

Yale CANCER
CENTER

answers

WNPR Connecticut Public Radio



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Compassionate Care for
Advanced Lung Cancer

Guest Expert:
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Yale Cancer Center Answers

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Welcome to Yale Cancer Center Answers with doctors Francine Foss and Lynn Wilson. I am Bruce Barber. Dr. Foss is a Professor of Medical Oncology and Dermatology, specializing in the treatment of lymphomas. Dr. Wilson is a Professor of Therapeutic Radiology and an expert in the use of radiation to treat lung cancers and cutaneous lymphomas. 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, guest-host Dr. Thomas Lynch, sits down for a conversation with Dr. Jennifer Temel. Dr. Lynch is Director of Yale Cancer Center and Physician-in-Chief of Smilow Cancer Hospital. Dr. Temel is Assistant Professor of Medical Oncology and Hematology at Massachusetts General Hospital and she joins Dr. Lynch this evening to talk about advanced lung cancer. Here is Dr. Thomas Lynch.

- Lynch Let's start off by having you tell us a little bit about what got you into the field of lung cancer?
- Temel When I was first training in oncology, I think I was struck by both the amount of physical and emotional suffering that patients with advanced cancers like lung cancer went through and seeing that made me interested in not only taking care of those patients clinically, but also researching ways to optimize and improve the care that they receive.
- Lynch How are we doing with lung cancer? If a patient has advanced lung cancer with disease spread beyond the lung itself, how do those patients do?
- Temel The news in the last couple of years is that we have really seen marked improvements in lung cancer treatments. Treatments are certainly getting better, especially novel targeted therapies and we are seeing patients, overall, live longer with their disease; however, where I think we have lagged behind is in supportive care treatments for patients with lung cancer, meaning making sure that they get optimal symptom management so they can enjoy their quality of life as much as possible and be as functional as possible. Be able to work and go out with their friends and family and enjoy social time.
- Lynch Dr. Temel, when you see a patient who has advanced lung cancer and the patient or the family asks how long is my relative going to live with this disease, what do you say?
- Temel That's a very important issue. Data tells us that overall patients who have serious illnesses such as cancer want general amounts of prognostic information, so they want to have a general sense of how they are going to do with their disease. But how patients want to hear this information, when they want to hear it, and how much information they want to receive, varies patient to patient, so I think it is important that clinicians get to know their patient and have a better understanding of what would be the optimal way for them to hear and receive this type of information.
- Lynch Some people have said, and I have heard patients and family tell me this, that you could be harming the patient by telling them that they have a bad prognosis where they could die from their cancer and they want to be protective for their family member. How do you react to that and how do you deal with that with patients and families?

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- Temel Traditionally that has been a concern on the part of clinicians that if they disclose a poor prognosis, for example, a short life expectancy, that they will cause patients to feel depressed or feel despair and that may have negative implications for their cancer, and what we know from recent data is that that is actually not true, it is not harmful for patients to know their prognostic information. Patients who have had conversations with their physicians about their end of life care or decisions about care are no more likely to feel depressed or panicked, or even sad and worried, so it is not harmful to disclose that type of information to advanced cancer patients.
- Lynch For our audience's benefit, who may not know a lot about lung cancer, the average person with metastatic lung cancer, how long does the average person live?
- Temel When people look up this type of information in the newspaper or on the internet, it can be somewhat misleading because we know that patients with advanced lung cancer who participate in clinical trials tend to be a healthier group of patients, and it is not uncommon in those situations to see people have a life expectancy of a year or greater, but for all patients diagnosed with this disease, older people, patients with other medical illnesses, the average life expectancy remains less than one year, about 10 months.
- Lynch Ten months, do you tell patients that the average life expectancy may only be 10 months?
- Temel My general practice is to not tell patients that and getting back to what I was saying before, I think it is very important for clinicians and patients to have an established relationship and for a patient to be able to some extent negotiate when they receive this type of information. My practice style is even when I am first meeting patients before, for example, I administer chemotherapy, I make sure that they have an understanding that their cancer is not curable, and I think that is a very important piece of information that should always be provided to patients before they begin chemotherapy, for them to understand that the intent of the chemotherapy is not to cure their cancer.
- Lynch Dr. Temel, you have lectured extensively on talking to patients about prognosis. Do you think it allows them to make better treatment decisions, if they have a better understanding of their prognosis?
- Temel I think that is 100% true. There has been data going back as far as 15 years or 20 years telling us that how patients view their illness and prognosis, certainly translates into decisions about their care. As a nation, we are seeing care in cancer and in other diseases become more aggressive, we are seeing patients spend more time in the hospital and less time at home, and what we know is that patients who have a faulty or over estimation of their prognosis, are more likely to choose this aggressive care and not only is that associated with a worse quality of death for patients, but also significantly worse bereavement outcomes for their family members.
- Lynch What do you mean by bereavement outcomes?

