

Yale CANCER CENTER *answers*

WNPR Connecticut Public Radio



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Palliative Care vs. Hospice Care

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Yale Cancer Center Answers

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Welcome to Yale Cancer Center Answers with doctors Francine Foss and Anees Chagpar. Dr. Foss is a Professor of Medical Oncology and Dermatology, specializing in the treatment of lymphomas. Dr. Chagpar is Associate Professor of Surgical Oncology and Director of the Breast Center at Smilow Cancer Hospital at Yale-New Haven. If you would like to join the conversation, you can contact the doctors directly. The address is canceranswers@yale.edu and the phone number is 1-888-234-4YCC. This week, Dr. Chagpar is joined by Dr. Jennifer Kapo and Leslie Blatt for a conversation about palliative care versus hospice care. Dr. Kapo is Associate Professor of Medical Oncology and Chief of Palliative Medicine and Leslie is APRN for the Palliative Care Service at Smilow Cancer Hospital. Here is Anees Chagpar.

Chagpar Why don't we start off with each of you telling us a little bit about what you do? Jennifer, why don't you start?

Kapo Thank you, I am trained in both geriatric medicine and in palliative care and I am Chief of the Palliative Care Service at Yale-New Haven Hospital. I direct the interdisciplinary team and take care of patients being cared for by our service.

Chagpar And Leslie?

Blatt My background is a little bit different. I have a background in adult mental health and palliative care and part of my role is helping not only take care of patients and their families, but educating the staff, nursing, medical students, and residents.

Chagpar Let's start off by defining terms, because I think that there are a lot of misconceptions about what exactly palliative care is? Dr. Kapo, what is palliative care?

Kapo I like to use a definition that was developed by the Center for the Advancement of Palliative Care, which is called CAPC and I am going to use language specifically from this definition because I think it captures so beautifully what palliative care truly is. It is specialized medical care for people with serious illnesses and this type of care is focused on providing patients with relief from pain and other symptoms for whatever diagnosis, so not just for patients with cancer. We see patients with other end organ diseases such as end-stage lung disease, end-stage liver disease, end-stage renal disease, etc. and the goal of care is to provide improved quality of life, both for the patients and the family. When we take care of patients we recognize that their illness affects not only themselves, but the people who love them and care for them. It is provided by a team of doctors, nurses, chaplains and social workers, and we are fortunate at Yale-New Haven Hospital to have a full interdisciplinary team to address suffering of many types, not just physical but psychological, social and spiritual and it is care that we provide along with the care provided by primary teams or primary subspecialists. We provide an extra layer of support for the patient and

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their families. We are not separate; we are not care that comes in after there is ‘nothing to be done.’ We provide integrated care throughout the course of a serious illness and it can be provided for patients at any age and any stage of serious illness, even those who are still seeking curative treatment.

Chagpar Leslie, tell me a bit more about this team. It sounds like the palliative care team has a whole interdisciplinary unit and is integrated into the larger team that is taking care of the patient. How does that work exactly?

Blatt That is correct, and I think that Jenn said it really well, we are a supportive service, so what we all bring is a little bit of a different perspective to the care of the patient and their family and we are lucky to have a full complement team of a social worker, a chaplain, as well as medical staff to help meet the needs of the patient and the family. Oftentimes we get called in for symptom management, but we find that it is so much more than that. We find that the patient and their families are struggling with financial aspects which then lead to other issues that they are struggling with as well, oftentimes they are existential issues that need to be discussed or explored and I think that our team is unique in the fact that we all have different strengths and we know who to call to be able to help the patient and the family so it may not always be myself doing this, I might want to call a colleague such as a social worker to come and help me with this family, or the chaplain.

Chagpar Jennifer, I think one of the things that people often struggle with, and it is something that you alluded to, is the difference between palliative care and hospice, or end-of-life care. Can you help us to understand what the differences are?

