

Yale CANCER CENTER *answers*

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The Crisis in Cancer Care

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Yale Cancer Center Answers is
a weekly broadcast on **WNPR**
Connecticut Public Radio
Sunday evenings at 6:00 PM.

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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 measuring quality of cancer care with Dr. Kerin Adelson. Dr. Adelson is Assistant Professor of Medicine and Chief Quality Officer for Smilow Cancer Hospital at Yale New Haven. Here is Dr. Steven Gore.

- Gore When I was recruited here about a year ago, I was told that we delivered really high quality outstanding state-of-the-art cancer medicine, so why do we need a quality officer to tell us what to do? What does a quality officer do?
- Adelson That is a great question. Increasingly in the field of medicine, we need to be able to look at and quantify the kind of care that we are giving. We need to look at aligning the care we are giving with national metrics with patient satisfaction and really begin to define the field of what quality care is.
- Gore How do we do that? I mean, I can tell you what I think quality care is in my subspecialty and people come to me because I am an expert, so shouldn't I be able to set that as the goal and say, "I am delivering quality care?"
- Adelson I think we all like to believe that we are providing the best quality care. Unfortunately, especially in the field of cancer, we sometimes do things that do not actually have positive outcomes on patient's quality or quantity of life and increasingly, as the amount of federal dollars available and actually all of our dollars for providing healthcare are being stretched further and further, we need to start looking at how to get the greatest value for the care we give. There are different ways to do that. Value can be defined by increasing quality or decreasing the cost that goes into care and sometimes in certain situations with cancer, I think increasing value aligns with increasing quality.
- Gore Is there an agreed upon definition of quality? Would your vision of quality and my vision of quality be the same or are there national norms?
- Adelson That this is an ongoing discussion. I think there are certain accepted elements, so quality is giving patients the right treatment at the right time and getting the best outcomes. Value takes into account what we are spending on those elements.
- Gore Just talking this through, if nationally every place were to agree upon a certain set of quality standards, if that is the right word, then it probably would not matter where you got treated right, I mean you would not come to a specialty hospital like Smilow, or am I misreading that?

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- Adelson Again, this is part of the national discussion and I think this is a critical issue because there are certain things that we know are better provided when you see a disease specialists in your area. However, proving that that care is better is hard and it is challenging. In cancer, for many years across the country including at the best cancer centers, we never actually tracked outcomes. That information is not easy to get from our standard electronic health records and so to justify why care at specialty centers is more expensive is really challenging.
- Gore And so that would be the value piece if the quality were better, even if it were more expensive, that might lead to better value, is that right?
- Adelson But we know sometimes with certain diseases patients treated at specialty centers, especially high volume surgical centers, do better than patients who are treated by doctors who see less of those special cases.
- Gore It sounds very complicated, are there complicated equations or programs or algorithms that take these data and give you a quality metric?
- Adelson This field is really in its nascent stages and because the meaningful long-term outcomes such as, did the patient live or die, how long did they live, how long did the patient go before the cancer recurred, those data types which are called outcome measures actually take a very long time to get, so instead quality metrics or endorsed quality metrics have often focused on very simple process measures, measures like did a patient with stage III colon cancer get offered chemotherapy because that is in line with the guidelines? Did a patient with hormone sensitive breast cancer get offered hormonal modulation? These are process measures that are relatively easy to get but when you actually look at cancer centers who have tried to participate in different quality systems where they are actually reporting, most of which is strictly voluntary, you see that providers are really about 97% adherent with those process metrics and so I would say those are not even really quality measures, those are minimum standards of care and the real challenge in the field is how do we begin to define that we are giving care that is in line with what patients want and value.
- Gore You are fairly new to Yale and Smilow, is that right?
- Adelson I actually went to medical school here at Yale and finished in the late 90s and then went back to my home in New York and spent many years at Mount Sinai where I built a very busy breast cancer practice. In the last several years through what began with running the implementation of our electronic health record and beginning to look at how we can use the electronic health record to really improve the kind of care we are giving, I became increasingly interested in quality and in quality research and ultimately was really happy to come back to Yale as Chief Quality Officer.
- Gore And how long have you been here?

