

# After A Cancer Diagnosis: Palliative Care And The Evolution Of The Doctor-Patient Relationship

Transcript for: [After A Cancer Diagnosis: Palliative Care And The Evolution Of The Doctor-Patient Relationship \(/shows/2013-10-03/after-cancer-diagnosis-palliative-care-and-evolution-doctor-patient-relationship\)](#)

**MR. KOJO NNAMDI**

13:06:39

From WAMU 88.5 at American University in Washington welcome to "The Kojo Nnamdi Show," connecting your neighborhood with the world. It's a paradox of cancer care in America. Cutting edge researchers and doctors are realizing the promise of personalized medicine, designing new therapies and drugs tailored to the unique genetic makeup of patients, extending the lives of millions of Americans. And yet the broader system itself is in crisis, so says a new report from the Institutes of Medicine. 1.6 million American are diagnosed with cancer every year. And too many of them end up paying too much for subpar care out of step with best practice.

**MR. KOJO NNAMDI**

13:07:28

Meanwhile, many doctors and patients dance around the difficult decisions they need to be having about how much different treatments cost, about whether it's better to fight an aggressive tumor or treat its symptoms without the misery of chemo and ultimately about how to tackle end-of-life questions. I'm joined this hour by Dr. Thomas Smith. He's a professor of oncology at Johns Hopkins Medical Institutions and director of its palliative care program. Dr. Smith, welcome.

**DR. THOMAS SMITH**

13:08:00

Thank you, Kojo. Please call me Tom.

**NNAMDI**

13:08:04

Thank you. Cancer is the second leading cause of death in America today. And while some doctors are delivering unprecedented care for patients, this new reports which you helped author is raising troubling questions about the way cancer care is practiced today and about the future. Is the cancer care system in crisis?

**SMITH**

13:08:25

It is and it's going to continue to be for the coming years. The good news is that more of us are getting older. I guess that's good news for most of us.

**NNAMDI**

13:08:35

Yes.

**SMITH**

13:08:36

More of us are getting cancer. The other good news is that more of us are surviving and for a longer period of time. The troubling part of that is that we often don't get the care that we should best get. And the care is getting so expensive going up at 8 to 10 to 11 percent per year in some cases for cancer care, that it's simply not sustainable. So we have to figure out a way to give people the best care but in a way that's sustainable for future generations as well.

**NNAMDI**

13:09:15

The broad statistics are pretty eye opening. You project that cancer diagnoses will spike by almost 50 percent by the year 2030, as our population ages. Meanwhile costs will continue to spike to unsustainable levels if we continue on our current trajectory. But I'd like you to talk about the current lay of the land on a more personal patient level. How would you assess the patient experience right now?

**SMITH**

13:09:44

It's extraordinarily variable. I'm a medical oncologist as well as a hospice and palliative medicine specialist. And I love the advances that we're having. I love seeing people get better from diseases that they couldn't get better with just years ago. There are drugs like Gleevec or imatinib for chronic myelogenous leukemia and a whole bunch of similar drugs that just make the disease go away for 90 to 95 percent of people.

**SMITH**

13:10:13

At the same time we're not having similar successes for the most common cancers, lung cancer, colorectal cancer, breast cancer, metastatic prostate cancer, although we're having more success with metastatic prostate cancer. And it's those solid tumors where people are often getting chemotherapy within the last month of their life. In the U.S. it's 20 to 30 percent of people are getting chemotherapy in their last month of life when it has almost no

chance of helping.

**SMITH**

13:10:42

The costs of chemotherapy are rising. The new drugs coming in are 10 to even more thousand dollars a month, oftentimes for what are very little gains. And the best predictor for the price of the newest drug is the price of the last drug that got approved. And there seems to be very little relationship between the price of a drug and its true value in treating cancer. I can't fix that part. I can fix parts that I control which is how we care for people.

**NNAMDI**

13:11:16

Dr. Thomas Smith is director of palliative medicine and professor of oncology at Johns Hopkins Medical Institutions. He sits on a cancer panel at the Institute of Medicine panel. It recently released a report on cancer care in America. It's titled "Delivering High Quality Cancer Care: Charting a New Course for a System in Crisis." If you have questions or comments for us, call us at 800-433-8850. Have you or a friend or family member gone through cancer treatment or palliative care? Call us at 800-433-8850, or you can send email to [kojo@wamu.org](mailto:kojo@wamu.org).

**NNAMDI**

13:11:52

Tom, one of the alarming findings in this study -- and there are a whole lot of them -- is that doctors are not adequately communicating with patients or that patients aren't really listening to their doctors, or maybe a little bit of both. I bring this up by way of preamble to a statistic that floored me. Eighty percent -- eighty percent of people who receive a terminal cancer diagnosis believe that they can beat the cancer. What does that statistic say to you?