Kapo Yes, of course. The definition of palliative care has been evolving over the last 10 years to 15 years. In the past people received palliative care in the form of hospice care, which is care that is provided at the very end of life when the patients and families are no longer seeking curative or disease remissive therapies. We like to think of palliative care as being integrated throughout the course of the disease, and the stage of the disease determines the degree and type of palliative care intervention that one would require. For example, in the early stages of a cancer diagnosis, palliative care interventions would include things like dealing with anticipatory grieving, symptom management, helping families plan for the future, and then as the disease progresses we are there to help with more serious symptoms, end of life suffering, and also to help with families making difficult decisions and it is helpful for us to be involved throughout the course of the illness because we build trust and relationships with the patients and their families and that allows us to help them struggle with these decisions that need to be made as a disease progresses.

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- Chagpar Leslie, do you find that when you are consulted early on in disease management, say for symptoms or for anticipatory grieving, that kind of thing, that the patients and their families may be a little bit resistant like, "wait a second am I dying here?"
- Blatt That is often what happens, where people are confused about why we get called in and I think our usual response is that we are just an added layer of support and that we have expertise particularly in pain and symptom management as well as helping with discussions that occur all the time. I think one of the things that we can do is help clarify the medical information, because in any big medical center there are numerous consultants giving information and one of our roles is to help the family tease out what everybody is saying and I think that is an important piece. I think the other piece that we say is that once you get to know us, to love us, because we stick with somebody wherever they go and that means whatever floor they are on, whenever they come back into the hospital and we actually hope to see them when they are out of the hospital as well. So we follow them through the continuum of their illness wherever they are.
- Chagpar Is palliative care both an inpatient service and an outpatient service? Is this something that is available in the community or only at large academic centers, how does that work?
- Kapo At Yale-New Haven Hospital our goal is to follow patients, as Leslie mentioned, throughout the continuum of their disease and that includes both outpatient and inpatient practices. We have an outpatient clinic that meets twice a week but we also see the patients with their subspecialist when they come to their appointments as outpatients. It is a wonderful opportunity to be able to see the patient with their oncologist, to say that we are here to support you, we are here to address your symptoms and we are also here just to talk about what the experience has been like for you. What are your concerns? What are your worries and what are your hopes? What is making you happy? So providing that supportive counseling, and we keep repeating this phrase, extra layer of support because it is parallel with and integrated with treatment, not instead of treatment for patients, and then our same core team follows these patients when they are admitted to the hospital, so if someone has a need to come in for symptom control or for any reason we will see them when they come to the hospital, hopefully within 24 hours of their admission. I have heard patients refer to Leslie Blatt, our physicians, and advanced practice nurses as the friendlies faces that they see during their hospitalization because we have trusted relationships with them. They feel they are supported and they feel that they will get the answers they need when they have questions that may not be answered by everyone on the team.
- Chagpar Leslie, if this palliative care service is that extra layer of support, should every cancer patient have a palliative care consult or is it just certain ones? Is it ones that are more advanced where there may be issues with pain control? How does that work?

