

KEYNOTE ADDRESS: INTEGRATING PALLIATIVE CARE INTO THE CANCER CARE SETTING: THE ROLE OF THE ADVANCED PRACTITIONER

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DR. VON GUNTEN ...of my career across many, many years. What Pam didn't say is I'm a medical oncologist; that's where I got started in this field. And it's from medical oncology and the palliative care part of it that my career then progressed.

So, talking about integrating palliative care into the cancer care setting is close to my heart and as close is the role of the oncology advanced practitioner. Whether you're an advanced practice nurse or a physician assistant or a pharmacist, it takes a team to do oncology; it takes a team that's slightly bigger to make sure palliative care is part of the care of a cancer patient.

Now, these are the learning objectives. By the end of this, I want you to be able to describe the data that supports the integration of palliative care with oncology. This isn't just about feeling good; there is strong data about why it's better care. I want you to be able to describe at least palliative care skills that anyone in this room can bring to the practice of oncology. I want you to be able to compare and contrast type 1 and type 2 oncologists in order to better play a team role in providing care. I heard that murmur in the room. And then I want you to be able to identify at least two barriers to the integration of palliative care into standard cancer care.

I have no financial issues to disclose related to this talk.

So, that point - I'm not going to show you a lot of graphs and data. The key message for you as clinicians is the data is in; it's clear, it's convincing. Palliative care leads to better outcomes for patients. So, the major challenge now is how do you make it a part of standard cancer care everywhere in the United States and then from there, everywhere else in the world?

Developing the workforce, including everyone that works in oncology, is a key next step and you are an important part of that. Now, the data is so clear that the American Society of Clinical Oncology has issued a clinical practice guideline. They only do this when the data is so convincing that concurrent palliative care from the time of diagnosis of serious illness forward from the beginning of cancer care is the best standard.

So, now how do we make it part of routine care? So, in translating it to routine practice, I would call the thing that each of you needs. No matter where you are in oncology, you need primary palliative care skills in the same way that you need primary cardiology skills. You know how to manage heart failure, you know the basics of heart disease, just like you know the basics of endocrinology, and it's part of routine practice. The same is true for palliative care.

And what every clinician—including every clinician in this room—needs to know about and put in part of his or her practice are the keys to patient-centered communication, to being able to communicate diagnosis and prognosis. “Doctor, what’s wrong with me? What will happen to me?” Those are being part of what patients have brought to healthcare since the beginning. We tend to be better

about communicating what's wrong and we tend to not communicate so well about what will happen.

Then, negotiating those goals of care. Knowing what we know and knowing who you are as a patient, as a part of your family, what are our overall goals so we can all be working toward them together knowing that for many patients, those goals change over time? And throughout, ensuring that symptoms are impeccably controlled. Those are key skills each of you should be working to master as part of your practice.

Now, since this is a large group and it's traditional in healthcare to start with a case, I want to start with a case that was from my earliest days as a medical oncologist; I had just finished fellowship. This is Frank sitting at a conference not unlike this with his son. He's at lunch, he developed a cough and a fever. And because it was bad enough and didn't get well on its own, he went to the emergency department and they diagnosed pneumonia. And because it was bad enough that he really couldn't be sent home for home treatment, he was admitted to the hospital for antibiotic therapy.

But, when the cough and the fever didn't clear in quite the way they expected, a CT of the chest was done. And you can see right here on the right side of the chest a mass that does not belong there. And because he had aches and pains that were worse than what you would expect from just community-acquired pneumonia, a bone scan was done. And you can see at the tips of the red arrows – don't you love it when scans come with arrows to look? You can see those arrows of uptake and you can see on his axial skeleton the areas.

So, when his sputum sample came back positive for adenocarcinoma of the lung, it wasn't really a shock after these findings. So, instead of being a 58-year-old man with community-acquired pneumonia, he has metastatic lung cancer with a post-obstructive pneumonia. Now, does Frank need palliative care now, today? You should say, "Absolutely." Does he have symptoms out of control? Does he need appropriate communication, not just about his situation, but about the future and his family and how he's going to cope with this? Frank wants the best cancer care, but he wants it in the context of not hurting his family and doing as well as he can.

Oh, and by the way, he's not insured. Well, he's a 58-year-old man, he thinks he's healthy, why would he need health insurance? That's for old people. So, the point is, it's all of it together that needs attention somewhat urgently.

Now, we know how this story will end. We know how Frank's story will end. No matter what we have developed, we still do not cure metastatic lung cancer. So, this is looking at the end of the story. This is from a study that Joan Teno did looking at a representative sample of all deaths in the United States—all of them. All deaths in the U.S. And looked at by where the person died and did a telephone survey of their surviving family members. And this is the answer to the question, "Did your family member get excellent quality of care?"