**SMITH**

13:12:22

It says, we're not communicating well. It also says that people have a deep and abiding desire not to be dead, that they think what happens to their neighbor won't happen to them. And a real struggle with how to adapt to death in today's environment. I think we can do a tremendously better job of communicating with people. When I look at that 70 to 80 percent of people that we called up on the phone in the Cancore (sp?) study and asked, do you think a person like you could be cured of your cancer? These were all metastatic patients whose disease had spread and weren't curable with lung and colorectal cancer.

**SMITH**

13:13:08

Seventy percent or more said, yes, there's a chance. It's possible. I think that's a failure of us to communicate successfully and to help people make the transition to the next step. So almost all oncologists now will say, you have a cancer that can't be cured. And then we'll quickly add, but it's treatable, leaving people to think, well, maybe it's just like diabetes or maybe it's like...

**NNAMDI**

13:13:35

A false sense of optimism.

**SMITH**

13:13:37

Yes. And then if you follow those patients along in their course, most of the time we never circle around to have another conversation about what's going to happen to people. So using lung cancer as an example, in the charts of patients who have died with lung cancer, you'll only find about 20 to 25 percent of the time any notation that the doctor and the patient ever discussed what was going to happen and how to plan for it. And two months before people die, half of the lung cancer patients haven't had anybody even bring up the hospice word. That's a failure on our part to communicate very successfully.

**NNAMDI**

13:14:22

Cancer occupies a very strange place in the American psyche. It's something that most people fear in a very visceral way. And perhaps that leads us to celebrate this idea of fighting it. We cast people who decide to fight it as heroes. And in many ways, that is totally appropriate, but does this idea of heroically fighting cancer also implicitly make us question the courage of people who choose not to fight it, even in the light of evidence that they can't?

**SMITH**

13:14:57

Well, that's a great point. We all use the terms fighting cancer. I don't think I've ever heard any patient say about another patient, well he was a real coward because he didn't fight his cancer. It doesn't go that way. But if we just concentrate on fighting the disease, that's great at the beginning and it's great for curable diseases like testicular cancer, lymphoma, Hodgkin's disease, breast cancer after surgery. It's a great strategy. Fight it, be as sick as you need to be. Get every opportunity to beat the disease.

**SMITH**

13:15:36

But when the disease comes back and starts getting resistant to treatment, that strategy doesn't work very well and has some real downsides later. So patients who keep fighting never plan. Just say, I'm just going to do chemotherapy. I'm sure there's a drug out there for me, even though my cancer's gotten resistant to five different chemotherapy drugs already. I know there's a drug that will make it go away.

**SMITH**

13:16:02

They may end up getting chemotherapy within a week or two of their death. They may end up dying in the hospital or dying in the ICU, never having made any plans for a transition. Never having settled family issues, spiritual issues, existential issues, transition business, never had any chance to create a legacy. So that fight, fight, fight

although it sounds good has some real downside too.

**NNAMDI**

13:16:30

Underscoring that point, this report says that one in four cancer patients in Medicare dies where? In an intensive care unit. So when we talk about palliative care and what you were just talking about, getting enamored with the kinds of drugs that are prescribed or how the home visit system might work, on another level, the level you were just describing, this is really about planning. And if we are not realistic about the likelihood then we don't plan.

**SMITH**

13:17:01

Absolutely. My wife who is a geneticist who also deals with many serious illnesses -- and I just wrote an editorial called "The Good Planning Panel," completely getting away from death panels -- that we really get the type of care we negotiate at the end of life rather than the care that's just handed to us in the best terms. Let me define palliative care.

**NNAMDI**

13:17:28

Please do.

**SMITH**

13:17:28

Because most people don't know what it is.

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13:17:31

**SMITH**

13:17:32

Palliative care is specialty care for people with serious illness given alongside their usual care. And our goal is to maintain your and your family's quality of life. And we'll help you set medically appropriate goals, medically appropriate goals that are achievable, have open and honest communication and do careful symptom assessment and management. And this can be done anytime during a serious illness, not necessarily just at the end of life. So we do palliative care alongside people getting heart transplants, alongside people getting bone marrow transplants.

**SMITH**

13:18:12

That's different from hospice care which most people have to have a diagnosis where they're likely to die within the next six months. There aren't any good curative options and it's really the best strategy we have for keeping people home if they want to be at home, symptom free and helping them with spiritual issues as well as health issues.