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- Temel Obviously after a loved one dies family members go through a period of sadness and grief and we know that the period of sadness and grief is extended and significantly worse when they view their loved one as having a poor quality of death, for example, a death that had significant pain or they were in the hospital with a lot of invasive care. So patients who have a better quality of death, their family members adjust more smoothly after the patient has passed away.
- Lynch As a doctor, how do you find the language to talk to patients about dying? It must be something that is difficult to do and how do you do that as a clinician?
- Temel Again, I think importantly data tells us that for patients with serious illnesses, especially advanced cancer, it is very important for them to know that their clinician is prepared for their death. So again, within the first weeks or months of meeting someone with a terminal illness, I do not necessarily think it is the right thing or necessarily appropriate to discuss their death, but as patients become more ill from their cancer and are becoming closer to the time of their death, I think that as their care providers we owe it to them to begin a dialogue about their life expectancy and about their wishes when they do become more ill, for example, do they want to be at home or in a hospice facility?
- Lynch Dr. Temel, do you think that oncologists in general, particularly those who treat lung cancer, do a good job in talking to their patients about death, or do you think this is an area that we could improve upon?
- Temel The good news is that this is becoming a more important area of research. Over the last couple of years, we have seen more data telling us that the patients want this type of information, even some data giving clinicians some suggestions on how to provide this information, so I think it is an area of oncology that is gaining more focus. For example, the American Society of Clinical Oncology just came out with a statement about encouraging oncologists to have these conversations earlier in the course of their disease, so I think we are going to see improvements in this area in the upcoming years.
- Lynch Among the many things you do at the Massachusetts General Hospital, you run the training program which trains future hematologists and oncologists. How do you teach compassion, how do you teach the ability to talk to patients about death?
- Temel I think the most important way for medical students, residents, and trainees to learn how to have a compassionate conversation and provide compassionate care to patients is to actually see someone do it well. When you watch a clinician have a very compassionate, sensitive, interested conversation with the patients and families, I think that's the best way to model your own style. Also, unfortunately, seeing clinicians do it in a poor way, seeing clinicians communicate poorly with patients, is also important for them to learn what not to do when they communicate with patients.

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- Lynch What's an example of clinicians both doing it well and clinicians who are doing it poorly? Think back to your own training, or to your own experiences of seeing it done well and then not done well.
- Temel One of the common mistakes that clinicians make when they are having these conversations with patients is that they do not give the patients a chance to observe the information and to ask questions. I think clinicians get very nervous when they are having these types of conversations, so they tend to speak incessantly and not give the patient and family time to process the information and ask appropriate questions, so I think it is really important to leave adequate time to have these conversations with patients and families. I think the other big mistake that we make is we provide the information to a patient, but they come back and say, you know doc, I should live a year right, or ask some sort of hopeful question, and at that time I will often see clinicians sort of back down and say you know, sure, that is something to hope for, so I think it is really important to give a consistent and compassionate message so that patients and families have time to observe the information and certainly to have a follow-up with them to see if they have any questions about the conversation.
- Lynch When you have seen it done particularly well, what are some of the things you have seen in that setting?
- Temel I think one of the most important things is just getting a sense from patients about what they are hoping for. I think as clinicians we often think that the only thing that patients care about is how long they have to live, but often when you sit down with the patient and you ask them what they are hoping for, they are hoping to get to their daughter's wedding, they are hoping to get to their son's graduation, and I think as a clinician it helps you make decisions about the patient's care if you have a sense of what these goals and wishes are. In addition, if you have a strong concern that the patient will not be there for this major event such as a wedding or graduation, it can be helpful, for example, to have the patient make a video tape or write a letter so that they can be there in spirit even if they are not there at that time.
- Lynch What I would like to do is talk in detail about your landmark study which appeared in the New England Journal of Medicine about treating patients with advanced lung cancer, but before we get to that, just for the audience, I would like you to frame what it is like to have metastatic lung cancer so that the audience can get a sense of how patients experience this disease. So someone gets diagnosed with metastatic lung cancer, they often go through some treatment, can you tell us a little bit about what the treatment is and what the natural course of disease is, so that when we talk about your study, the audience will have some way of putting that into perspective.
- Lynch One of the most important things to know is that this patient population is incredibly ill even when they are first diagnosed with their disease, and they remain ill throughout the course of their disease. Most patients when they are diagnosed with metastatic lung cancer have symptoms such as fatigue or pain. In this patient population, they also have very high rates of breathing symptoms