And this is whether they died with a home health home care, died with a hospice agency, died in a nursing home, or died in a hospital. And you'll notice this is the percent of the families, these large numbers. This is nearly a two-fold difference. So, it is also, I think, fact that hospice care provides the best end of

life care and it should be the conclusion of every patient's care who is expected to die because of this data, because the care is nearly twice as good as in any other setting.

Now, in this next graph from the same paper, this goes into some of the component questions. "Did the patient want more pain relief? Did the patient want more physician contact? And did the patient get no respect?" Same sort of layout here with where the person died and the percent of family members saying this.

Well, as your eyes go over this, what strikes you about this data? Well, the first one that should strike you as really odd is that 50% of family members said that when the patient died in the hospital, they wanted more physician contact. Now, if someone was sick in Hollywood, Florida, and said, "I need to get to a doctor," where would they go? To the hospital, right? Hospitals are crawling with doctors. How could it be that patients dying in the hospital want more physician contact when they are everywhere?

Where was it that patients got no respect? Well, the highest factor was in the nursing homes. Where was it that they wanted more pain relief? Well, that was at home with a home health agency following. And where were these, the best of all three places? In-home hospice care where you know home hospice care is not crawling with doctors. At home is being at home with only intermittent visits and yet, they said they got excellent care and these core things/needs were met. I think this is really important for each of us to know because hospice care is

no longer an alternative, a choice; it is best standard of care for those who are expected to die.

It also costs less. This is cost data published in *Health Affairs* and it shouldn't surprise you. This is the cost of hospitalization. When people stay at home and aren't hospitalized, overall cost of care is less. And that is an enormous challenge in the U.S. now. So, making sure that people have their symptoms controlled, their families well looked after and so, they can stay out of the ED and out of the hospital is a major push for healthcare moving forward.

So, palliative care grew out of and includes hospice care and I think this is important. And for those of us who come from oncology, this should strike you as not the least bit strange. Where did standard medical oncology come from? It came from the care of the dying. It still comes from care of the dying. Phase 1 studies are done by definition in those who are dying of cancer and nothing else will work.

And when we find something that works, we then look to, "All right, well, who else will it work for?" And for those that aren't dying, we move forward in the trajectory of illness. I view palliative care as no different than every other aspect of oncology in that regard.

Now, this is a diagram of, I would say, the conceptual model of healthcare. Some of you have seen it, and the reason I include it is because I think this still bedevils healthcare professionals, families, patients. So, if this in the red box is all the healthcare that someone will get – like Frank, from the time he presented in the ED to the time he dies – many people think about this as anti-disease

therapy, anti-cancer therapy. This is certainly the way I was trained as a medical oncology fellow and it wasn't that long ago and I still see it as the same patterns in the cancer centers where I go.

“Oh, Frank, it's a little lung cancer. Come on, come on, we've got great, new things. There's so much to offer. Come on, come on, we've got to fight it. You're a fighter, we're going to fight it, fight it, and fight it. Come on.” “Oh, we lost one. Oh, well, another casualty in the war on cancer, on to the next.” Now, you laughed. I hope it was an uncomfortable laugh.

And so, we just came up with comfort care. Comfort care at the end of life, which I've put here in the yellow box. And we developed the hospice care model and the hospice care approach to funding it, including bereavement care for family, clearly an improvement over the red box alone. But, what's the problem with this model? Well, it's an either/or model; you're either in red land or in yellow land, care land or comfort only land.

Nicholas Christakis when he was working at Harvard described this the over-the-wall model. You pitch the patient over the wall from curative land into comfort land. That either/or model, think about the language. You wouldn't do it, of course, but others, “Is he palliative yet? Is he ready to stop yet?” Any of that language is an either/or red, yellow model.

And if we use the word “palliative care” and we do nothing to change our mental model, it shouldn't be a surprise that patients, families, oncologists, “No, no, not the palliative care. Please, no.” Recognize that? Sure. It's because it's the same model, you're either in red land or yellow land. Yet, I said what we've

discovered is the best are possible. Right now, our ability to relieve suffering and improve quality of life has never been more powerful than in the history of human medicine, 5,000 years. The key is how do we make sure it's available to those who need it whenever they need it? In other words, making it available from the time of presentation of illness through the course. In this model, hospice care becomes the completion of good cancer care.

Now, this makes things more challenging. Either/or, black/white, red/yellow is much easier than both/and because negotiating that with a patient, with other team members is much more challenging. But, the data is clear: people do better. And what I advocate for you is this is your mental model because if it isn't yours, there is no way you'll be able to transmit that to the patients and the families who need it, as well as the rest of the oncology team.

Now, this is the data that rocked the oncology world. Many of you will have seen this; this was published in the *New England Journal of Medicine*. Jennifer Temel and her group, they randomized patients like Frank—advanced metastatic cancer from the time of diagnosis—to one of two groups: either those that got standard care, which permitted palliative care consultation if the oncologist asked for it, or in the red line, combined concurrent specialist palliative care. An advanced practice provider, and a social worker or a doc and social worker saw the patients concurrently throughout their course.

