

Yale CANCER
CENTER

answers

WNPR Connecticut Public Radio



Hosts

Edward Chu MD

Chief of Medical Oncology

Kenneth Miller MD

Director of Supportive Care

Compassionate Care for Cancer Patients

Guest Expert:

Janet Abrams, PhD

*Author of a Physician's Guide to Pain and
Symptom Management in Cancer
Patients*

Yale Cancer Center Answers

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Welcome to Yale Cancer Center Answers with Drs. Ed Chu and Ken Miller. I am Bruce Barber. Dr. Chu is Deputy Director and Chief of Medical Oncology at Yale Cancer Center and Dr. Miller specializes in pain and palliative care. If you would like to join the discussion, you can contact the doctors directly. The address is canceranswers@yale.edu and the phone number is 1-888-234-4YCC. This evening Dr. Miller speaks with Dr. Janet Abraham, Associate Professor of Medicine and Anesthesia at the Dana-Farber Cancer Institute. Dr. Abraham is the author of "A Physician's Guide to Pain and Symptom Management in Cancer Patients."

Miller Janet, thanks for being with us tonight.

Abraham You are very welcome.

Miller I just have to say, there are some books that you just keep on your shelf, and there are other books that you keep on your desk; your book is one that I keep on my desk.

Abraham Oh, that's great.

Miller Thank you very much for writing it.

Abraham I am really glad it's useful. That's what I wrote it for.

Miller In the past, symptom management and palliation of symptoms did not have the biggest emphasis in medicine. Could you tell us a little about your career and what you have seen in terms of the field of palliative care?

Abraham The field of palliative care is brand new and has evolved over the last 10 years or so. Certainly when I trained in oncology, there was no field of palliative medicine and there was not even much pain management. I think that one of the impetuses for the development of the field of palliative care in the United States was the Kevorkian situation. There were a lot of very compassionate doctors who thought that people should not have to choose death if they were suffering, that there should be a specialty designed to help people who were suffering while they were trying to be cured of their disease. The hospice movement was there from the 60s and as I understand it Branford was the first hospice in the United States, so Connecticut and Yale are definitely pioneers. Palliative medicine is one of the academic thrusts of the hospice and palliative care movement. What happened was, Kathy Foley, and some other leaders in the country, got together and decided that we needed to bring together people who are interested in developing this area of medicine in terms of research, education, and clinical practice. They got some funding from George Soros with the Open Society Institute and formed something called "The Project on Death in America." Using the word 'death.'

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- Miller Which I have to say is not a term that we use very often in the hospital or in the oncology clinic.
- Abraham Exactly, and this was also when Elizabeth Kubler-Ross was doing her work, and when she went into hospitals to interview dying patients, they would say that there aren't any dying patients here. We brought together people from all over the country. There were faculty scholars led by Dr. Susan Block, and 10 to 12 of us a year, over a number of years, were brought together and we found that we weren't the only ones who really wanted to partner with oncologists and cardiologists and neurologists and people who are dealing with people with very advanced disease. We wanted to partner with them to help people find meaning in their lives, decrease their suffering and help them decide their goals of care. We felt that to do that we needed to have an official specialty.
- Miller Let me ask you a question that I have been asked before. I vividly remember a patient coming to me and saying, "Dr. Miller, I have cancer, what can you do to get this over with quicker?" That was early in my career, but I remember it to this day. How do you respond to that?
- Abraham I think a patient asking for a hastened death is one of the hardest questions a physician is asked. There is a very interesting paper by Dr. Block and Dr. Billings regarding this called *Patient Requests to Hasten Death*. From that I learned that it's often a cry for help. The first thing I do is say, "Tell me more about your suffering; tell me more about your request. Do you have pain or other symptoms that aren't being dealt with? Are you worried about losing control, about what's going to happen as this goes forward?" "Tell me what you see in the future. I want to be there with you. I want to be sure the road is populated by people and services you need." I also like to find out if the patients are worried that their family won't be there for them or if they have seen someone else suffer and don't know that there is relief for that suffering. I like to unpack that question and find out what pieces of it I can help with.
- Miller The term 'I want to be there with you' is really a lovely one because that is really what it is – it is talking with someone and just being with them.
- Abraham It is sometimes just a cry for help. The organ experience has shown that people often really do want to hasten their deaths. It is not an issue of uncontrolled symptoms. It is not that their finances are a problem; they are not worried about spending their last dollar. It is not that their families are not there. It is more a matter of control and just having the means to do it sometime enables them to live as long as anybody else would. Very few people actually avail themselves of that option once given the medications.
- Miller One of the things you talk about a lot in your book is goals of care. What are the goals of care

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that are open to people?