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- Blatt That is a great question and I think that everybody should have palliative care support, but not necessarily from the palliative care team. I think that there are certain skills that all physicians and practitioners should have and perhaps our role might be best utilized with people that have serious illnesses such as a metastatic cancer. They may have the beginning of an illness that is terminal or the families are having difficulty coping with it. So the earlier the better, yes everybody should have palliative care but I would be worried that we would not be able to provide what we do so well to everybody.
- Kapo I want to add to that that one of the missions of our service is to provide education to primary providers of all sorts so that they can provide this basic palliative care to all their patients, basic symptom assessment and management, basic supportive counseling, and then I think about our care as specialized palliative care, or tertiary palliative care, so when there are complex pain issues, when there are complex issues with coping, I ask providers to consider the question, is my patient suffering in a way that I can't address? And if that suffering exists whether it be physical, psychological, social or spiritual, could the patient benefit from our involvement?
- Chagpar One of the things that I think is so compelling about the palliative care service is, as you mentioned, this integration of all different kinds of suffering. Often we think about palliative care as being pain and symptom management, but Leslie, could you talk a little bit about the other aspects of suffering that palliative care addresses? You have touched on some of them, but tell us a bit more about how that works?
- Blatt With any serious illness people often undergo role changes or anticipatory grieving that may lead to a lot of psychological symptoms such as depression or anxiety, which need to be treated. People often have questions about, why did this happen to me, what did I do in my life, is this a punishment from God, and as you hear these questions you can see where certain members of our team might be better able to answer or help people find the answers to those questions. What our whole team does is listen really well to whatever the patient or their family is talking about and then can bring in the resources that they need.
- Chagpar Speaking to Leslie's point that this is a package deal with the patient and their family, can you tell us a little bit more about the support that you provide the caregiver, because I can imagine that this is a harrowing experience for the patients, but it is also a harrowing experience for everyone who is a caregiver or a loved one of these patients who may not have the resources and the background and the ability to know how to support these patients?
- Kapo We recognize that suffering from an illness extends to families and loved ones and we really try to assess that suffering and determine what would be most helpful to that family. Supportive counseling is provided to the loved ones, so when we enter a hospital room and the daughter who is always there with her mother, who is sick, we want to spend some time asking her what has this experience been like for her, how has it affected her. We also think about practical support at

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home, because you are right, people are sent home from the hospital to their caregivers, who are loved ones, who may not have any training on how best to care for a very ill person and so our social worker and Leslie and the other advanced practice nurse are able to assess what practical skills and knowledge and just practical equipment and other support needed at home and then we began to think more about bereavement and the importance of following patient's families and loved ones after one dies in the hospital, and so there is a large initiative that over the next one to two years we will be developing a comprehensive bereavement program as part of the palliative service as well.

Chagpar This has been such an interesting conversation. We are going to pick right back up there after we take a break for a medical minute. Please stay tuned to learn more information about palliative care and hospice care with our guests Dr. Jennifer Kapo and Leslie Blatt.

*Medical
Minute*

Breast cancer is the most common cancer in women. In Connecticut alone approximately 3000 women will be diagnosed with breast cancer this year, but there is new hope. Earlier detection, non-invasive treatments, and novel therapies provide more options for patients to fight breast cancer. Women should schedule a baseline mammogram beginning at age 40 or earlier if they have risk factors associated with the disease. With screening, early detection and a healthy lifestyle, breast cancer can be defeated. Clinical trials are currently underway at federally designated comprehensive cancer centers such as Yale Cancer Center to make innovative new treatments available to patients. A potential breakthrough in treating chemotherapy resistant breast cancer is now being studied at Yale combining BSI-101, a PARP inhibitor with the chemotherapy drug irinotecan. This has been a medical minute brought to you as a public service by the Yale Cancer Center. More information is available at yalecancercenter.org. You are listening to the WNPR, Connecticut's Public Radio Station.

Chagpar Welcome back to Yale Cancer Center Answers. This is Dr. Anees Chagpar and I am joined today by my guests Jennifer Kapo and Leslie Blatt. We are discussing palliative care and how this field has become something that a lot of people do not have a good sense of, that it is far more than end of life care and hospice, but that it really extends to an extra layer of support, symptom management, mind, body, soul, the whole works. Jenn, tell us the genesis of this change in palliative care. How people have changed perceptions of what palliative care is over the last say 5 to 10 years and where you feel it is going?

Kapo Over the last five years palliative care physicians and teams have recognized that focusing just on end of life care had been a barrier to engaging the teams and the services that could be provided by this interdisciplinary team that are specially trained to address all sorts of suffering and so there was a movement and this definition evolved to define the care as being integrated throughout the

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course of a serious illness. Centers, such as the Advancement of Palliative Care, which is identified by the acronym CAPC, has been a huge supporter of this change. So CAPC's main mission is to help medical centers integrate palliative care throughout their health systems and they have been paramount in helping define palliative care as a field over the past 5 to 10 years.

