

Yale CANCER CENTER *answers*

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The Future of Palliative Care

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Welcome to Yale Cancer Center Answers with your hosts doctors Francine Foss, Anees Chagpar and Steven Gore. Dr. Foss is a Professor of Medicine in the Section of Medical Oncology at the Yale Cancer Center, Dr. Chagpar is Associate Professor of Surgical Oncology and Director of the Breast Center at Smilow Cancer Hospital and Dr. Gore is Director of Hematological Malignancies at Smilow. Yale Cancer Center Answers features weekly conversations about the research, diagnosis and treatment of cancer and if you would like to join the conversation, you can submit questions and comments to canceranswers@yale.edu or you can leave a voicemail message at 888-234-4YCC. This week you will hear a conversation about palliative care with Dr. Andrew Putnam. Dr. Putnam is Assistant Professor of Medicine in Medical Oncology at Yale School of Medicine. Here is Dr. Anees Chagpar.

Chagpar Andrew let's start off with a definition. What exactly is palliative care?

Putnam Palliative care, and this is Cancer Answers, so let's think about it for a patient with cancer, a patient with cancer has an oncologist and the oncologist fights the cancer. And some of the things that the oncologist will do, will make the patient feel awful, chemotherapy can do that. However, they are fighting the cancer. I am the mirror image of that. In palliative care, we do not do anything about the cancer, but we fight nausea, constipation, and pain. We try to make the patient feel better. So palliative care is pain and symptom management, and also what we do is we with lots of conversations that can be very challenging to have both with patients and families about how things are going and mainly how the patient wants them to go, and then the last part is I find myself doing lots of interpreting of medical English from CAT scan reports and things like that where the patient looks and says, I have no clue with this says. So, we do a lot of communications of that as that.

Chagpar That really makes it sound like you are part of the medical team that you are fighting the symptoms so that the doctors can deliver the therapy better, and that you are helping the patient understand the results if their primary team has not communicated those well enough, but for a lot of people when they hear palliative care, no offense, they are thinking death panels, where does that imagery come in?

Putnam The joke among many palliative care docs is that when we go up onto the floors of the hospital, we should wear a black hood and carry a scythe because that certainly is how some people feel about us. The actual name of my subspecialty is hospice and palliative medicine, and so people hear hospice and everyone knows what hospice is and you are supposed to have less than 6 months to live and it is end-of-life and this is where people go to die. So that will often get mixed up with palliative care. Palliative care, the whole range of it, probably about 20% of it is actually hospice end-of-life stuff, but the other 80%, the vast majority of my patients, are actively getting chemotherapy, they are getting surgery, they are getting radiation, and I am helping them get on with their treatments, so the way we think about it is we are an extra layer of care, an extra layer of support for the patient and the family as they are going through the journey that is cancer.

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- Chagpar So when are you actually called into the whole process, are you there at the minute of diagnosis, or once treatment starts or is this something that it when things are not looking so good, and that is when people call your team?
- Putnam That can vary a great deal obviously. The World Health Organization back in 1990, their statement was that when someone gets their oncologist, they should get a palliative care doctor at the same time. Now obviously that is going to be far too expensive for the medical system to support. So where we get called is when the oncologist, or physician because we see lung disease, heart disease, so whenever the primary team feels that they want us to come in and help. Sometimes that can be at the very beginning. I have certainly have been called by oncologists the first time they see a patient saying, I want to give this person chemotherapy, but they are in a lot of pain or having severe nausea and we want to get them more comfortable, can you come and see them now? For patients like that we are involved at the same time that the oncologist gets involved. Other times we get called when someone is in the hospital and they are actively dying and we may get called into help in the very last moments of life, but most of the time we get called in obviously in the middle of those two, when the oncologist or the cardiologist, or the pulmonologist has been treating symptoms and has reached the point where they say it looks a little bit more challenging than I am able to do, let me call in an expert in pain and symptom management.
- Chagpar Do many hospitals have a pain team? Often there is a team of anesthesiologists who deal in pain management, but it seems to me from your description that palliative care is more than pain management. It is nausea management and constipation management, and I cannot sleep management, and all of that, is that right?
- Putnam Yes, that is very true, the list is something like 41 symptoms that cancer patients get and one of them is hiccups and hiccups are not very horrible most of the time. I had one patient who had been hiccupping for 5 months straight, and he had not been able to stop.
- Chagpar Gosh!
- Putnam And so they asked me to come and help with that, but as you said, poor sleep, I cannot poop, cannot pee, I am pooping too much, I am peeing too much, all of these things, nausea, vomiting, poor sleep, lack of energy, all of these things can really get in the way of a patient's quality of life, while they are on chemo, after chemo, and even before chemo.
- Chagpar Let's suppose you are called in to help with all of these 41 symptoms, how do you do that? How do you assess a patient and figure out what it is that is their main issue, because many of these patients I would assume have many issues, and then how do you help to deal with all of that?
- Putnam Hopefully they do not have all 41 symptoms at once, but going in and seeing a patient and/or a patient and their family, it is new and different every time, and so the main part is keeping your