**NNAMDI**

13:18:34

This idea of palliative care that you describe is still viewed skeptically by some. We heard of the debate during the debate over -- we heard of the point made during the debate over the Affordable Care Act that these would be so-called death panels. And it seems to me that if you're talking about planning for what is likely to eventually happen because that is what the scientific medical evidence indicates, that calling that a death panel may in fact be telling people that they shouldn't plan.

**SMITH**

13:19:15

And it's completely the opposite, as you suggest. So palliative care is about as far away from the death panel as you can be. In fact, we call it the anti-death panel. I have slides that have anti-death panel on them. Really think of palliative care as being one of the homeruns of American medicine in that whenever palliative care has been studied compared to usual care -- so it's your usual care plus palliative care versus just your usual care. People who have the palliative care part have better symptom management. They have better quality of life. They have less depression and less anxiety even though they know more about their illness.

**SMITH**

13:20:00

They have better quality of care particularly towards the end of life. Far fewer are going to end up in the ICU. Far fewer are going to end up dying with resuscitation. They may in fact even live longer. So third base in my homerun analogy would be people actually live longer with palliative care. Who knew? It turns out if you get your symptoms controlled you can keep going to little league games. You can keep going to synagogue. You can keep going to church. You can maintain your social role and be active and probably have less chance of dying of pneumonia or a pulmonary embolism or blood clot to the lungs.

**SMITH**

13:20:39

And the fourth part, really the run into home plate, is that this is care we can afford. There isn't a single study that shows adding palliative care increases the cost of medical care. In fact, most of the studies show substantial cost savings by finding out what people's choices are, honoring those choices. And most people choose to be at home rather than in the ICU in the hospital when it's not going to help them.

**NNAMDI**

13:21:12

Several people have to join this conversation and I do have to take a break. But before we go there, since you bring up the issue of cost, this has been a very big week within the American health care system with the rollout of the

Affordable Care Act. And many of the themes you highlight in this report read almost as a microcosm of the broader challenges facing our health care system, more people needing care, costs trending upwards. How does this report line up with the broader problems plaguing our health care system?

**SMITH** 13:21:41

Well, this report from the Institute of Medicine really lays out some nice ways that we can reduce the cost of care without reducing the quality of care. And that's really the tension. How can you maintain the good care that we have for a lot of people, not everybody-- you know, we've got 50 million people who don't have care -- how can we maintain the good quality of care for people who have it? How can we continue to have advances and pay for some of these new medicines and yet cut out the care that doesn't seem to help?

**SMITH** 13:22:16

And some of the things we mentioned were having really good clinical pathways based on the evidence. So taking some of the guesswork and imagination out of what to do for people, doing only those things which are really based on the evidence. That can save, in some cases, up to a third of the cost of caring for a cancer patient, one-third.

**NNAMDI** 13:22:42

Now we'll take that -- oh, please, you were -- finish your thought.

**SMITH** 13:22:43

And finally getting palliative care involved earlier in the care of people who have a serious illness, because that improves the care and is something that we can afford.

**NNAMDI** 13:22:55

Now we'll take that short break. If you have called, stay on the line. We will get to your calls. If the lines are busy, shoot us an email to [kojo@wamu.org](mailto:kojo@wamu.org). Why do you think we have such a difficult time talking about cancer and end-of-life issues, 800-433-8850. You can also shoot us a Tweet at [kojoshow](https://twitter.com/kojoshow) or go to our website [kojoshow.org](http://kojoshow.org). Ask a question or make a comment there. I'm Kojo Nnamdi.

**NNAMDI** 13:24:58

Welcome back. We're talking about palliative care and the doctor-patient relationship with Dr. Thomas Smith. He's director of palliative medicine and professor of oncology at Johns Hopkins Medical Institutions. We got a caller who couldn't stay on the line who said, "A couple of moments ago you referred to something called evidence-based medicine. Now as a patient I would like to think that all medicine is evidence-based but you're saying that isn't always the case?"

**SMITH** 13:25:23

That isn't always the case, Kojo. Let's use lung cancer as an example. I'm a medical oncologist. I love making cancer go away when I can. So someone has lung cancer that's spread to liver and bone. We know the average person lives eight to twelve months in the United States and in most of the world. Our survival figures are no better than anyone else's. Chemotherapy does add three to four months to that person's life and it helps relieve their symptoms. It will help maintain their quality of life but it's not a cure. So a first type of chemotherapy makes absolute sense in people who are well enough to withstand it.