Now, for those of you who have been to enough oncology meetings, just when you see Kaplan-Meier plots like this, you usually associate this with the latest new drug, right? And then curves separate this far, you know, “Oh, my

God, this is going to be a blockbuster, billion-dollar drug.” You can see the drug reps salivating.

And the journals love it because, “Oh, the ad revenue is going to come in because this is a major step forward.” People lived, on average, 3 months longer for people with advanced lung cancer. They lived better, they had a better understanding of their prognosis, there was a better determination of overall goals of care. They got less IV chemotherapy, and yet, they lived longer. And all measures of quality of life—pain symptoms, mood—everything was better. If it was a drug, it would sell billions. But palliative care doesn’t have a for-profit model behind it; it’s knowledge, it’s people like you working together.

So, let me take it to another real patient. This is Peppy Chernoff. She had moved to Columbus from New York City. She was diagnosed in Columbus with inflammatory breast cancer right after she moved, sort of welcome to Columbus. And it was a stage IV diagnosis; it had spread to her bones, her liver, and her lungs. Her primary care doc asked for palliative medicine to help with pain management, her medical oncologist agreed, and so, I saw her at home.

[A video clip is now played.]

MS. CHERNOFF: I was originally diagnosed with stage IV metastatic breast cancer. From the get-go, do not pass go, do not collect \$200, just go to the top of the class. And I thought it was a death sentence and I took very, very, very aggressive chemo that practically killed me, but I was getting over it.

Anyway, I get a call from Cindy saying that you would like to come and see me. And I’m thinking, “A doctor that makes house calls? This is very

interesting.” But I was sort of skeptical because then I figured, “Oh, God, I’m in worse condition than I thought.” And I knew I was bad, but I didn’t know I was that bad. And when I first met you, I remember the first thing I said to you, “Do not mention two words to me. Do not mention ‘palliative care’ and do not mention ‘hospice’.”

[End of video clip.]

DR. VON GUNTEN So, I heard the chuckles out there. Pepe is a colorful character, right? So, a show of hands, how many of you have ever either lived or have visited the Midwest? Okay. So, somebody like Peppy from – you can tell she’s a New Yorker, right? Yeah. She scares people in Columbus. And I think that’s part of the reason I was asked to see her. But this little snit from an interview that Peppy gave – she wanted to give – do you catch the pieces that don’t fit? Peppy knows her diagnosis. She is smart, she has read, she knows what stage IV metastatic breast cancer is, and she knows that the outcome of the chemotherapy that nearly killed her is not good. Her cancer did not shrink. And, yet, she says, “Don’t use the word ‘hospice,’ don’t use the word ‘palliative care.’”

Well, Peppy is using that mental model of either/or; you’re either in red land or in yellow land. Peppy would say she’s a fighter. She’s from New York, can you tell? The challenge is, all right, how do we care for someone who this is the presentation? And too often I see this: “Oh, all right, fine. No, I won’t talk about that, we’ll just talk about the next chemo.” Is that fair to Peppy?

What went through your mind? Why is Peppy saying that? She’s scared to death. She’s so frightened, just saying those words out loud frighten her, so, she

doesn't want them mentioned. It doesn't mean she doesn't know the truth, she does. The data are very clear. The patients who look to us to be in what we would use Kübler-Ross stage denial, are not. All they are saying is, "I don't want to talk about it, it makes me anxious." So, my response to Peppy was, "Fine, I promise I won't use those two words. Tell me how I can help you." And we were off to the races.

I don't care what we call it. But what's the care that she needed? She had a husband with bad heart failure, and she was sure he was supposed to die before she was and now that – and she had two daughters, one who was living at home who has an opioid use disorder. Think she has a lot on her mind? Yeah. So, there's a lot to work with Peppy with. She also has cancer pain.

Now, I was asked to help build a palliative care program at an NCI-designated cancer center some years ago, UCSD. You can take from this photograph how they think of themselves. There is no touchy-feely here. This is about hard science; cancer is cured in the laboratory. But they had a high medical oncologist turnover. Fifty percent of the clinical oncologists were leaving every year, as opposed to the research oncologists who were 80% in the lab. They needed help and what the doctors were saying is, "Please, we need palliative care."

So, this is the palliative care team – advanced practice nurse here, secretary to take the calls, psychologist, pharmacists, social worker, and the somewhat middle-aged palliator. Now, you notice it says the Doris Howell Service, the Doris Howell Palliative Care Service. Why? Well, first, I wanted to

name it for this woman, just pointing out that Heather here as the heroine for the purposes of this crowd. But I would ask for those of you who are advanced practice pharmacists, the pharmacist also practices in an advanced way in this team.