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ears open, keeping your eyes open, and trying to figure out what is important to this patient and this family. Sometimes we are called for one thing, for example, we make a call for pain, please come and help with this patient's pain and that is relatively easy to understand, narcotics are medications that a lot of people are not comfortable with especially at higher doses, but we may get in and start talking to the patient and what is actually bothering them even more than their pain is their anxiety and there are various studies about this, that anxiety makes pain worse. So if you are treating pain, but not the anxiety, you may not make any progress with the pain, so sometimes we get called in for one thing and we find out that it is something else that it is actually the bigger problem. Sometimes we go in and there are five, six, seven, eight symptoms and not really understanding what is going on and just all sorts of things in which case a lot of it is the main part, listening to the patient, listening to the family. Asking questions that are open ended, that allow them to explain their feelings, their understanding of what is going on, and then going from there as to what we can do to help, usually we cannot help with everything in the first visit, but as I tell medical students, the main thing that I want to have happen when I leave that room is that the next time I show up I want the patient to smile, to go okay, here is someone who is on my side, here is someone who is going to help me. And so it may be that we just do the pain and the constipation that first day and then the next day, we are going to deal with the anxiety and other things, but we can do so much at one time without getting the patient lost in the process.

Chagpar How much of what you do is kind of psychosocial support versus pharmacologic therapies?

Putnam When you ask that question, I guess the main part of the answer is that palliative care is not just the physician. My team, our team, and by the definition of palliative care team, it has physicians, nurses, we have a physician's assistant, social worker, and chaplain, and then you can have other groups as well, but at least it is those four disciplines and so depending on the problems that the patient is having, different aspects of the different parts of the team will be more important. I had a patient who said they are comfortable, but cannot understand why God is doing this to them. I have been a good Catholic all my life, I have gone to church and here is God punishing me. Now I can talk a little bit about that, but getting my chaplain involved helps take that discussion to a whole new level that the patient and the chaplain can discuss. Other times it can be the patient is having some troubles, but the main concern is what is going to happen to my wife? She does not drive, I have always done all the bills, and there is no one at home to take care of her, what are we going to do? And again my social worker is much better at taking care of those things. I can do the pharmacology, I can do some social support, but our nurses come at problems that patients have from a totally different training, a totally different way of looking at things and they see things that I miss and I see things that they miss. So as a team working with the patients and families, we get far more done than we would just working individually.

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- Chagpar The other piece that you mentioned and I want to bring in just briefly is that you mentioned the family. How much is your treatment directed solely at the patient and how much of it is really encompassing the patient's family unit?
- Puntnam I think about palliative medicine, and I come from a background of family medicine, that was my training before palliative, and there we do not just look at the person in the bed, we look at the family, the friends who are standing around the bed, because the patient is suffering in one way, the physical symptoms, the actual having the cancer, however, the family and the friends close to that patient are also suffering. Often in very different ways, and the way of torturing someone is you do not hurt them, you hurt someone they love and make them listen, and that can break someone down much faster than if you do something to that individual because we can stand things ourselves. We just cannot stand things happening to the ones we love. So, it is really important helping families navigate what is going on with the patient, talking with them, seeing how it is affecting them, because so much of American medicine does not include them. We just figure that they have got to keep the stiff upper lip and move along taking care of the patient, but if the family cannot do it, then the whole care plan falls apart.
- Chagpar Tell me in the one minute that we have before the break, is all of your work focused on adult patients or does this affect kids too?
- Putnam Palliative care very much is involved with children as well. There are somewhere near 95 training programs or fellowships for palliative care around the country and something like 7 are more specifically for pediatric palliative care and there is a requirement for some pediatric palliative care in all the training programs whether they are adult or children focused. Here at Yale we are trying to start a pediatric palliative care program and that is very important as well.
- Chagpar We are going to pick up on the differences between adult and child palliative care after we take a short break for a medical minute. Please stay tuned for more information with my guest Dr. Andrew Putnam.