**SMITH** 13:26:03

And a second type of chemotherapy makes good sense. It's been tested and compared to not giving chemotherapy and the average person will live about two months longer. Again, not a chance of cure but relieving symptoms, making people live better. A third line of chemotherapy can help some people. But if the cancer's now grown resistant to three different types of chemotherapy, the chance of a fourth chemotherapy or a fifth chemotherapy is only going to cause side effects and has no proven benefit in actually treating the cancer.

**SMITH** 13:26:41

And yet because it's so difficult to have these conversations and people are so hopeful -- and again this deep and abiding desire not to be dead -- sometimes patients and doctors will get a fourth type of chemotherapy, which has almost no chance of helping and a substantial chance of actually shortening someone's life by infection or bleeding complications, not to mention fatigue, nerve pain, other symptoms. That's where the evidence supports first and second and possibly third line chemotherapy in well people. But the evidence doesn't support giving additional chemotherapy right up until the time the person dies because we're so afraid of having the conversation.

**NNAMDI** 13:27:25

I think this would be an appropriate time for us to talk with Terri in Bethesda, Md. Terri, you're on the air. Go ahead, please.

**TERRI** 13:27:32

I couldn't have asked for a better segue. Thank you very much for this. This is an extremely difficult subject for me. I lost my father August 24 under this exact scenario. He had MDS, which is a form of leukemia, Struggled with it for many years. Almost 80 years old and had gone through an unnecessary surgery of exploration for an esophageal mass, which turned out to be benign but almost killed him. And then after that they tried third and fourth line forms

of chemo. And it cost me very precious time with him.

**TERRI**

13:28:21

At what point does it become malpractice when a doctor keeps treating, knowing it will actually not help and will harm the patient? Even if you can't say statistically, you know, as far as like a malpractice suit, you know, this person's 80. They're quantitative value on the books is less but that does not reduce the emotional value and my spiritual value and connection. When do you stop torturing people and when does it take the doctor's responsibility on that part?

**NNAMDI**

13:28:52

Tom Smith.

**SMITH**

13:28:54

Well, first of all, I'm very sorry for your loss of your father. It sounds very fresh and it sounds like it wasn't the best planning. I think as oncologists we all tend to be sometimes way too optimistic. And there are some treatments for MDS or Myelodysplastic syndrome that actually do help. But at a certain point the chance of the treatment helping is much less than the chance of the treatment harming. And yet it's hard for people -- oncologists like me to sit down with people and say what's truthful.

**SMITH**

13:29:36

We use -- or we try to use the ask, tell, ask method. We always want to ask, what do you want to know about your illness? What do you know about your illness? And maybe some important questions like, what's important to you? What are you hoping for? And then 90 percent of my patients will say, tell me everything, Tom. I need to know it in order to plan. And then we'll try to tell in understandable terms what the chance of the treatment helping is compared to the treatment side effects.

**SMITH**

13:30:15

So you can ask your doctor to please write down what's the chance of the chemotherapy helping and what are the top four side effects? How common are they and what can be done about them? And what are my alternatives if I don't take chemotherapy? And then the ask, tell, ask part, the second ask is to say, now that we've discussed this, what's your understanding of your situation as opposed to, any questions, usually as we're trying to get out of the room to the next patient.

**SMITH**

13:30:52

Patients and family should feel empowered to ask difficult questions like, what are my alternatives. What's the impact of this treatment proven to be on survival? And I don't know any third and fourth line treatments for my Myelodysplastic syndrome that have been proven to make people live better or live longer. And then if the treatment is making you sick, just stop it. We're also trying to counsel oncologists and hematologists like me to have what I would call a hospice information visit when we think people have three to six months left to live. So that when you do stop chemotherapy, you don't suddenly get abandoned by your hemoc (sp?) doctor and transition to a hospice team that you've never met before.

**SMITH**

13:31:47

If I've, as the oncologist, have had you meet with the hospice team six months before I think you might need them, then I can say, remember Bob the nice nurse who came out to meet you and Maria the social worker from hospice? Now it's time to get them more fully involved in your care. And that really helps that transition. It helps me with the transition and it helps families with the transition. I suspect it might have helped you and your father with the transition to know who would be taking care of you and know what that treatment would look like and let you put the resources in place to help your father stay at home.

**NNAMDI**

13:32:24

Terri, thank you very much for your call. On to Susan in Reston, Va. Susan, you're on the air. Go ahead, please.

**SUSAN**

13:32:31

Hi. Thank you for taking my call. I had a close family member who had glioblastoma brain cancer for about four or five years and then died seven years ago. He was married and had a young child and had had many types of the standard treatment. The end of his life was -- he was incontinent, urinary, bowel. He could barely put a sentence together. You know, his quality of life was so minimal.