But it's named for Doris Howell, a pediatric oncologist. You know, she's older than I am. She's been in this longer than I am. And she had been advocating for palliative care as part of standard pediatric cancer care for her entire career and didn't feel like she had gotten very far. Anywhere on campus if you said Doris Howell's name, people say, "Oh, I love that woman. I love her." Well, wouldn't you want a service that had that kind of a name and that kind of brand recognition? Of course.

And I went to every oncologist in that NCI-designated cancer center and I said, "I know that you know that palliative care starts from diagnosis and is woven together, but the patients that are sent to us are frequently told, 'Well, there's nothing else, you might as well go to the University unless you want palliative care.'" And, also, you know how hard it is sometimes for oncologists to bring it up. Not you, of course, but the other oncologists, and to a person. Every one of them said, "Charles, I agree. Absolutely. I get it, I know, but my colleagues here, oh, terrible, terrible."

And the patients that come, they expect a miracle when they come dragging themselves in. You get the picture? It's like your picture, right? So, this is data from just the first few months of that service. This is the oncologists

across the bottom letter and this is the number of patients that are referred to the Howell Service by doctor. So, let your eyes go over this for a minute.

Now, many people when they look at this, they say, “Oh, Charles, that A must be you, that superuser.” And I would say, “No, I’m not part of these data. I was a consultant, I’m not practicing medical oncology in this setting.” But for that person that thinks, “Oh, that warm, fuzzy kind of teddy bear–like doctor who loves taking care of patients and who gives them a warm embrace and involves the whole team,” well, that’s Dr. E. That’s why he went into oncology. He loves the people part.

Dr. A. is the busiest medical oncologist in the practice. She is on multiple national committees. She knows her patients need palliative care, but by God, it’s not going to be her. Think about it. It’s about working as a team and collaborating, it’s not about changing who people are for specialist teams.

Now, I’ve circled this group, there’s a medium to high user group. This is the bone marrow transplant group. Now, bone marrow transplant is not known for warm, touchy-feely doctors in the U.S., maybe except for your place. And, yet, they after the introduction of this service said, “Oh, my God, we cannot do transplant without it.” Now, no one goes to transplant for palliative purposes, everybody goes to transplant for a cure or long-term remission. And, yet, nearly a third were transplant patients and that continues to this day.

So, the point is, that this can be done even in highly research-intensive places if it’s sensitive. And that’s why I think this data is so important, the type 1 versus the type 2 oncologists. This came out of Massachusetts General Hospital

– Vicki Jackson and her group – as well as at the Dana Farber. The type 1 oncologists, they do biomedical and psychosocial together. That’s why they went into oncology; they love it. This would correspond to me. I love the people part; I love the emotions and the relationships. The cancer and the cancer biology is fine, but it’s part of a package. This group has clear communication strategies.

They have a sense of positive impact on patients and families, and like Dr. Ian McGrath, they need specialist palliative care for difficult symptoms or as Dr. E. would say, “When I got the family from hell.” Type 2, on the other hand, they went into oncology; they enjoy oncology because of the biomedical, they love the science. But they tend to be characterized by relatively distant patient and family relationships; they have poorly developed communication skills; and they have a deep sense of failure if things don’t go well with the cancer and they withdraw.

Now, what I’m not presenting this for is for you to judge, this simply seems to characterize the population. And as I go from place to place, the proportions of these seem to be different, but every place generally has some of both. Well, it’s like the graph I showed you, the role that palliative care needs to play is different depending on who you’re working with. And to assume that everyone needs the same thing is to make deep mistakes.

So, for you in your role, titrating yourself and your other colleagues, as well as the environment, will tell you the role that you need to play as an advanced practice provider in providing these direct skills or whether you take a seat with the oncologists because that’s what the oncologists find most meaningful in the work.

Palliative care is done as a team, physician and advanced practitioner. Most practitioners, CNSs, PAs, social work, chaplaincy, pharmacy; it's a team together, it's not one discipline alone.

The other point I would make—and I think this is what I've learned the past 25 years—is one of the reasons that physicians or nurses so often make such a good pair if there's recognition. Physicians are taught just like nurses are taught to assess with facts, but physicians are taught that your feelings are not fact. They will lead you to errors; you will kill patients if you listen to your feelings in making decisions about patient care.

Nurses are taught – and I learned this as I was setting up programs for nursing education at a number of nursing schools – the first pages of the textbook say, “Your feelings are additional facts.” That's why nurses can do better assessment, better care. You can be better advocates for patients because you see your feelings, you use what you know and feel about a patient to advocate. It makes a wonderful pair. It also means that's often what leads to conflict, if there isn't a recognition, that fact base is actually different between the two.

So, let's go back to Peppy. She's 5 years after diagnosis. The initial prognosis was less than 6 months with standard cancer care.

[A video clip is now played.]