*Medical
Minute*

It is estimated that over 200,000 men in the United States will be diagnosed with prostate cancer this year, with almost 3000 of these diagnoses here in Connecticut. One in six American men will develop prostate cancer in the course of his lifetime. Major advances in the detection and treatment of prostate cancer have dramatically decreased the numbers of men who die from the disease. Screening for prostate cancer can be performed quickly and easily in a physician's office using two simple tests, a physical exam and a blood test. Clinical trials are currently underway at federally designated comprehensive cancer centers such as Yale Cancer Center and at Smilow Cancer Hospital at Yale-New Haven to test innovative new treatments for prostate cancer. The Artemis machine is a new technology being used at Smilow that enables targeted biopsies to be

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performed as opposed to removing multiple cores from the prostate for examination, which may not be necessary. This has been a medical minute brought to you as a public service by Yale Cancer Center and Smilow Cancer Hospital at Yale-New Haven. More information is available at yalecancercenter.org. You are listening to the WNPR, Connecticut's public media source for news and ideas.

Chagpar Welcome back to Yale Cancer Center Answers. This is Dr. Anees Chagpar and I am joined today by my guest, Dr. Andrew Putnam. We are talking about palliative care and the things that are new in palliative care and I guess one of the things that might not be quite so new but still reasonably new is this whole idea of palliative care being for kids too, because children do get cancer and I can imagine that that is not only a punch to the gut to the child, but also to their family and when you talk about treating the patient and the family and both their physical symptoms and their psychological symptoms, I can only imagine the challenges that palliative care has in that arena. Do you want to talk a little bit about that?

Putnam A large part of it is that we expect our older people to die. It is not easy to lose a parent or grandparent but at least when someone is 80 years old, 90 years old, we can say, well they had a good life. You know, they smoked, they did this, they did that, but at least we can understand it and usually families have friends or other people who had similar experiences. It is so different for the families who have a young child who has cancer or some other life limiting disease that's likely to end their life quickly. Most families will not know other people who have experienced that and so the amount of support that they need is huge and the amount of support that is available is often not very large and so pediatric palliative care is designed to again, help with the pain and other symptoms that the children suffers, but a lot of what we do is talk with families about what does this mean for them, what does this mean for their child and is chemotherapy the right way to go? If they are saying there is not much more to do we bring up the idea of hospice and it is very hard to do with parents who obviously love their child and they are looking at their 5-year-old, 10-year-old, 2-year-old child who is going to die soon and how to help them is a great challenge even for those of us who do pediatric palliative care.

Chagpar I can imagine even before it gets to the point of hospice when you are talking about symptom management, watching your child go through nausea and vomiting and hair loss and all the other things that many of us think about with chemotherapy must be incredibly difficult.

Putnam It is very difficult. Not to mention the amount of time that the patient and the child and the family now spend in the hospital. It is time spent out of their own life, time spent away from work, away from what is normal for them, at a place that is taking care of the child's cancer but it is not their normal life, it is very hard.

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- Chagpar And one of the things we often talk about palliative care with regards to patients, with regards to their family but when you talk about kids, I just reflect back on my own experience in residency doing pediatric surgery and seeing some of these kids with cancer that we were operating on. There is a huge amount that affects their providers as well. Does the palliative care team have a role in terms of compassion fatigue and helping with coping of the care team?
- Putnam A great deal actually. We will get called in to talk with the hospital care providers, the nurses, the doctors, who are taking care of these patients. We got called in a month or two ago because there were a couple of very difficult patient deaths that the team really cared about and knew well, they had been in the hospital a lot and it happened quickly in a couple of cases. So we go and support there. A child of course is always the need for support for caregivers because in a pediatric population, the child who dies is very out of the norm by definition and we do a lot of support for caregivers as well.
- Chagpar I feel for the patients and I especially feel for the families but as healthcare providers working with cancer patients every day we get pretty attached to our patients and often go through that same emotional turmoil.
- Putnam We do and people expect that because this is our job, our human element is sort of expected to take a back seat and not be important and we are doing a lot of teaching of medical students and residents these days about, you can try and lock all that up but that is a sure way to burnout. It is really important to acknowledge that we have feelings about our patients, acknowledge that we have a sense of loss very different obviously from the families of the patient but in our own way we have sense of loss that we have to acknowledge and deal with.
- Chagpar I want to spin this conversation to the happy because I am not really good with the sad stories. There was a great study that came out in the New England Journal several years ago that actually talked about palliative care increasing the quantity of life, not just the quality of life. We talked about palliative care in terms of symptom management. But we always think palliative care is still going to be as you say, like the grim reaper knocking at the door. This study actually shows that palliative care was associated with the lengthening of life. Talk about that because that seems unbelievable to people who have not read the study.
- Putnam It is a great study, it was done with Dr. Jennifer Temel who was the lead author and was published in the New England Journal in 2010 from the Massachusetts General Hospital and I should put in a plug, the senior author was Dr. Tom Lynch who is my boss so I hope he hears this, but they took people with metastatic lung cancer and some of them got palliative care consults automatically and some did not, and the study went as expected, they found that people's quality of life was better with the palliative care, there was less depression, but they did find something that really nobody expected which was the people who got palliative care consults early on lived longer. Now we are talking a couple of months longer but there was a very significant difference.