Abrahm Goals of care, when I first heard that term I thought, what is a goal of care? I suppose a goal of care is cure. The first goal is “Can I be cured?” Another goal is “Could my life be prolonged as long as possible?” As an oncologist and hematologist for 20 years those were my goals. In palliative care what we do is broaden that definition. In addition to living as long as they can, we want to see if people want to live as well as they can. We also want to find out what things need to get done, because hopelessness is really a lack of purpose. In goals of care there are some things that are worse than dying for some people, and there are burdens to several treatments. So if their goals are to finish a book, take a special trip with their family or be at home with their family to really cement relationships, then there might be treatments that would be more of a burden than a benefit, either financially or time wise. We need to let patients know that their doctor is not going to abandon them no matter what they choose. That relationship is there and their oncology team is very concerned, I am speaking as an oncologist, but this applies to any advanced disease; be it liver disease, lung disease, heart disease or a neurologic disease.

People worry that if they do not take a treatment that their treatment team will treat other patients. They also worry about their "right" to take a place in that room. We try to explore with people and their families how this treatment can help them, what their goals are and what family events are coming up. People, at least in cancer treatment, sometimes only have a cancer calendar; no more birthdays, Thanksgiving or other holidays. If you try to suggest to someone that maybe we could delay the treatment until after Thanksgiving, they may say, “Are you trying to kill me?” We need to bring their lives back in and we need to say to them that we are happy to give treatments that will work just as well, but can fit around important events in life such as a 40th anniversary or graduation. Those are part of the goals of care.

Miller When you and other clinicians open up these conversations, some of this is new territory for people. They are not used to talking about these things. How do patients do in terms of sharing these kinds of feelings?

Abrahm That’s a very interesting question. I used to be worried because I was so used to asking people, for example if they have breast cancer, “When did you find the lump and what treatment did you get?” I never asked, “How did you feel when you found the lump?” It turns out that people are very happy to share that information, not always with their oncologist though. I have trained many clinicians and many of them are oncologists or oncology nurse practitioners as well as being palliative care skilled, and they tell me that when they are the oncologists, the patients and families don’t want to talk about that with them. They want them to fight for them, and they want to talk about the treatment. What’s important is to partner with the palliative care team because the patients do want to talk about this. As a palliative care doctor

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when I talk about this, they are very happy to share their fears and their hopes with me. They are happy to share what they are afraid to tell their doctor. They may have already thought about hospice treatment, but do not want to let their doctor down. I have heard that so many times – “She has tried so hard. She cares about me so much. I would just hate to let her down by telling her that I want to think about hospice so that I can be at home and my family will get the support they need.”

Miller As an analogy, a sports teams, or a football team; if a football player is out there trying to win the game and they tell their coach that they have a problem at home, would the coach not be rooting for them as much, or rooting for the team. Does that strike a chord at all?

Abrahm It completely strikes a chord. I think most patients want to be the patient you are happiest to see, especially people who come to places like Dana-Farber and Yale Cancer Center, or any cancer center. These are people who have selected us because they want to get the best treatment. The face they put on for the doctor is – "I want it, I am with it, I am for it." They may not even tell their doctor that they do not want to be resuscitated because they do not want to be a quitter. The way we find out is when they go to get their treatment and they tell the nurse how much pain they are in and the nurse will call us. They need someone fighting for them and they want to be that "good patient."

Miller Let us take it a step further from the oncology because you wear two hats; you are an oncologist and you are a palliative care specialist. Wearing your oncology hat, if a patient were to say to you, "I want to be fighting the cancer, but you know, I have a birthday coming up, or it's my 40th anniversary." Do you feel less engaged with fighting the battle?

Abrahm I think it's even harder than that. I do not think the patient is going to tell you that. I honestly don't. What I think you need to do if you can, you and your team, is make it clear to the patient that you care about those issues as well. If you have your fifteen minutes, you can tell the patient that you are definitely going to talk about their treatment and the results of all the tests, but that it is also very important to know how they are feeling and how they are doing. Let them know that you want to integrate this treatment with their life because the more energy they get from their family and from those things that make life worth living, the more energy they will have to fight the cancer. If they are feeling low or if are having pain, that takes energy away from their fight against the cancer. So, they need to tell me about it so I can get them some help.

Miller In many ways these dialogues really help people to battle and in no way do they stop them.

Abrahm They definitely help them. Think about the energy you spend keeping the closet door closed. It

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is very important to say - tell me about your pain, tell me if you are feeling low. I want them to get the help they need so that they are spending all their energy fighting this cancer.