MS. CHERNOFF: I think people have to be educated on really what is palliative care and that it doesn't mean that you're going to die tomorrow or you're going to die next week and it doesn't mean hospice. It means the whole

system of care, it means pain management, it means having somebody as wonderful as Charles coming to your house, you know, once a month and talking to you and giving you a lot of courage and a lot of moral support and listening to you – I hate to say bitch, but, you know, complain about things or tell him happy things.

[End of video clip.]

DR. VON GUNTEN So, what changed? How did the lady that said, “Don’t you dare use those words,” and scary and look like she meant it because the world’s greatest advocate for palliative care? Because she experienced it. Because her health professionals were not scared off by Peppy, who recognized where that was coming from and worked with her anyway. I cannot explain why Peppy is still alive; her medical oncologists can’t explain it either. She has not been getting chemotherapy. She says it’s because of her daughters. They still need her; they still need a good Jewish mother and they’re not ready yet.

I’m frequently told, “But, Charles, there’s a workforce shortage. What you imagine, that all sounds very good, it’s impossible.” So, worried about where I’m working now. When I got started there with that team approach for an entire system – I’m in charge of palliative care for a system of 11 hospitals, so it’s three and a half million people over 20 counties. That’s the sum total people we had; four physicians, seven advanced practice providers. Now, in 2018, 28 docs, 23 advanced practice providers. And I think in the next 5 years we’ll be here. I have 13 open physician positions. Yes, it’s hard, people, but if you don’t have the

vision, if you don't see where you're going, you can't pull people with you. So, the vision comes first and then perseverance.

Now, one point I want to make about medical oncologists—and I can say this because I am one—they make money from chemotherapy, they don't tell the truth, they don't tell prognosis, they're cold, heartless, and they don't care. They're anti-palliative care and anti-hospice. Anybody else heard that about them? Sure.

So, in our oncology group – because the issue of incorporating palliative care and particularly hospice care as part of that was important – so, I got the data for them, median length of stay, for every medical oncologist of our big teaching hospital and I listed it out, again, by doctor. And this is the median length of stay of the patients referred to the hospital program under their names from their hospitals.

And you can see they vary here. Dr. O. is seven days, Dr. D. is 50 days, but their average here was 21 days. The national average for all oncology patients is 44 days and I showed it to each one of them. And they were asked as a group, "What should it be?" And they said 90 days. So, this is a classic QI process. You said it should be 90, the national average is 40, and you're at 20; gee, there needs to be improvement.

And after 1 year with only one letter, their median length of stay doubled with no other intervention. They want to do the right thing. They all said to me, "Charles, I thought I was doing better." Well, that's like all of us; we all think we're

better than average, we think our patients are better than average. But, with a little data, with help, with support, things improve.

So, oncologists value palliative care highly. It's interesting, among our oncologists 25% want the palliative care specialists to do it, all right? Those are the type 2 oncologists. "Fine, we'll do it for you." And when they're given their own data, they improve.

This is a photograph of the wall in the 700-bed teaching hospital where the oncology unit is, but it says, "Oncology and Palliative Medicine." And nobody runs screaming, all the referrals don't run across the street to OSU. It's just part of how we do things and I think that's the way the rest of oncology – it will be this way with your participation, getting the skills, and moving forward.

But I want to transition now to thinking about the outcomes in a very patient-centered way. Maryn was a woman with stage III ovarian cancer, diagnosed in 2014, died at Christmas 2016. Her husband, Dr. Paul Been, was an emergency medicine physician and they interviewed him in front of a new class of fellows in July of 2017—so, about 6 months after his wife's death—at Kobacker House, which is our inpatient hospice unit. Dr. Hudak, who was Maryn's hospice doctor, is on the right.

[A video clip is now played.]

DR. BEEN In November of 2014, I took my wife on a surprise trip to Napa Valley and it was fun. We're not much of wine drinkers, but it's a beautiful part of the country. We came home and she's like, "I just don't feel good; I feel bloated." I said, "Of course, you just drank too much, you know, merlot or

whatever.” So, she just continued to be bloating and finally, the symptoms became pretty significant that I actually mis-utilized what emergency departments are for and brought her to one of our emergency departments—an Ohio Health Emergency Department—and had one of my partners take care of her and got a CAT scan and her belly was full of cancer.

And her life changed forever. That was a couple days after Christmas 2014. My wife was diagnosed with IIC serous ovarian carcinoma. It had traveled everywhere in the abdominal cavity.

[End of video clip.]

DR. VON GUNTEN So, beautiful description, summarizes it, straightforward. It makes sense, doesn't it? Okay? She went to OSU, the James Cancer Center, which is our NCI academic cancer center in town. She was debulked, a port was placed for chemo, she got standard therapy. And when she progressed after that, she was on experimental chemotherapy. She developed inoperable bowel obstruction with intractable nausea and vomiting, and one day she woke up after a bad night and said, “No more chemo.” And they organized being admitted to Kobacker House with the idea that she'd get better symptom control, but she expected to die within days.