Chagpar Leslie, as we think about palliative care being this integrated extra layer of support alongside acute care teams, one of the things that became very clear as we were talking before the break was this whole idea of support not just pain and symptom management, but other layers and this team approach. Can you talk a little bit about all of the members of the team and what exactly their roles are? I think we can understand the role of the physician and a nurse and a social worker, but maybe the role of the chaplain?

Blatt I hope I do this justice, the chaplain is so important on a palliative care team and the reason for that is that there is a lot of research that shows that how people make decisions about what they do and what treatments they want, is not always based on the facts. It is often based on their faith or their spiritual beliefs regarding life and we are lucky to have chaplains at Yale-New Hospital that are nondenominational. So the chaplain has experience in many different religions, but does not bring to the bedside their own religion and can kind of help the patient no matter what type of religion they are. They help to answer some of those questions that are very common once a critical illness strikes, why is this happening to me? What did I do? Is this a punishment from God? Did I do something? And they can help tease out how their faith plays a role in helping them cope going forward. They also have great ties to the community, so that if there is a particular religion that the patient is they can reach out to the community. For instance, if somebody is Islam, they know a lot of Imams, if the person's own Imam is not readily available to come into the hospital. So not only are they able to do it but they have a huge community support.

Chagpar It sounds like this is a really integrated service that embodies mind, body, and soul. Jen, maybe you can tell us a little bit about how one trains to be a palliative care physician because you can imagine, when you think about chaplains having as Leslie mentioned this experience in all of these religions, what is the training for a palliative care physician like?

Kapo Palliative care physicians are fellowship trained. So just like a cardiologist has special training in heart disease, palliative care physicians are specially trained in palliative medicine. It is a one year clinical fellowship and we are very pleased that we will have a one year palliative medicine fellowship training program starting in July 2014, where we will train up to two fellows a year to become specialists in the field. It is an intensive one year clinical fellowship where fellows spend time taking care of the patients alongside the team with adequate oversight by an attending physician, and during this year they spend time in the hospital, in the outpatient clinic and at

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hospice to learn about all the tools needed to take care of these patients. They observe with the chaplain, the social worker and the nurses to really understand the full array of treatments and counseling that we can provide for our patients.

- Chagpar Do they get speciality training in all of the pain and symptom management more than you would say with a medicine residency?
- Kapo Absolutely, it is an intensive one year fellowship with a focus on symptom management, but also other fields to really understand what are the tools that are available in an interdisciplinary team and how best to work with each other. This is a very collaborative process, we meet every morning as a team to discuss our patients and so I have learned a lot about spirituality and about the role of a chaplain. I have learned a lot about the role of the social worker. I have learned about nursing in general but also about the specific skills and knowledge held by their team members and so it is really collaborative process that is taught to the fellows who may not have learned this model of care during their previous training.
- Blatt If I could just add one other thing to that, in many hospitals there is hierarchy of who is in charge and I think on the palliative care team, each discipline is recognized for their unique contribution that they bring to the team and so nobody has more say than another member. So the social worker or chaplain is equally as important as say the doctor regarding the patient and their family and I think that is unique to palliative care.
- Chagpar The other thing that I think is unique to palliative medicine is how intense that treatment is, and the intensity of the relationship that you have with your patients. Just listening to you talk about developing relationships with the patients and their families early on and building that relationship of trust through their care right until the end of life is incredibly strong and incredibly intense. Tell me about how that feels as a palliative care physician?
- Kapo I can tell you that it has been incredibly rewarding. I have been in the field for twelve years now and it has been incredibly rewarding to get to know the patients and their families and to have the honor of caring for them and it brings me tremendous joy, but it is a challenge to see suffering and to witness suffering, and so as a team, we talk about self care and the importance of practicing clear self care. The importance of talking about difficult cases and when we are feeling sad or when we are feeling burned out, it has been a particular focus of our team meetings to make sure that we address these concerns. Our chaplain, our social worker, and the nurses, we all come together and think about how best to address self care, how best to prevent compassion fatigue and burnout and these are clear risks for people in this field, but we need to address that proactively and think about it as a team, how best we can support each other, so we can then support patients and their families to the best of our abilities.