**SUSAN**

13:32:53

And I think you bring up a good point about like any other profession, some doctors are more meticulous than others. The idea of bringing in a team, whether it's a hospice team or even having an advocate type of person in an oncology office who can really ask some of those questions that between the doctor-patient relationship might not come out. For my uncle -- it's my uncle -- his quality of life was so minimal that there really wasn't anything to say. Yet he was given some major experimental treatment. I'll take the rest of this off the air. So the idea of having a group is fantastic to communicate that so it's not all on the doctor.

**SUSAN**

13:33:32

But I'd also appreciate it if you could speak to the fact that the family found out that the doctor's office had a direct

financial gain for the medication that they suggested, the type of chemotherapy. And we actually took this to the doctor. And they ended up stopping the treatment. But the family met with the doctor and we felt it was a serious conflict of interest that had not been disclosed. So I'll take the answer off the air. Thanks.

**NNAMDI** 13:33:56

Susan, thank you very much for your call. Tom Smith, another major driver of costs in our health system is the way doctors and hospitals make money based on the number of tests they conduct or the number of things that they do.

**SMITH** 13:34:10

That is correct and that's not the main focus here today. But it is an issue with oncology in that in the past, in particular, oncologists have made money off the chemotherapy drugs that we deliver in the office or deliver in the hospital. And many of us have said, there's at least the potential for conflict of interest there. Luckily that model is moving away from us fairly quickly and the...

**NNAMDI** 13:34:36

To something called the pay for performance model.

**SMITH** 13:34:39

Well, pay for performance model would mean that we get paid based on the results we achieve. This, it's just the profit on chemotherapy has been cut from say 20 percent of the cost of the drug down to 6 percent because you do have storage costs and administrative costs. And I have to have nurses and a whole team and a pharmacist to make these drugs. So that whole process is in transition.

**SMITH** 13:35:06

I do think it makes very good sense for any seriously ill cancer patient to get palliative care involved early. And that's actually the recommendation from the American society of clinical oncology, that any seriously ill cancer patient should have palliative care involved early. A couple of reasons for that. Some oncologists are really good at helping people plan, helping managing the transition away from chemotherapy to more hospice type care. Some of us are really good ferreting out, well what's important to you? What goals do you have? What do you want to do with the rest of the time that you have?

**SMITH** 13:35:54

And we see that planning as being part of our job. And we concentrate on fixing people's symptoms and their depression and their fatigue and their pain. About half of us are wired another way. We're just not born that way. And we concentrate on fighting the disease. We never had any training in having these difficult discussions. And we don't know how to do it and we often don't see it that it's part of our job. Those -- and for those doctors, no death is satisfying, even if it's a well-planned-out death that achieved everything that the person wanted to in the time they had left.

**SMITH** 13:36:34

For those doctors in particular, getting palliative care involved early is going to make their experience better, their patient's experience better and their family's experience better. It turns out the more honest we are with people about their diagnosis and their prognosis, the more their hope is maintained. Completely avoiding these discussions doesn't help maintain even false hope.

**NNAMDI** 13:37:04

Bethany in Arlington, Va. would like to know, I think, as to how to have that discussion. But Bethany, you're on the air. Speak for yourself. Go ahead, please.

**BETHANY** 13:37:14

Hi, Kojo. Thanks for having me on the show. I'm a huge fan of your show. And thank you, Dr. Smith. I think is a really important subject. Yes, I have a sister who I'm very close to who has stage 4 metastasized breast cancer. And it's in her lungs, liver, you know, a lot of other areas. It's very serious and it's a very upsetting situation for all of us. And she's been bringing me to her doctor's appointments with her oncologist for the last couple months.

**BETHANY** 13:37:40

And what I haven't heard in any of these appointments is her prognosis. And I haven't heard much discussion about planning or palliative care or anything since my sister's still able to live at home and she's still able to drive. But I have the feeling that there's a lot coming at us, you know, down the road. And I wondered what your advice would be to a close family member who's been brought into the doctor's appointments with the oncologist but who -- but doesn't know how to raise these questions. Because I get the sense my sister may not want to know some of the answers.

**BETHANY** 13:38:12

But as someone I think who's going to be in her primary sort of caregiver circle, how do I -- how -- and what's appropriate for me to ask? And is it appropriate for me to try to talk to the doctor on the side? I'm so sorry it's a messy question but...

**NNAMDI**

13:38:26

I think the kind of question that Tom Smith is fairly used to.