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Adelson I have been here six months now.

Gore So you have been here for six months, how do you start to take the temperature of the quality?

Adelson I think quality assessing is a sort of low-lying fruit which is looking at things like rates of infection an hour, rates of readmission or inpatient mortality rates, all of which was an ongoing field before I got here and making sure that those things are heading where they need to and sometimes they are and sometimes they are not, and then it is trying to understand the culture of the oncologists and the cancer providers at Yale and understanding where we need to start to move that culture to be providing the care that the patients want.

Gore I know that oftentimes when clinicians hear quality and value and metrics or some combination of those kinds of words, they are thinking cost savings, limiting care, taking away my autonomy.

Adelson Yes.

Gore Do you get that pushback?

Adelson I have run up against that a lot and I think there are a couple of ways to think of it. We know that care that is provided in a standardized manner has less variation and less room for error and when you give every patient who meets certain categories, the same kinds of treatment, you can begin to study the outcomes and that is how we will be able to define whether the care we are giving at Yale is better than the care that is being given at the community hospital around the corner, but until we standardize that care, we cannot make that argument.

Gore So have you gotten buy in from many of your colleagues?

Adelson Yes and no. I think there are some of us who are very comfortable practicing in the way we have always practiced and not being held accountable, but I think increasingly everybody is starting to understand that we are not going to be able to get away with that. Both payers, government payers and private insurance companies, want to know that you are providing evidence-based care and so we are looking at the process of beginning to implement clinical pathways here at Yale, with of course the option to customize those pathways to take our expertise as disease specialists into account and to also take into account the research that we do here. Another issue with culture that I wanted to talk about, is when you start to say is quality about saving costs or is quality actually about improving care, I think the example of end-of-life care is really where you see these issues dovetailing. In the care of patients at the end-of-life in this country, we provide very overtly aggressive care. We see that patients go to the intensive care unit shortly before they die, they have multiple hospital admissions, they often actually undergo chemotherapy in the weeks close to the end-of-life and these things are very expensive and actually when you ask patients what they want, there have been lots of studies showing that patients want to die at home with their families and if you ask oncologists what they would want, 70% of them say they would want to be on

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hospice at the end-of-life and so you have got a situation where the care that we are providing is not actually in line with what we would want for ourselves or what patients want, at least some of the time, and if you start to think about changing the culture of how we care for patients at the end-of-life, you actually have significant cost savings by lowering such aggressive utilization at the end-of-life and by bringing care more in line with what patients want.

Gore Why do you think that is, why do you think that physicians or oncologists behavior seems so blind to their own wishes as you have explained or what the wishes of the patient may be, or do you think we get so attached to the patients that we no longer maintain the objectivity that is required to say, I am not really helping this patient anymore, or my ability to help the patient in terms of quantity of life is falling off?

Adelson I think all of these elements are true. One factor is that we do not receive training in having discussions at the end-of-life as we go through fellowship and many oncologists and hematologists went into this field with the idea that we would be able to cure cancer and save lives, and so there is a feeling of failure when a patient has progressive disease and you are running out of disease modifying things to offer them. I think that is one very strong reason. Another reason is I think there is a fear of causing the patient emotional distress and inflicting suffering by having those conversations. On a more cynical note, our healthcare system rewards the kind of care that leads to aggressive treatments, so we are paid on a fee for service basis for providing chemotherapy, for having rapid focused office visits, and the kinds of conversations about goals of care are hard to have, there are long discussions and there is no clear-cut reimbursement pathway for that kind of care.

Gore That is a little cynical, but I hear what you are saying. It seems to me that in our sort of culture, it is almost as if the family and maybe the patients, need to see this escalation of complexity and sickness before they are willing to accept that this is a terminal illness or something like that.