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such as shortness of breath or cough. When we give them chemotherapy, which often has significant side effects such as nausea or fatigue, sometimes these symptoms can get better but what we know is when you are balancing the symptoms of cancer and the side effects of chemotherapy, overall patients tend to not feel significantly better when they are on treatment and many of these symptoms persist throughout the course of their disease and often in the months before someone actually passes away, the symptoms actually get much more difficult to manage and that is when we really need assistance from a specialized provider such as hospice providers.

Lynch And does chemotherapy really help in advanced lung cancer, that's a question I think a lot of families and patients ask.

Temel Chemotherapy definitely helps patients live longer and to some extent it makes them feel better. Chemotherapy can certainly improve symptoms related to cancer, so if someone has a mass that's causing them pain and that mass shrinks from chemotherapy, certainly that symptom will get better. One thing that's commonly talked about in oncology is something called quality of life, how a patient feels as they are living with their disease. The impact of chemotherapy on quality of life is actually less clear. Again, chemotherapy improves symptoms, but so many components or aspects of one's life contributes to their quality of life such as their emotional functioning, their spiritual and religious functioning, that overall chemotherapy does not significantly improve.

Lynch Dr. Temel, we are going to talk more about that after the break. We are going to take a short break for a medical minute. Please stay tuned to learn more information about advanced lung cancer with Dr. Jennifer Temel.

*Medical
Minute*

There are over 11, 000,000 cancer survivors in the US and the numbers keep growing. Completing treatment for cancer is a very exciting milestone but cancer and its treatment can be a life changing experience. Following treatment, the return to normal activities and relationships may be difficult and cancer survivors may face other long term side effects of cancer including heart problems, osteoporosis, fertility issues and an increased risk of second cancers. Resources for cancer survivors are available at federally designated comprehensive cancer centers such as the one at Yale Cancer Center to keep cancer survivors well and focused on healthy living. 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 Health Forum on the Connecticut Public Broadcasting Network.

Lynch Welcome back to Yale Cancer Center Answers. This is Dr. Tom Lynch and I am joined by my guest Dr. Jennifer Temel and we are discussing advanced lung cancer, particularly the role that palliative care can play in advanced lung cancer. Dr. Temel, you are obviously the expert in the treatment of lung cancer, you are someone who has been doing this for more than a decade in terms of treating patients with advanced disease, what got you interested in the role that palliative care can have in lung cancer?

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Temel I think simply, I did not think as oncologists we were doing a good enough job. There were clearly areas where we could improve care to lung cancer patient's both in their symptom management and providing psychological support for symptoms of depression and anxiety and also to do a better job educating patients and families about the illness, the patient's prognosis, and to help them make better decision about their care.

Lynch What exactly is palliative care?

Temel Palliative care is multidisciplinary, what that means is, it consist of doctors, nurses, chaplains, and social workers, so a multidisciplinary team of clinicians whose goal is really to improve the patient's quality of life. These clinicians have specialized training in symptom management, for example, they have special training in how to manage pain, not just from cancer but from any illness. They also have specialized training and help deal with distress or anxiety surrounding a serious illness, and probably most importantly, the training that they have that is very different from traditional oncology training is that they have specialized training in talking to patients about their illness, their prognosis, and helping them make decisions about their care that are aligned with their goals and wishes for the future.

Lynch You had a landmark study in the New England Journal of Medicine that was considered one of the most important breakthroughs in all of medicine in 2010. Tell us a little about what brought you to design that study and what you were seeking to learn from the trial?

Temel Traditionally, palliative care clinicians do not see people until very close to the end of their life and often in the hospital. For example, if someone is within days or weeks of dying and they have issues with pain control or the family is having issues coping with the patient's death, that is traditionally when palliative care providers would be called in to see the patient. My thinking was a patient with metastatic lung cancer has a short life expectancy, again in general, of less than a year and have an incredibly high physical and emotional symptom burden, so my thinking was why don't we have this team of clinicians, doctors, and nurses, see patients earlier in the course of their disease, so they can focus on their symptom management and support beginning at the time of diagnosis, and hopefully have an impact in their quality of life throughout the course of disease.

Lynch Was there resistance from your colleagues to having a second set of doctors involved in the care of the patient?