**SMITH**

13:38:31

Well, first of all, thank you for going to your sister's doctor appointments. Having somebody as an interpreter is critically important and somebody to ask the tough questions when the person is afraid to know can be really, really helpful. And you shouldn't be shy about either getting the services you need or asking the questions you want and getting the answers to the questions that you ask. A simple way is to go to a website called [GetPalliativeCare.org](http://GetPalliativeCare.org). So [GetPalliativeCare.org](http://GetPalliativeCare.org), all one word.

**NNAMDI**

13:39:02

You can find a link at our website [kojoshow.org](http://kojoshow.org).

**SMITH**

13:39:06

So [GetPalliativeCare.org](http://GetPalliativeCare.org) and that will tell you the palliative care providers in your area. You can ask your oncologist, does he or she have any established relationships with palliative care providers? They may have one and just not be using it in your particular case. And I think you -- it's fair to ask either with your sister present or ask the oncologist him or herself, what does the future look like for my sister? On average how long do people live in her situation? What's likely to happen to her?

**SMITH**

13:39:45

A friend of mine who's in Belgium just did a study with patients with metastatic breast cancer and tried to figure out what scenario helps people make this transition from actively getting treatment to recognizing that at some point they're going to die within the next year or two.

**SMITH**

13:40:05

And it turned out, getting as much honest information as possible, but specifically saying we won't abandon you. And an example of a good statement that an oncologist might make would be, well, the average person in your sister's situation lives about eight months. And if your oncologist is giving your sister chemotherapy, he can look up on the article on which he's basing the chemotherapy, and say the average person lived eight months. Some people lived as long as two years, but many people didn't live more than a few months either. Remember it's an average of eight months.

**BETHANY**

13:40:46

Right.

**SMITH**

13:40:47

And we will be there with you every step of the way. So that non-abandonment part is really critical. But I think it's fair to ask the oncologist in the presence of your sister, well, what is the prognosis? And don't settle for, well, we're just mere mortals, we can't really tell. That's baloney. And then ask, can we get palliative care involved.

**BETHANY**

13:41:15

Mm-hmm.

**SMITH**

13:41:15

And how are we going to make the transition from active treatment to admitting that my sister at some point, likely within the next year or two, is going to die from this. We have to make some plans for her, for me, if she has children. If she has children, what a great time this would be to take advantage of her being relatively well and make some notes every year until they're 18, and then a note for going off to college, or a little DVD of things that I've learned in my life that I want to pass onto you. Sort of create a legacy now because in the setting of breast cancer spread to lungs and liver, life is very uncertain, and she might get a year or two with chemotherapy, but it could also be death in a month or two.

**BETHANY**

13:42:12

Mm-hmm.

**SMITH**

13:42:13

So take advantage of that time to do now. This is one of my pet peeves with oncologists, like myself, is that we often don't have these really heart-wrenching conversations early in this situation to let people know what's going to happen to them.

**NNAMDI**

13:42:31

Bethany, thank you very much for your call.

**BETHANY**

13:42:33

Thank you.

**NNAMDI**

13:42:33

We're going to take a short break. When we come back, we'll continue this conversation. If you have called, stay on the line. We'll try to get to your calls. If the lines are busy, send us an email to [kojo@wamu.org](mailto:kojo@wamu.org). Have you or a friend or family member gone through cancer treatment or palliative care? You can send us a tweet @kojoshow, or simply go to our website, [kojoshow.org](http://kojoshow.org), and join the conversation there. I'm Kojo Nnamdi.

**NNAMDI**

13:44:40

Welcome back to our conversation with Dr. Thomas Smith, director of palliative medicine and professor of oncology at Johns Hopkins Medical Institutions. We're talking about palliative care, and the doctor/patient relationship. We got an email from Susan Burket who is director of communications at Montgomery Hospice, who says, "We at Montgomery Hospice are huge advocates for educating cancer patients about the benefits and burdens of treatments. We also hold education programs for physicians, teaching them effective methods for communicating with patients."

**NNAMDI**

13:45:12

"Most physicians don't get any training on how to hold these difficult conversations." But you, Tom Smith, do teach young doctors about cancer treatment and how to talk with patients, and in some cases tell them something that nobody wants to hear, that they have a terminal illness. No disrespect to people in your line of work, but some doctors really aren't very good at things like empathy. Is that something you can teach them?

**SMITH**

13:45:37

Yes. The good news is that empathy can be taught. First off, hats off to Montgomery Hospice which is one of the wonderful providers here in the area. They do a great job taking care of my patients, and they offer services that can be really helpful to patients, and they are one of the hospices that will go out and see somebody when they're diagnosed. They don't have -- so they're not rushing in when the person has three days left to live to try to set up hospice services. So at Johns Hopkins, we train on the oncology fellows, the cancer treatment people, by having them work with simulated patients.