Adelson I think there is a culture where as patients get sicker and come into the hospital where they are often cared for by doctors who are not their primary outpatient oncologist, the repeated admissions begin to signify the end-of-life and so those conversations start in the inpatient setting but the truth is, if you look at solid tumor patients, on average, a patient who has a metastatic solid tumor who is admitted to the hospital is actually very likely to die within the next three or four months, so if you wait till that hospitalization, it is probably already too late to make a big difference in the patient's quality of life and that is where the issue of cultural change comes about and we need to start having these discussions much earlier in the course of disease, especially for diseases that are not going to be curable and it needs to be an ongoing iterative discussion with the patients about what to expect from treatment and the kinds of treatment they would want in multiple scenarios as their disease progresses.

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Gore This is such an important set of topics and we are going to come back to them after the break, but in the meantime, we are going to take a short break for medical minute.

Medical Minute

In 2014, 200,000 Americans will be diagnosed with lung cancer and in Connecticut alone, there will be over 2500 new cases. More than 85% of lung cancer diagnoses are related to smoking and quitting, even after decades of use, can significantly reduce your risk of developing lung cancer. New treatment options and surgical techniques are giving lung cancer survivors more hope than they have ever had before. Clinical trials are currently underway at federally designated comprehensive cancer centers, such as Yale Cancer Center and Smilow Cancer Hospital at Yale-New Haven to test innovative new treatments for lung cancer. Advances are being made by utilizing targeted therapies and immunotherapies. The BATTLE-2 Trial at Yale aims to learn if a drug or a combination of drugs based on personal biomarkers can help to control non-small cell lung cancer. 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 WNPR, Connecticut's public media source for news and ideas.

Gore Welcome back to Yale Cancer Center Answers. This is Dr. Steven Gore and I am joined tonight by my guest, Dr. Kerin Adelson and we are discussing the crisis in cancer care. Kerin, what is the crisis in cancer care, are we having one?

Adelson We are unquestionably having one. The costs of cancer care are increasing exponentially. The costs of new drugs have doubled in the last several years and are increasing at a rate that is absolutely unsustainable. New drugs that are approved for cancer care cost on an average of \$10-12,000 per month. Patients are going bankrupt from the cost of their co-pays for their care and increasingly it is not clear that we are getting better outcomes for the amount of money that we are spending, and so we really need to self-consciously begin to say, what are the interventions we are doing that benefit patients and that give the patients the kinds of care that they want and where is the waste in the system that we can begin to tease out.

Gore It seems so hard because you know as these new drugs, many of which really are miracle drugs, get approved, they go to these various groups that make guidelines and they get incorporated somewhere in a guideline and then of course, doctors want to use them in patients, patients talk on the internet, among themselves, and in support groups and they hear about the great new difungal muctane targeted therapy and why would they not want it? Doesn't everybody want to be treated with the latest and best?

Adelson I think we need to look at what drugs are miracle drugs and what drugs are really making a difference and what drugs are just me-too drugs. In the history of drug approval for cancer, drugs were often approved in a stage IV setting just by a measure of either causing a tumor to shrink or preventing the amount of time before a tumor grew, but not every drug that gets approved actually

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improves patient's quality or quantity of life. In the UK, they have a whole governing agency called NICE that actually takes value into account and says, is the benefit of this drug worth the cost?

Gore Which is not always so nice if I hear some of my colleagues in the UK.

Adelson Right, so while we have our miracle drugs like imatinib for the treatment of CML or trastuzumab for the treatment of breast cancer, that really have a profound impact, we also have a lot of drugs for which billions of dollars have been spent that do not always make a huge difference in a patient's quantity or quality of life, take the example of bevacizumab in breast cancer.

Gore It is Avastin, is that right?

Adelson Yes, which was actually approved in breast cancer on that marker of the cancer going more time before it grew again, and then as more studies came out, it became clear that it really was not having any impact on patients overall survival and the FDA actually withdrew approval for that drug.