Temel There was some resistance, but only in the way that as oncologists I think we put our heart and souls into our jobs. I think most oncologists really care about their patients and do the best they can and I think some oncologists were worried that adding another clinician would take away from the patient-doctor bond that they already had.

Lynch Tell us more about the design of your study, how was the study designed? What questions was it designed to answer?

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- Temel As I mentioned, palliative care traditionally does not see people until very close to the end of their life and so what our study was looking at was asking these palliative care clinicians to start seeing patients from the time of diagnosis and follow them along with the oncologist throughout the course of their disease. The design of the study was what is called a randomized study, so the patients were coin flipped into either the palliative care arm or the standard care arm. The patients who were randomized to the early palliative care arm would receive the same standard high quality oncology care that all the patients of Mass General get and in addition to that they also saw the palliative care providers periodically throughout the course of their illness.
- Lynch What would they do when they saw the palliative care provider? Who would they see and what would that palliative care provider do for them?
- Temel As opposed to many types of intervention studies, the nature of the palliative care visits were not scripted or prescribed, meaning they it was not required, for example, in visit one to focus on pain management, in visit two to discuss illness or prognosis, the palliative care providers were given the freedom to see the patients and evaluate them and focus on what seemed most important to the patient. One of the main palliative care providers in the study, Vicki Jackson, would say that sometimes she would go in with an agenda to talk about coping or illness understanding, but the patient was clearly very uncomfortable and in pain, so the focus of the visit became pain. Other times she would walk into the room and expect to focus, for example, on fatigue because the last couple of visits they were trying medication to improve the patient's energy level, but she would open the door and the patient would say "am I going to die," and clearly then the focus of that visit was about helping the patient prepare for the end of life.
- Lynch Do you think that the patients talk to the palliative care provider about different things then they might talk to you about?
- Temel As an oncologist that is a little bit hard for me to admit, but I do think that is the case. I think there are many very companionate and sensitive oncologists, but no matter how wonderful you are, how companionate you are, I think the patients view the oncologist as holding the chemotherapy key and to some extent they are afraid to be truly honest and open about all of the symptoms that they are having or all of the distress that they are going through. They want to put on a brave face and receive their cancer treatment. I do think that patients are a little bit more willing and open about speaking more honestly with palliative care providers.
- Lynch In your trial, you had a group of patients that saw palliative care doctors along with oncologists and a group of patients who just saw their oncologist, what were the differences between the two groups in the end?
- Temel We are very excited to see that there were marked differences in many aspects of care in these patients. First and foremost, the patients receiving early palliative care had marked improvements in their quality of life, meaning they felt better, they were able to be with their family more, they

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were able to be more functional. We also saw marked differences in rates of depression. The patients receiving early palliative care were significantly less likely to be depressed compared to the patients receiving standard oncology care.

Lynch Why do you think that was?

Temel One thing we know is that it was not from more antidepressants. In addition, antidepressants do not seem to be as useful for depression in cancer as for example in other illnesses. So it does seem like again, just having that team of doctors and nurses available to talk to the patients about their wishes, their fears, maybe patients felt more prepared for what was going to happen and their mood was just overall better.

Lynch In addition to the improvement in quality of life and the reduction in the rate of depression, my understanding is you also showed that there was a survival benefit, patients actually lived longer who were seen by a palliative care team?

Temel Surprisingly, we did see a survival advantage. When we initially designed the study, we planned to follow patients throughout the course of their disease and look at the survival rates more because we thought there might be oncologists or other clinicians out there who would think that having palliative care involved in patients would actually lead them to receive less aggressive care throughout the course of their disease and potentially be worried that the survival would be lower, but in fact, what we saw was the opposite. The patients receiving early palliative care had about a 2-1/2 month survival advantage compared to the patients receiving standard care.

Lynch Just for the listeners, can you put that into perspective compared to what chemotherapy does for patients with advanced lung cancer?

Temel In general about a two month survival advantage is what we discuss with patients when we are giving them chemotherapy, so for example, if you have a thousand patients who had newly diagnosed metastatic lung cancer and half of them received no chemotherapy and half of them received chemotherapy, the patients who received chemotherapy would live about two months longer, so the survival difference that we saw in our study is about the same magnitude of benefit that you would see with chemotherapy.

Lynch Also one of the things I found most interesting about your study is the idea that talking to patients about death or talking to patients about end of life did not seem to shorten their survival, if anything it lengthened their survival, why do you think that was?