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There are various studies now that are trying to replicate that, but as I think about it, I think that people who are more comfortable are probably going to feel better and have a better chance of living longer.

Chagpar I mean a tremendous plug for palliative care and symptom management. I think the other thing that is interesting and I want to talk about is symptom management. We talked a little bit earlier in the show about managing people's anxiety and doing kind of social work interventions with the chaplain and psychological support. We talked a little bit about medicines that we can use to help with pain, to help with nausea, to help with constipation. What about alternative therapies? How much do you use herbs, and what is going on in terms of the national forefront when you think about other things being used in that setting, things like medical marijuana? Talk a little bit about the complexities of your field and where it is going.

Putnam It is a great question, as far as the complimentary therapies, Reiki and acupuncture, herbs, aroma therapy, massage all of these things have a place in helping people's quality of life improve. There is not a whole lot of data on them at this point and that is the problem because when you work at a major cancer center people want to see data, they want to see the things work and there have not been a whole lot of studies on many of these treatments yet, but many people swear by them and they definitely help with a certain number of patients. The big, you could say national point of discussion right now, is medical marijuana and the number of states, including Connecticut, that have ratified it and there are dispensaries I think that have opened now in Connecticut and so the same problem is there in that there has not been much research done. There is some, but certainly not enough to make it clear what areas, what symptoms it helps, how much it helps and it would be great if these studies could be done.

Chagpar Even more broadly, when we think about all of these therapies, things like acupuncture, I think a lot of people use acupuncture without the data. Are we on the forefront of doing these clinical trials, looking at clinical trials, randomizing patients to music therapy versus not or massage therapy versus not. A lot of these seem fairly innocuous and may potentially provide benefit but are we on the forefront of getting hard data?

Putnam I am not sure about that. I do not know the extent of clinical trials around the country for a lot of these therapies. I am sure that there are some that are going on, but that is going to take some time. There is not a lot of money out there for those types of trials. Not the way there are for cancer drugs and other therapies where you have companies that are willing to front the money that make it happen and there are a lot of patients who are willing to do them.

Chagpar I guess the other issue, especially with many of the complimentary therapies especially with herbs, is that there is such a variation in terms of quality because it is a non-FDA regulated environment and that makes it difficult to do those kinds of trials. So back to medical marijuana, is that

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something that is going to be an issue when people start to think about doing trials to look at whether medical marijuana can actually help cancer patients?

Putnam I know that there are four companies in Connecticut at least that have been accepted to be providers of the drug. I guess if you want to call it that, and so there is hope that there will be clinical trials on some of these that will be in a standardized form in the form of a medicine so that you can generalize, this pill or this oil works in a specific way as opposed to leaves of the cannabis plant that may vary from leaf to leaf.

Chagpar Even more generally I guess, when you think about some of the more psychological interventions that you have, the counseling, and the behavioral modifications and so on, have there been studies that have looked at different techniques of doing that? Different techniques of counseling patients, whether spending so much time with the patient and their family listening to their concerns and so on makes the difference?

Putnam There have been some ongoing studies for that, but not enough really to make any generalizable conclusions.

Chagpar One of the things that I think is interesting is a study that is currently ongoing at the Breast Center at Yale where we are using palliative care techniques with our School of Nursing to help with symptoms management. So in our last 30 seconds, Andrew if you were to give our audience one final thought with regards to palliative care, what would that be?

Putnam I would say, palliative care conditions can be very helpful to people with severe illness. We get called in at all times of the disease not just at the end, so please do not be worried if one of us walks into your room, it is because your oncologist has realized that there are ways that we can help and they are trying to get us involved often much earlier than we used to be, so please do not look at me as having a black hood on.

Dr. Andrew Putnam is Assistant Professor of Medicine in Medical Oncology at Yale School of Medicine. We invite you to share your questions and comments, you can send them to canceranswers@yale.edu or you can leave a voicemail message at 888-234-4YCC and as an additional resource archived programs are available in both audio and written format at yalecancercenter.org. I am Bruce Barber and hoping you will join us again next Sunday evening at 6:00 for another addition of Yale Cancer Center Answers here on WNPR Connecticut's Public Media Source for News and Ideas.