Miller We would like to remind you to please e-mail your questions or thoughts to canceranswers@yale.edu. We are going to take a short break for a medical minute. Please stay tuned to learn more information about compassionate and palliative care with Dr. Janet Abraham.

Medical Minute

Here in Connecticut, the American Cancer Society estimates that almost 1000 people will be diagnosed with colorectal cancer every month. The good news is that when you detect it early, colorectal cancer is easily treated and highly curable. That means if you are over the age of 50, you should have regular colonoscopies to screen for this disease. In the case of patients that develop colorectal cancer, there are more options than ever before, thanks to increased access to advanced therapies and specialized care. Clinical trials are currently underway at federally designated comprehensive cancer centers like the one at Yale to test innovative new treatments for colorectal cancer. The patients enrolled in these trials are given access to medicines not yet approved by the Food and Drug Administration. This has been a medical minute and you will find more information at www.yalecancercenter.org. You are listening to the WNPR Health Forum from Connecticut Public Radio.

Miller Welcome back to Yale Cancer Center Answers. This is Dr. Ken Miller and I am here with Dr. Janet Abraham from the Dana-Farber Cancer Institute discussing symptom management for cancer patients. Janet, we have been talking about supportive care issues and symptom management, what are some of the barriers that prevent patients, families and doctors from engaging and caring for people's symptoms?

Abraham One of the biggest barriers that patients and families have is that they assume that cancer comes with pain and suffering. In terms of pain, many patients are afraid that if they treat the pain, they won't know if the cancer is getting better. It is very important to explicitly say - we have other measures to monitor if your cancer is getting better, we do not need the pain, so please let's treat the pain. They are certainly afraid of getting addicted to opioids. The common term is narcotics. They are afraid of being addicted. They are afraid of being doped up. They are afraid they won't be able to drive their cars, and you have to reassure them. One of the phrases that I used to use is that, you are not going to start stealing TV sets if you take this stuff.

Miller And now we have you on record saying that.

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Abraham Absolutely. And yes, there are patients who have a history of abuse and you have to be careful with them and work with a team to support them. A big barrier would be if there was substance abuse in the family and they imagine that will happen to them if they take the medications. For families, one of the issues tends to be that they don't want to see the disease getting worse, so they will sometimes under-medicate the patient because seeing the pain means seeing the disease getting worse. It is also complicated to take the medications and it is expensive, so insurance is a huge barrier. In some states you still have to write triplicates and doctors do not want to do that. In other states in the New England area, New Hampshire for example, there are limits on the number of pills in a given prescription.

Miller Which is the case here in Connecticut.

Abraham It is, and if you need flexibility to treat pain, doctors are really hampered by how many prescriptions. It can also be shameful to go to the pharmacy and get a drug like methadone, which is actually quite wonderful for patients with nerve pain, but think how shameful it can be when the pharmacist doesn't understand that, or when everybody around you thinks you are an addict. So there are a lot of stigmas to getting pain relief.

Miller I want to talk more about families. One of the things you talk about in your book and lecture on is compassion fatigue. Can you tell us more about that?

Abraham Compassion fatigue is something that happens more to clinicians, though it can certainly happen to families. Mostly it comes about when a clinician or a counselor is faced with ongoing suffering that they cannot fix and they have expectations that they can fix it, or they are in a situation that doesn't allow them to debrief. When I was an intern and in the ICU, there could be five different people in the same bed in one night that died; I had to take care of five different people in a night and all of them died. I never got to talk about it the next day; it was not something we talked about. If you are an oncologist, or if you deal with people who are suffering, like counselors of rape victims, and you don't have enough time or a place to talk about it, you don't feel that you are in control of what's happening; you stop feeling. If you are a nurse, for example, working with physicians who really don't understand well enough how to use opioids and other pain medications, you have a floor full of cancer patients in pain and you just stop answering the bell. You cannot see that pain anymore because it hurts too much. Those become rooms for us as physicians that we just don't want to enter and we become numb and stop feeling, that is what compassion fatigue is. It makes it so that you can't talk to families anymore because it hurts too much. The cure for that is to have a forum that honors that suffering. A wonderful professor of mine, an ICU professor Dr. John Hansen-Flaschen, a pulmonary doctor down at Penn, and his whole team down there would make rounds on the empty bed. They would talk about what happened the night before and what it felt like. At