**SMITH**

13:46:19

So they have to tell a 57-year-old who came in for a gallbladder surgery that in fact that spot in her lung was cancer. And then in the next scenario, they have to tell her that the cancer has come back and has spread. And in the next scenario, they have to tell her that the cancer is growing through treatment and her time is limited. And in the last scenario they have to tell her that it's time to stop active treatment against the cancer and to help her transition to hospice care at home, which hopefully has been established already, and help her plan for the remainder of her life.

**SMITH**

13:47:03

We also do -- coming up in a week and a half, we're doing that with our third-year medical students, every single one of them. But if you're over 29, like I am, you got almost no training in this. And so most oncologists in practice probably never worked with a simulate patient, never had to learn how to give bad news, and so if they've learned it, they've learned it on the fly. And oncologists quickly divide themselves up into these two groups. One group is really good at it, and one group doesn't see it as their job. That's the group that really needs palliative care involved.

**SMITH**

13:47:43

If you feel like you're not getting adequate communication, first of all, tell your oncologist because he or she may be completely unaware, and may be in fact capable of doing a better job. Ask them to write down the diagnosis, the stage, what the treatment options are, what the main side effects are, what the alternatives are, is this curable or not? Ask them to write it down. It actually doesn't take that much longer to write it down then just say it, and it's a great way to set up a communication.

**SMITH**

13:48:20

The good news is that all of these skills can be taught, even to people who don't necessarily want to learn them. So there are plenty of ways for oncologists to learn these skills if they don't have them now.

**NNAMDI**

13:48:31

Here now is Julie in Arlington, Va. Julie, your turn.

**JULIE**

13:48:36

Hi, Kojo. Thank you so much for taking my call. I have a rare recurrence of Stage 4 squamous cell carcinoma. It only happens in about one percent of the population, and it's my second recurrence, and I've had two rounds of chemo and radiation. It's now recurred a third time, metastasized to my lymph nodes, and I just had a CT scan today, so I'm hoping the results are good. But I've been seeking out alternative treatments. I went to the Raw Food Institute in Connecticut with Lisa Wilson over the summer, and I also am looking at treatment through National Integrative Health Association, through NIHA.

**JULIE**

13:49:14

My question is, when there's so much compelling evidence for boosting the immune system and fighting and curing diseases via alternative methods, except for the fact that the doctors say there's no real research behind it, why are doctors so averse to supporting alternative methods of treatment? Insurance companies won't cover them, and generally will only discuss conventional treatment. I'm waiting on clinical trials through NIH, but I don't qualify

yet because of the size of my tumors, and I'm scheduled for an appointment at NIHA.

**JULIE**

13:49:43

I feel really good right now. I'm in a good, healthy place right now, except for the cancer, of course, and I have a supportive family and husband and two boys, and I'm just wondering what comments or advice can you help with me on that? I'm a full-time teacher and a full-time mom, so I'm not a stay-at-home mom with time to do all this.

**SMITH**

13:50:02

I'm sorry to hear about your cancer coming back, but it sounds like you're faring pretty well. And my first advice to you would be to keep as active as you can be, and keep exercising and keep eating a good diet. Many of us are more than happy to accept alternative or complimentary therapies if they've got really good proof behind them. A good example would be a study that one of my friends, Debra Barton from the Mayo Clinic, just published about using American ginseng to fight fatigue, and in fact, it really works.

**SMITH**

13:50:40

It's not gangbusters, but it helps, and there are essentially no side effects, and now they're testing even more concentrated parts. The problem with a lot of alternative and complimentary therapies is that there's no evidence behind them, and sometimes the assumptions in the science leading people to use them aren't going to work. The problem with immune therapy in particular has been that this is part of you. It's got all the same proteins and sugars on the outside of the cancer cell that makes it look just like any other squamous cell in the skin or wherever it came from.

**SMITH**

13:51:19

So it's been really difficult to get the immune system to recognize this cancer because it's only expressing thing that are you on its outside. There's some really exciting work with something called PD1 and anti-PD1, and ways to essentially fool the immune system into attacking something that it should recognize as self, and those are some of the most exciting clinical trials going on right now, and I would urge you to keep looking at the NIH, and keep looking other centers for those.

**SMITH**

13:51:50

But before you sign up for someone's alternative therapy, I would say show me the results in the last 60 patients you treated. What was the chance of the cancer shrinking? How long did that last? What were the main side effects? What was the quality of life? Things that we would all ask on a routine clinical trial. I guess the good part about most alternative and complimentary therapies that most of them are not too toxic, but frankly, if an alternative and complimentary therapy works, it's probably working by a mechanism that means it isn't an alternative and complimentary therapy.