[A video clip is now played.]

FEMALE If I may ask one follow-up question to you? You mentioned that day when she woke up and said she wasn't – you know, no more treatments, had that ever been discussed prior to that day? Had that ever been

kind of an option that was really discussed on the table with her treating teams, her oncologists? I'm curious.

DR. BEEN Yeah, it wasn't an option for me ever to give up. For me. And I don't think it was an option for Maryn, either. The team had never – we never heard the word “hospice” or “palliation” from the gyn onc team. Never, not once. In fact, we always had a contingency. You know, these trials are kind of crazy. One trial was pretty cardiotoxic and her EF dropped to like 22%. But, we already knew what Plan B was going to be, you know, if the trial didn't work.

So, it was never presented to us and we never asked about it. We were the patients and the family members, it wasn't our job to ask about therapies. But it wasn't presented to us. And Maryn woke up and said it was a horrible night; she was vomiting the whole night. Finally, got symptoms under – we were doing medicines at home and she had a port that we just accessed and – but, we woke up one morning and made some calls and the rest is history.

[End of video clip.]

DR. VON GUNTEN Now, I don't for a minute think that the possibility of death wasn't mentioned as part of her standard ovarian cancer care at the university. Think about Peppy. Think about what we've learned about patients and their families and how they cope. Did you notice he didn't really answer the question? He said, “I wasn't going to quit and she wasn't going to quit either.” Well, how often do you hear that? All the time. All the time. And, yet, I'm sure the data is pretty clear that patients are told. But you know that. You know that

actually better than all the oncologists. What people are told is not what they hear, it is not what they take in.

But what we can do is say, “All right, then we’ll never bring it up again.” Because I remember this model when I was still in oncology and asked one of the medical oncology faculty at Northwestern, “Oh, my God, what – you know, these patients, they go on and on and it’s like they have to cry ‘uncle’ before we stop.” And he just said, “Yeah. Yeah. Yeah, that’s just what happens,” and he walked out of the room.

To me, that’s not good enough. That’s not good enough when someone says, “I’m a fighter.” “All right, then we won’t talk about any palliation, we won’t talk about any of that.” But that is often the standard. Even if it’s brought on by the defensive protective mechanisms of patients, which is what I think is what happened here.

But whose responsibility is that for making sure that the symptom control was done well across the course, the goals of care negotiated over time because they evolve over time, they are nuanced, repetition is frequently required. And that planning for end of life care, which is important in someone like Maryn, because we know how the story ends as we know how it will end for Peppy and for Frank.

I think this is something each of us needs to wrestle with it. And it depends on whether you’re working with type 1 or type 2 oncologists and although the study has not been done, I suspect there are type 1 and type 2 advanced

practice providers. We need to know ourselves and our way that we interact so that the patient and family get the best care over time.

[A video clip is now played.]

By no means is my objective to slander the James. Or we can just refer to it as Maryn's site of care preinitiation of palliation.

But they just went like this when we said we're going on hospice. Honest to golly. I emailed with her primary once or twice and that was it. I called them when she died and --

[End of video clip.]

DR. VON GUNTEN So, I heard the murmur in the room. And I showed that to be a little shocking because when he said it, it was shocking. Do you feel that visceral sense of oh, that's not right? No patient wants to feel abandoned. But that's that red/yellow line. "Well, I guess you're moving out of our box into the next box. Goodbye." Do you think there's any -- because people are emotionally -- that it's hard? That these transitions are hard, particularly if they're sudden and abrupt as opposed to well developed?

Interesting, in our setting when we built the new Kobacker House—which was because of its size was at a distance from the main hospital—the medical oncologists stopped routinely seeing their patients when they were admitted. Simply a geography issue; it just wasn't on the route anymore. That happened 8 years ago. They still -- when I see them in the halls, they're kind of sheepish about. "Oh, I know I should come by." Well, what is that? It's an emotional need, right? It's an emotional need on the part of the oncologists.

So, I think for each of us – and I think it is particularly true in the advanced practice community where you are taking care of not just patients and families, you are taking care of your oncologists – whether they have radiation/surgical, radiation/gyn/onc or pediatric, recognizing what those needs are and how those are met and how to support that, I think is a key issue that this illustrates. And it illustrates because this is a doc; he expected something different from his physician colleagues.

And that's as true as everyone, but I think particularly those of us who are in the practice, in the field. Well, we've got to build those because right now we don't have a good model for that.

So, this right relationship between oncology and hospice care – even if you weave palliative care well, if somehow we have the idea that palliative care, well, that's different from hospice. Somehow, it's a disconnect and once you cross that line, you've crossed into another country. We're not serving the patients and families well. We've got to figure out how to build those bridges so it feels like the patient and family are well cared for across time.

[A video clip is now played.]