Temel It is not completely clear at this point what led to the survival advantage, I think there are many things that could have contributed to it. We said a moment ago that patients receiving early palliative care had better quality of life and lower rates of depression and we certainly know that in many advanced cancer populations, if you have a better quality of life, if you have a better mood,

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you also live longer. One other thing that we showed is that patients received less aggressive care at the end of life. So they were less likely to receive chemotherapy at the very end of life and were more likely to be on hospice for longer and I also think that those events contributed to them living longer with their disease.

- Lynch Just recently the Center for Medicare and Medicaid Services was considering this year's Bill of Services for Medicare recipients and they initially had wanted to include end of life counseling as a covered service that a physician could provide to a patient. In the end, because of political opposition to that the decision, it was not included as a covered service, why do you think there is political opposition to that principal?
- Temel First of all I should say that I think that if that had gone forward that would have been a wonderful paradigm changing practice. As I said earlier, I think conversations about prognosis and about decisions at the end of life are incredibly time consuming, and I think it is very hard to do it in less than an hour in many cases. So I do think having the healthcare system support these conversations and allowing reimbursement for them would have been an important change to our healthcare system. I think the nation is afraid of dying. Often when we talk about cancer, we are not having conversations like you and I are today, we are only focusing on finding the cure, finding the next best treatment and in general people in the United States do not want to have conversations about the end of life. I think it is really a fear of recognizing death and dying that leads people to not be willing to support these types of initiatives.
- Lynch Where do we go next with your work? You have shown that at a single hospital and in a single disease that early palliative care makes a difference. As you consider next options with your research, where you are planning on going and what questions are you thinking of asking next?
- Temel You are making a very important point, we were very excited about the results that we found; however, it was done in just a single institution at Massachusetts General Hospital and in a single patient population. So before we think about, for example, disseminating this model to other care centers or other hospitals, we need to do a little bit more work and figure out what are the key components of palliative care, what can be exported to other care centers, does it have to be by a palliative care provider, and can it be done by nurse or nurse practitioners? So the next step is to try to hone down exactly what the key components of the intervention were and also to see if the findings will be reproducible in other cancers, for example, pancreatic cancer and breast cancer.
- Lynch Do you think that the role that the palliative care provider played at Mass General, in other circumstances, may be played by an internist or a family practitioner, perhaps in a more rural environment where advanced palliative care may not be available? Do you think that there are other caregivers who could provide that or play that same role that the palliative care team played in your study?
- Temel I definitely think that is true, I think even in major academic institutions like at here or MGH, there

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are many primary care physicians and internal medicine clinicians that want to serve that role to cancer patients. I think a big part of this is relationship building. At Mass General, the lung cancer team has been working with the palliative care team on this type of research for over a decade, so we have a significant amount of experience co-managing patients, sharing the team, sharing how to manage their experience with their cancer, and so I think in other care settings if oncologists could team up with other care providers, develop relationships, figure out how to navigate these roles, that can also have a big impact on the cancer patient's experience.

Lynch And do you see nurse practitioners possibly performing this role?

Temel Definitely, right now, although palliative care is a growing specialty, there are still many areas that do not have palliative care providers. I also think nurse practitioners in general do have a different role than, for example, physicians. They are more focused on symptom management, and often have more time to have conversations with the patients about their illness and prognosis. In our study, we had several nurse practitioners participate in the palliative care intervention, so again thinking about nurses and nurse practitioners doing this kind of work is an incredibly exciting endeavor.

Lynch And the last question, I suspect is on our audience's mind, is you have accomplished a tremendous amount in the last ten years looking at this question, but it is also something which I think could certainly take a big personal toll talking to patients about death and talking to patients about end of life. Do you enjoy your work and how do you find the ability to keep going, despite having lots of difficult discussions with patients?

Temel Yes, I love what I do. I love taking care of lung cancer patients. It is sad for me when my patients die. In addition, after the patient dies, we also do not see their family members anymore and I think those of us who take care of patient populations like lung cancer also become very close to the families. I guess how I get through it emotionally is unfortunately, the patient is going to die whether I take care of them or not, but I feel like because I am taking care of them, they have a better experience with their cancer, they get more support and more care so it makes me more able to get through the day.

Dr. Jennifer Temel is Assistant Professor of Medical Oncology and Hematology at Massachusetts General Hospital. Dr. Thomas Lynch is Director of Yale Cancer Center and Physician-in-Chief of Smilow Cancer Hospital. If you have questions or would like to share your comments, visit yalecancercenter.org, where you can also subscribe to our podcast and find written transcripts of past programs. I am Bruce Barber and you are listening to the WNPR Health Forum on the Connecticut Public Broadcasting Network.