not a matter of they don't want the drip still on, but they don't want it stopped abruptly. There's been some nice litera-

ture to at least walk clinicians through how that can be done in a respectful way, which might hopefully minimize symptoms. I think from my experience when I have had patients that have left the hospital and gone home, with hospice and parenteral prostanoids, the two things to point out I think are: one, that it's very rare that a small, not-for-profit hospice can handle that, because the overhead, as Anne mentioned earlier, the costs associated with it are prohibitive. But I think when there are larger agencies that are hospice and home health companies combined, they may have their own pharmacy services that can get the prostanoids and work with them in an appropriate fashion to provide that type of care. That's been one thing. The second thing when I've talked to hospices about this and they've agreed to consider, I usually do explain everything we've talked about, but I also explain that if we're looking at \$300,000 a year, we're probably not looking at survival longer than a few days. So, the cost of that \$300,000 a year might not be an issue as the person might have the drugs at home already, just waiting to be mixed up. So, it might not be that the hospice is going to be responsible; it might just be where they're going to be responsible for the transition. And then there are centers: I know that Traci Stewart and colleagues from the University of Iowa have discussed the idea of a drug repository, where they work with patients who have passed away to try to have non-expired medicines available to patients that might be considered for home hospice. So, it's just some thoughts for outside the box. But you're right; the majority of folks do end up dying in hospital because it's even hard to get them out of there on that regimen.

Dr Groninger: Thanks. I wanted to conclude by just asking people on the call for any sort of final thoughts or anything that I didn't introduce in this conversation that would be helpful for people to share. I might start with Chris.

Dr Barnett: I think the big takeaways—what we are hoping to accomplish—is to have more PH providers have some

ideas about how they can integrate palliative care or at least palliative care concepts into their practice. And like Donna pointed out, I don't think this is something unique to PH, the timing that's probably best is starting at the time of diagnosis. And then as Anne said earlier, it really shouldn't be book-ended. It shouldn't be at the beginning and the end; it should be in the middle. I think it's a challenge to PH providers like me to find ways to do this. I think it's really incumbent upon us to try and achieve this and do better with this. So, I hope that that's something that folks reading this will walk away thinking about.

Ms Hershey: I think integrating it with the PH providers is probably the best thing to do, because then you don't have to introduce a new person who doesn't know the patient. But the more that providers can be familiar with just asking questions like, “What are your goals in life and how are we helping you meet them,” and “What's holding you back from having what you feel would be your best life right now,”—whether it's particular symptoms, side effects, whether the shortness of breath is getting in the way or whatever it might be, maybe they're traveling too far to come to appointments. Maybe there are little things that could be done. I don't know the best way to integrate those kind of things so that PH providers are more familiar with asking about them, but I'm sure that tools could be developed to get people thinking about those kind of topics, rather than just how far can you walk and what is your oxygen saturation and things like that.

Dr Groninger: Keith and Anne, any final thoughts to share?

Dr Kinderman: I would say, piggy-backing off of that, there definitely are tools that are available that could be incorporated. There are things like the palliative care group at Harvard has developed, the *Serious Illness Conversation Guide* (<https://www.ariadnelabs.org/areas-of-work/serious-illness-care/resources/#Downloads&c%20Tools>), that providers can be trained to use. There are

symptom screening tools and things that could be used routinely in a PH practice that then could trigger for when people need more help or more support from a palliative care specialist, as opposed to the day-to-day management of these complex illnesses. The other thing that I would mention that we haven't really talked about is something that I've experienced with a PH patient that we had a few months back that was really compelling for me is it was really hard for her to emotionally make the decision to transition to hospice, in part because she felt like she was giving up. That's not uncommon, but I think in this case in particular, where people sometimes have a relationship with their PH providers for years and they've seen them through really hard times and they've cheerlead-ed them when they're feeling down or hopeless, and so they really feel like, “I can't tell Dr Barnett that I'm going to stop, because I would be disappointing him.” Or with the other patients that they're involved with in support groups. I had a patient who had been really active on a PH Facebook group and she felt a lot of pushback when—and actually was deciding not to be on the group—when she was making the decision to transition to hospice, because she felt judged and there was a lot of pushback around that decision, which was the right decision for her. So that's something, too, that I wanted to throw into the mix.

Dr Groninger: Keith, you get the last word.

Dr Swetz: I have taken care of many wonderful patients but two stick out in my mind who were excellent friends back in Minnesota. One did go on to lung transplant and still is alive and one did not; she ended up passing away just before New Year's Day, on her husband's birthday, a few years ago. My promise to them of why I thought this field was important was because we always can do better, and we always can focus on helping people to live each day the best that it can be, as many of you said. I think that this roundtable and the work that each of you is doing to advance this field speaks to that. I know that they would be very honored and very proud for all of

your efforts. So, thank you for allowing me to be part of this. And may we all continue to do this good work and find out how we could do it even better.

Dr Groninger: I echo what people said. I'm grateful to all of you for being a part of this. And especially Donna for bring-

ing your unique perspective here. I think one thing that makes me hopeful for the next iteration of our work together, not only do I think about how we can bring palliative expertise into collaborative care with PH providers and with patients, but I'm also thinking about how—some of you sort of alluded to—how we can help

PH providers learn more about what it is that we do. And that we use the term primary palliative care to consider the skills of the conversation and symptom management and so on. It's almost like a multiplier effect. And I would sort of gently charge all of us to work on that together in the future.