**SMITH**

13:52:31

There are a lot of things we use like taxol made from the yew tree, and etoposide made from roots that are natural products, but they're really seen as chemotherapy rather than as natural products.

**NNAMDI**

13:52:47

Julie, thank you very much for your call. We got a tweet from KEI (sp?) who says, "First you're blaming the cancer patient, then doctors, how about big pharma?"

**SMITH**

13:52:57

Well, I'm not blaming anybody. Cancer is a terrible, terrible disease. We see the consequences of it all the time, and I'm not blaming patients at all. I am -- I would ask pharmaceutical companies for a lot more transparency in their costs, that every pharmaceutical company thinks, well, the cost of the -- the price of the last drug coming to market against cancer was \$10,000 a month. We'll just price ours at the same price. And that works well for the first three or four drugs on the market. But when every drug costs that amount of money, it's simply not sustainable, and there doesn't seem to be any relationship between the value of a drug in terms of its treating cancer, and the price.

**SMITH**

13:53:49

So you've got drugs like Gleevec, that actually makes chronic myelogenous leukemia go away, and it's priced the same as a drug that keeps your cancer from growing for about two months. And that's not sustainable, and we have to, as a nation, address it.

**NNAMDI**

13:54:07

A recent report finds that the costs of care are going to skyrocket. Many of the reasons are not unique to the cancer care side of the health industry. In the current system, patients are asked to make decisions about their care without really knowing how much their different options will cost. Consider the following fact of 13 cancer treatments approved by the FDA last year. Only one was proven to extend survival by more than six months, but each of the 13 drugs costs more than \$5,900 per month.

**NNAMDI**

13:54:34

You mentioned \$10,000 per month. Here's this email we got from Mannan. (sp?) "I'm a cancer patient, Stage 4, there's no Stage 5, whose cancer is so far under control with chemo since 2010. I know and understand that there

is no cure and only progression and death, but each month is one more month for me and my children. Until the side effects are not bearable or resistance is evident, I will keep doing it. I know I'm costing a lot, about \$10,000 per month, but not providing the drugs to save money or because I will die anyway is just not acceptable.

**NNAMDI**

13:55:08

"The issue is mostly high prices and too few new good drugs for cancer. The drug industry is failing and its greed has to be reined in. They need money for R&D. Okay. Let's give them a big prize when they discover a great drug, but let's separate the prize of drug to the access for consumers." What say you, Tom Smith.

**SMITH**

13:55:27

Well, first, I'm glad he's doing well, and if he's on something that's working, he should stay on it for as long as it's going to work. And that gets to the crux of the problem, is that these individual drugs coming out for the individual person are \$10,000 a month, and may work quite well for the individual. But when you add that up year after year, it is simply not a sustainable strategy for our country, and will lead to even more of people who have health insurance and those who don't. So I'm no health economist, and I can't fix that.

**SMITH**

13:56:02

What I can argue for, as we argued for in the Institute of Medicine report, is that people are -- know what their costs are so that they're given at the beginning of the treatment what their costs are. So at a minimum, they can figure out how much they would have to pay and whether or not it's going to bankrupt them. If you've got a 20 percent co-pay on \$10,000 a month, it may well indeed bankrupt you. If it's a life-saving drug, then it's probably worth it. If it's a drug that's not going to save your life and not going to prolong your life by much time, then it may not be worth it, and you may want to have a frank discussion with your healthcare system or your doctor about it.

**NNAMDI**

13:56:47

Dr. Thomas Smith is director of palliative medicine and professor of oncology at Johns Hopkins Medical Institutions. He sits on a cancer panel at the Institute of Medicine panel which -- on the Institute of Medicine, which recently released a report on cancer care in America titled "Delivering High Quality Cancer Care: Charting a New Course for a System in Crisis." Tom Smith, thank you so much for joining us.

**SMITH**

13:57:13

Thank you, Kojo.

**NNAMDI**

13:57:14

"The Kojo Nnamdi Show" is produced by Brendan Sweeney, Michael Martinez, Ingalisa Schrobsdorff, Tayla Burney, Kathy Goldgeier, Elizabeth Weinstein, and Stephannie Stokes. Our engineer, Tobey Schreiner. Natalie Yuravlivker is on the phones. Podcasts of all shows, audio archives, CDs and free transcripts are available at our website, kojoshow.org. To share questions or comments with us, email [kojo@wamu.org](mailto:kojo@wamu.org), join us on Facebook or send a tweet [@kojoshow](https://twitter.com/kojoshow). The managing producer is Brendan Sweeney. I'm Kojo Nnamdi.

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