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- Chagpar Leslie, as an APRN in palliative care that must be a tremendous challenge in terms of dealing with compassion fatigue and you give so much of yourself to your patients. How do you deal with that?
- Blatt That is another good question. I have a practice where I meditate every day as a way to allow me to kind of let go of some of those intense feelings that I may have. I need time for myself in order to be able to rejuvenate and I think the difficulty is carving out that time that you need in order to be able to do all the things that you want to do. Exercise is huge for me and that helps my mental health and so I make sure that I exercise pretty much every day. Each member of our team does something a little bit different and we all look out for one another, when we see signs of one of the team members kind of looking a little afraid or looking a little worried. We will ask how things are going. What can we do? Do we need to give you a little bit of a break? Do you need a light assignment? So not only do you have to do it internally, but I think as a team we need to look out for each other as well.
- Kapo A point to add to that, we also make sure that other staff members have the same support that we are creating in our own team. So the bed side nurses in oncology, for example, care deeply for their patients and see tremendous suffering themselves. Our chaplain has created programs to help support those nurses that we hope to spread throughout the hospital recognizing that it is hard to care for the patients who are suffering. It can be tremendously rewarding, but there is a cost to it as well.
- Chagpar As you are talking, I am thinking about the care givers of these patients who care so deeply about their loved ones and they may not have a team necessarily they can off load to. What advice do you give to care givers in order to care for themselves?
- Blatt I think the best thing people can do is take little breaks for themselves. Try to encourage them that they do not have to be there at the bedside 24 hours a day 7 days a week and that may be a struggle for a lot of people and so then it is even a little bit smaller than that. How can you feel comfortable going down to the cafeteria to get some food? Would you feel comfortable walking around the block, because really just going outside and feeling the sun on your face on a beautiful day, it can do amazing things for rejuvenation. So we ask them what would help them? Because people know themselves what would help them and then just encourage them to do that. Say it is okay, it is okay to leave for a little bit.
- Kapo We also stress that if they do not take care of themselves, they are not going to be able to sustain this and be able to be there for their loved one. So it is important not only to maintain it for yourself but also to be there, so you do not burnout yourself.
- Chagpar I imagine that this must be particularly difficult in patients who are in critical care situations. Can you talk a little bit about how you address the people who may be in ICU units and so on?

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Blatt We are working hard to develop a comprehensive plan for patients in the ICU at Yale-New Haven Hospital. It is started by surveying nurses and doctors who provide primary care for the patients in the ICU. What is your experience with providing support, symptom management, addressing spiritual concerns, providing supportive counseling and what we found was although many of the doctors and nurses felt comfortable, they still felt that they needed more help and more training in many of these issues. So we have taken that information and we are going to create an educational series and then think about how can the palliative care team be more available to the ICU teams? That would involve rounding at least weekly, but the team is seeing all the patients and hearing about all the cases and helping identify which patients might benefit from a palliative care consult early. So again, it does not have to be the patients who are struggling with the decision to withdraw care at the end of life. It is patients who are suffering in the ICU. It is patients who will likely survive but need to get over this challenge of an ICU admission and the fear and physical pain that can accompany that.

Dr. Jennifer Kapo is Associate Professor of Medical Oncology and Chief of Palliative Medicine and Leslie Blatt is APRN for the Palliative Care Service at Smilow Cancer Hospital. If you have questions or would like to add your comments, visit yalecancercenter.org where you can also get the podcast and find written transcripts of past programs. You are listening to the WNPR Health Forum on the Connecticut Public Broadcasting Network.