Gore Just to clarify, it looks like it slowed down the progression of the breast cancer, but the patients were not living any longer.

Adelson Exactly.

Gore But is not slowing down the progression a value in and of itself?

Adelson Not necessarily, I think it depends on whether it improves clinical symptoms. If the endpoint is strictly something that you see on a CAT scan, that may not have clinical significance for the patient, and as is the treatment with many metastatic disease presentations, patients get drugs in sequence and so just because you improve one moment in time, it does not mean it has impact on the overall trajectory because they are going to go on to get four or five more drugs in the future.

Gore It seems to me that societally this is so difficult because the pharmaceutical companies, you can say what you want about them, but they do spend gazillions of dollars developing these wonder drugs, or hopefully wonder drugs, so they have costs they want to recoup and they serve to make a profit in our capitalist system. And so they get their approval and yet it sounds to me from what you are saying that we have not really done the assessment to know whether this should fit in and for which patients, so now all of a sudden you and I are able to prescribe anything we want.

Adelson Our FDA, the agency which allows for a drug approval process is actually not allowed to take cost into account, so if a drug looks like it has some benefit and if it is safe, the drug gets approved regardless of whether or not it has 'high value' and so we certainly do not want to decrease the

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entrepreneurship and the initiative of discovering these amazing, really increasingly miracle treatments, but at the same time we probably should not be bankrupting our system paying for drugs that do not have a large impact overall.

Gore It seems like this whole area is open for all kinds of research questions, is there anything that you are involved with research wise in this area?

Adelson Yeah, I think one of the most exciting things that I am working on now is a grant that we got for a randomized trial and it is a very different type of randomized trial because it is actually the physicians who are randomized. It is funded by the Patient Centered Outcomes Research Institute which is a new agency funded through the Affordable Care Act that is looking to improve the quality of care and the evidence for different treatments to help patients and physicians make decisions about what they use. You may have heard the term comparative effectiveness research.

Gore I have heard the term death panels, is that the same thing?

Adelson No, not at all, it is very different. So I worked on a grant that is actually looking at teaching oncologists to have discussions about goals of care and so the oncologists are actually randomized to educational sessions about conducting goals of care discussions and then the really exciting part is that the oncologists in the intervention group will go through four consults with a palliative care doctor who is trained to have goals of care conversations using a proven scripted format for the best way to have those discussions with empathy built in, with identifying that the patient understands their prognosis and through each of those four consultations which are done with the oncologist's own patients within their own practice, the oncologist takes on more and more elements of this proven format for having goals of care conversations and at the end, we are going to ask the patients, were you able to address your goals of care, do you feel you had this kind of conversation, and we are going to try to measure whether patients who are in the intervention oncologists group actually receive care that is more in line with their wishes than the patients who are in the standard arm.

Gore Fascinating. So the control group does the conversations with the patients but is not prepped, is that right?

Adelson Exactly. They will go along according to their normal practice.

Gore I see, so it is not that everybody has the test conversation with a read out, it is not like that?

Adelson Right.

Gore It is just the normal care.

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Adelson Yes, but the patients will be surveyed.

Gore And do the doctors know that their patients are going to be surveyed at some point?

Adelson Yes.

Gore So everyone knows that?

Adelson Well, the doctors will enter into it willingly not knowing which arm they are going to get randomized to.

Gore I see, so even the ones who are in the control group at least should have their antennas up for a while and a little bit after being in the study, right?

Adelson Yes, absolutely. There may be a sort of intervention affect even on the control arm. But that is okay. This is going to test whether the intervention helps beyond just sort of a normal antenna going up or normal awareness.

Gore And is this for junior doctors or will you also include experienced physicians?

Adelson This is a great question. This is for very experienced oncologists. We have a community site, an academic hospital and a city hospital, and it is for established oncologists who are treating patients in those settings. I think if we see a positive effect, I could imagine this being incorporated into oncology fellowship training in the future.