DR. BEEN: Maryn went home about a week after Labor Day, she spent 7 days here. It was amazing. As amazing as a place like this can be. Maryn was eating cornflakes, she was doing great. We kind of did octreotide. Dr. Hudak did octreotide for her, you know, bowel symptoms and it gave her a new life. A couple of things that Maryn said was, "I'm living now; I'm eating my cornflakes, I'm playing with the boys." And we went home and in between Labor Day and a

couple days after Christmas when she died, we went to Hocking Hills and rented a cabin with the kids and some friends and family. Maryn and I took a cooking class, and she was not able to do any of this during her illness.

[End of video clip.]

DR. VON GUNTEN It was amazing? An ED doc who said he's a fighter and will never give up and his wife is the same way and then they decide they are going to Kobacker House to the place to die, expecting to clasp their hands and start the IV morphine and the Ativan and fade away. It was amazing? And she was eating cornflakes when she was barfing up everything that she was eating and drinking before? The answer is yes.

Octreotide is an extraordinary, highly sophisticated advance in the treatment of malignant bowel obstruction that was not offered at the university for reasons that are not clear to me, but it's standard approach. A standard palliative medicine doctor and the APP working with her, standard approach, and guess what? The symptoms got better and she wanted to eat cornflakes and get the hell out of here.

And, in fact, "I really want to go play with my kids, they're three and five," and they did that. And they did it for 3 months and she felt better. Her pain was controlled, her nausea and vomiting was controlled, and she lived for 3 more months before she died.

Well, in thinking about that red box model and then the yellow box model, why was something that she didn't get until she got to the Kobacker House – why wasn't that available earlier? We should all say, "It should have been, I agree."

There's so many that – again, this line needs to be erased so these approaches are available across the course. Maryn should have had this across the course. But it also speaks to, “Oh, once you go to the hospice, we know what they do.” “Yeah, everybody, I know. I have 3 days.” And they do it to them. No, no, if people are referred 3 days before death, that's right, they die in 3 days. And it's an illusion that, “Well, if you kept on fighting and if we did, you would have lived longer.” The data is so clear that isn't true. People live longer when they get palliative care, whether it's in a team and part of a hospital or whether it's palliative care that's organized by a hospice program to be delivered at home. We've got to address these fundamental fallacies in our thinking or we won't move forward.

Maryn is a striking example just meant for teaching purposes. And her husband knows that I'm using it in this way for teaching purposes because from his point of view, he wants everybody to get the benefit because it was, as he said, amazing.

[A video clip is now played.]

FEMALE And how do you feel your role as a physician influenced this whole experience, you know, for both Maryn and your family?

DR. BEEN You know, we're ER doctors, so we like instant credit. I know there's a couple other ER doctors in the room. We like instant gratification. We were talking before, I cut my own lawn because it's long and I'll probably do it when I leave here. And then it's short, so it's instant gratification. It's great. I mean, I'm never going to – Evan's like, “You should just outsource it, you're so

busy.” I’m like, “No, it’s a very small lot, so, you know, it takes an hour. So, it’s just fun and it’s just gratifying.”

And like in the ER we like to fix things, you know? If a lung is down, we put a tube in it and then the lung is up, you know what I mean? If their blood pressure is low, we give them a couple bags of fluid and if that doesn’t work, we give them some pressors and we fix it and it’s amazing.

And, you know, I work at Riverside and Grant and they’re very busy as I’m sure the majority of you guys probably – you guys know, you know? So, don’t have time to sit down with patients for a really long time like you did with Maryn.

So, in the team that saw Maryn at the James – she was inpatient all the time for various complications, bowel obstruction, etc., etc. – they have one foot out the door, you know? You see the intern at 5:00 a.m. maybe or because they were drawing her blood at the same time, but you barely remember it. And then the team comes in and they’re out so quick.

And then you have a question, so then the intern or the mid-level resident comes back, “I don’t know, I’ve got to ask my senior.” The senior comes back, “I don’t know, I’ve got to ask my fellow.” The fellow comes back and says, “Well, it’s July, I don’t know, I’m a brand new fellow, I’ve got to ask the attending.”

So, you start at attempting to get an answer of, you know, “Are we going to go home? Are we going to switch from heparin to Lovenox to something else?” Well, you got the answer, “I don’t know,” 12 or 24 hours later. And that’s not what I like and that’s not what an ER doctor is, you know?

So, it has taught me to slow down in the ER, to sit down with the patient, to re-evaluate the patient more frequently. Come back and say, “Hey, you know, Mr. Jones, the chest x-ray looked great.” Patients want to hear results really quickly and I never realized that. I would go in at the beginning and say, “We’re going to do a big workup and we’ll get a lot of CAT scans. We’re going to give you some pain meds and I’ll come back when the workup’s over and you’ll probably go home.” And now I go back into the room as much as I can and the patients love it.