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Harvard we now do grief rounds for oncology interns so that they can talk about what it is like taking care of those patients and we can honor that commitment. As an oncologist I benefited from having the nurses and other colleagues talk about the hard deaths or the suffering. As palliative care doctors, we do that all the time. We are there for our colleagues because we know how hard it is. You want every bit of energy as a physician or a nurse going into fighting the cancer, but we want to honor how hard it is and how much it hurts. If you grieve, if you help your families in bereavement, and you see that they heal, you can grieve. You have to grieve, as hard as it is. You have to feel that pain and then you can heal and then you can go on. Without that you keep it in as I did in my years, I put it all away and after awhile it's just too hard. I had this strange habit of grieving at the symphony. I would go to the symphony and in the slow movements I would think about the patients and their families and that worked for awhile until I became an oncology fellow. Then I remember one summer, my husband and I used to go out to Robin Hood Dell in Philadelphia which was wonderful, and he said, "Let's go to the concert tonight." I said, "I just can't deal with that tonight." And he said, "But it's Mozart. What is there to deal with?" I realized I couldn't deal with the litany of my grief and that I had to find another place for it.

Miller Talking about the issue of bereavement, you raised an interesting point. Loss is not just for the families, it is also for the doctors.

Abrahm Yes, we have relationships with our patients and some we identify with more than others, but we cannot blame ourselves for each loss, we need to realize that it is medicine's failure not our failure, and that the sadness on our patient's faces, that we read as anger or disappointment, is just their grief and their sadness. When we read into the faces of the nurses who are just sad, I think we sometimes project our own feelings of impotence or grief and we feel that we failed. We have to understand that we haven't failed and we haven't abandoned the patient. We have to understand that what they are hoping for from us is just to be there, not to withdrawal as they are dying, not to emotionally remove ourselves, but to be a "we" with them. If we can be there with them and be emotionally there with them, then we can find our own ways to grieve with our colleagues, in a movie, walking or playing squash, whatever it is we do. I will be present for my patients. That is what they want from us.

Miller All of us will face, at one time or another, a serious illness or some trouble in life. How do we empower our patients to make that connection with their own clinicians?

Abrahm I think that if patients want to make that connection it is easiest to tell the clinician. You should be able to tell the doctor, nurse, somebody, that what you need from your doctor is for them to be there with you. You can't expect them to work miracles, but tell them you want to be a part of the conversation. You want to know not just the risks of the treatment, but what

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burden it is going to have on the entire family. Tell them you would appreciate it if you could talk to them about those things; that you want to live your life along with the treatment. You are a fighter, but it will help you to fight if you can see as clearly as they do, not in a medical way, but help you understand what they need from you, and tell them what you need from them.

Miller They are powerful words and really beautiful words. There is a concept of growth at the end of life. What does that mean, the opportunity for growth?

Abraham There is a new book out from the American Cancer Society for patients and their families. I do not recall the name at the moment, but it is written by a wonderful collection of people, Kathy Foley among them, and maybe physicians could have that in their offices for patients, or Joanne Lynn's book *Mortal Lessons*. Those are books that can help you understand what is possible.

Growth at the end of life is when you find that you may have a limited time to live. As Susan Block says, what if time were short? It starts you and your family thinking about the things that need to get done. Ira Byock talks about this too – What are the things I need to be sure to say? Do I need to thank somebody? Do I need to give somebody forgiveness? Do I need forgiveness? Do I need to tell people I love them? What is my legacy for my family, for the world? What are the things that really matter to me? In doing this some people find that they are growing in the breadth and depth of their worldview, they find it satisfying, meaningful, and their families take that with them forever, as do their doctors. When patients say goodbye to me and I say goodbye to patients, I find that I take them with me and that they give me a gift. They feel very good about that gift, sometimes as a teacher, and sometimes just as a gift that they can give.

Miller Lovely things, and as I look back over the last 20 years of my own practice, the people that I remember the most are my patients that have shared a gift in one form or another; an inside or personal moment in a little part of their life and who they are.

Abraham Exactly.

Miller It is wonderful to think about this as being a partnership between doctors and patients and that we are all people.

Abraham That may be what holds us back from the partnership; the fear of the pain, of the loss, but I think that as we learn to process that loss and honor it, we are able to connect in more meaningful ways and are more open to our patients and have a much more satisfying practice.

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Miller

I want to thank you very much for being with us tonight, Dr. Janet Abraham, Associate Professor at the Dana-Farber Cancer Institute at Harvard up in Boston. This has been a wonderful program. Until next week, this is Dr. Ken Miller from the Yale Cancer Center wishing all of you a safe and healthy week.

If you have questions, comments, or would like to subscribe to our Podcast, go to www.yalecancercenter.org where you will also find transcripts of past broadcasts in written form. Next week, we will meet Dr. Marion Morra, chair of the American Cancer Society's Board of Directors.