Gore That seems like a no-brainer.

Adelson Yeah.

Gore It is interesting to think that you can retrain an old dog, like I might call myself in this case. I think I am pretty good at it, but I am sure there is always more to learn.

Adelson I think the study will test whether we can be retrained.

Gore That is really fascinating, and how many physicians will be involved in this study? Is it in the 100s or dozens?

Adelson No, probably 25 to 30.

Gore It sounds like it is pretty labor intensive.

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Adelson Yes, it is. There is a lot of documentation, analyzing transcripts, audio tapes, to really start to understand the nature of the conversations that we are having.

Gore It sounds like you have got this big quality piece which is so important for the care at Smilow. You have got this research piece which is kind of establishing you in the forefront of measuring and impacting quality nationally or internationally, and then you also have a clinical oncology practice, is that true?

Adelson Yes, I am a breast cancer oncologist, I have been for many years and breast cancer actually, because it is often a curable disease, is one of the diseases in which we see many quality metrics focus and my patients are my eyes and ears, so I say to every single patient I see, listen if there is something wrong with the process of your care, you better tell me because that is how I am going to know what is going on, and I think if I did not treat patients, I would lose touch with what it means to provide quality care.

Gore So given those three major jobs, I am assuming you have no personal life or children or anything like that, right?

Adelson I have got two kids. I think sometimes they do feel they could use a little more of me present.

Gore I think all children of professional parents feel that way and I think that we just do the best we can.

Adelson We do our best.

Gore Quality at home, quality at work, that is fascinating. It sounds like you have got your plate full and I am just wondering, you came from Mount Sinai, do you feel the culture here is different, and if so, in what ways?

Adelson It is different. In terms of translational science and treatment focused cancer research, it is much stronger. We have tremendous faculty doing really exciting cutting edge clinical research and very close involvement with the basic scientists as well. In terms of the culture of palliative care or goals of care or patient-centered care, I think that has not been as active a topic here at Yale as it was at Mount Sinai where I came from. Mount Sinai probably has the strongest palliative care department in the country. But interestingly, in most of my years there, there was very little intersection between the oncologists and the palliative care doctors, and one of my early projects was about bringing palliative care into standard oncologic care and I did a quality intervention which got a lot of publicity through the ASCO quality conference over a year ago.

Gore That is the American Society of Clinical Oncology.

Adelson Yes, their quality conference. We developed standardized criteria for inpatients who had metastatic solid tumors for involvement of palliative care, so if patients had stage IV disease or uncontrolled

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symptoms or had been in the hospital for a long time or had been readmitted within the prior month, they were automatically seen by palliative care and it bypassed the oncologists role in that process and the palliative care doctors were allowed to address whatever needs the patient had and what we saw is that one intervention had tremendous impact on the inpatient mortality rate, not saying that we cured our patients so that they were not dying, but they began to die in more appropriate settings than in the inpatient acute care oncology ward, so they went to either a palliative care unit or to hospice or to home hospice and we actually dramatically lowered our 30-day readmission rate which is one of the quality metrics that we all look at and again I think we lowered the readmission rate by doing a better job addressing prognosis so that patients went home knowing that they were likely to get sicker with a plan to go into hospice, or to where their disease was going, and so I think it had tremendous impact in that sense and then we also saw significant increase in our use of hospice.

Gore And did the oncologists pushback about that, feel like their bounds were being overstepped?

Adelson It is about timing and readiness. Yes, there were some oncologists who did pushback, but I think that the palliative care department at Mount Sinai had spent years and years building goodwill and then the intervention was really pushed by myself and a colleague of mine and we were both oncologists, so it came from within. There is no way that a department outside could have done it.

Dr. Kerin Adelson is Assistant Professor of Medicine and Chief Quality Officer for Smilow Cancer Hospital at Yale-New Haven. 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 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.