And after Maryn died, I find myself – with exceptions that you can count on one hand, I’ve never cried with a patient. I’ve cried in some pediatric resuscitations that unfortunately don’t go well because – even before I was a parent – but, we’re numb, right? I mean, I don’t know, I worked Friday and a guy coded and died and that’s what we do. It’s terrible. It’s terrible. And I walked into the next room and it’s almost as if it hadn’t happened.

And now I’m getting out later, I’m spending more time with patients, I’m reassuring patients more, I’m sitting down with patients. Press Ganey’s. Do you guys know about Press Ganey’s? My comments were, “Great doctor, really nice, really funny, loud, fast talker, and seemed like he was in a rush.” And now those aren’t my comments anymore. So, it was – and it’s because of you.

You sat down with Maryn and we said, “Don’t you have to go see another patient?” You said, “No, I’m in no rush.” And I never understood that. I was not able to not know rushing because that’s what we do. And I wish some of my partners would learn a little bit from this too.

You can't sit for an hour in a patient's room at Riverside, you just can't. Because you have 29 patients to see before your shift is over and you just can't. But it's nice to just sit down for a minute or two and spend time with family. So it's made me a much better physician, a much better human, a much better dad – not rushed – a much better friend and son. Great question.

[End of video clip.]

DR. VON GUNTEN So, not everyone needs to learn this because their wife dies. But I think this video clip illustrates what the integration of palliative care does for us as health professionals. The way we do practice changes. I remember when my practice changed, when I was first exposed to this. It makes a difference, it matters.

So, it brings up the importance of education. How do we learn this? In developing education programs over many years, we've asked everyone – first, the fellows, then the residents, then the nursing students, everyone – to do a personal reflection project, something that corresponds with what they learned at a deeper level. And I want to show you one that was designed to be given without words.

Now, in preface, I want you to notice the music. It uses the song from *Beauty and the Beast*, which has been used as a metaphor for the relationships between men and women, but it's also been used as a metaphor for the issues of life and death or life and bad things. I want you to notice that it begins with a reflection as all of us reflect on what's happened to us, who got good palliative care, who didn't.

And, finally, there's a slide in there with a horse. Yes, it really did happen. A kid who wanted to see a horse before he died, the volunteer happened to know somebody who had a horse who brought it up, who brought the horse to the patio so the kid could see the horse. Doing things that are extra special, that's part of what's fun about this field.

[Music is now played.]

DR. VON GUNTEN So, you can see what the doctor learned. I don't have to tell you, it was there. It's what each of us has to learn. So, let me finish with finishing off the story of Frank.

So, Frank got the best of cancer care. His lung cancer was treated and you can see here—and I'm grateful to the family for these photographs—he's losing weight, he's in a wheelchair, his performance status is now a 3. It's time for enrollment in hospice care, so he was enrolled. He spent 3 months enrolled in hospice care, did the things he wanted. And then he lapsed into unconsciousness and I thought he was dying. And I told the family I thought he had 24 to 48 hours left to live.

I got a call that he was restless and seemed uncomfortable and he had been taking dexamethasone as part of his pain regimen, but he could no longer swallow. Well, I said poke it up his bum, it's absorbed as well from a rectal mucosa as it is from an oral mucosa. I was sitting at my desk on Tuesday morning, it was 7:30 in the morning and the phone rang and it was Frank. "I want to go to Pennsylvania." So, that great palliative care phrase, "Tell me more."

His son was getting married, there was no way they could see Frank before he died and get married and keep with their work schedule. And they had just had his first grandchild and he wanted to see the grandchild. So, if it was you, should he go? Yeah. Is it up to Frank? He can't walk, he can't get out of bed, his doctor said he had 2 days left to live and that was 3 days ago, so his family was all for it.

But what are the rules? There was no way for him to go by air ambulance, there was no way he could go by car; he had to fly a commercial airline. Well, what are the rules? Well, it was the social worker on the team, "FAA says you must land if someone dies in route." So all of you who were so enthusiastic, if you'd been on that plane and he died and you put down in Kansas City instead of Philadelphia, you'd be a little less pleased, right?

So, the team's message was, "Okay, you're doing this last-ditch effort, it's fun to have something last ditch, it's fun, but you don't want to put other people out for it. So, if he dies, just tuck the blanket up under his chin and if anyone asks, say he's sleeping. Because once you get there and everybody gets out, well, then you can attend to the death and you can at least have tried."

But he did get there. If you were at the wedding, you would be on the lawn out behind their house in very rural Pennsylvania and they got married. And there's Frank with his wife and his new daughter-in-law and his son.

Yeah. Is this an outcome of medical care? I think it is. I think it's comprehensive cancer care that started from the day he encountered the healthcare system that carried him and his family through to an ending that was

right for them. So, for all of our patients, for all of your practice, I want you to commit to making palliative care part of what you do and building that expertise.

Thank you so much.

[END]