Welcome to Yale Cancer Center Answers with your hosts, Dr. Francine Foss and Anees Chagpar. Dr. Foss is a Professor of Medicine in the section of Medical Oncology at the Yale Cancer Center and is an internationally recognized clinician and clinical researcher. Dr. Chagpar is Associate Professor of Surgical Oncology and Director of the Breast Center at Smilow Cancer Hospital at Yale-New Haven. Yale Cancer Center Answers features weekly conversations about the most recent advances in 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 with Dr. Joseph Jacobson. Dr. Jacobson is Chief Quality Officer at Dana-Farber Cancer Institute, here is Dr. Francine Foss.

Foss Can you start off by telling us a little bit about yourself and about your background?

Jacobson I am a medical oncologist by training and I have spent my entire medical career in the Boston area. Most recently, I moved to the Dana-Farber Cancer Center and that was about three years ago. My training is in general internal medicine and that was followed by training in medical oncology and hematology, and I have practiced in a variety of settings over the last 25 years, both in academic medical centers and in the community.

Foss Can you tell us a little bit about this role of Chief Quality Officer, what actually do you do in that role, and how do you prepare yourself for that kind of a job?

Jacobson It is easier to ask the first question than the second. I joined Dana-Farber in April 2011 for the newly created position of chief quality officer and I have spent the last two and a half years really defining that job and what I would say, generally, is that as chief quality officer, I share responsibility for the quality of care that is delivered at Dana-Farber itself, its main campus in Boston, as well as in the growing network of community sites, and quality really should be viewed broadly. Quality includes first and foremost, patient safety, so part of my responsibility is to be sure when patients travel to our center for care that they know they are safe, that systems are in place that guarantee that they are looked after along their journey from diagnosis through treatment, and that chemotherapy and radiation are provided in the safest possible way. My responsibility as a chief quality officer extends beyond safety and also includes guaranteeing that patients are getting the right therapy, that the tools that clinicians need to make decisions are available and that patients are receiving their care in a timely fashion and that we are doing it responsibly. Part of what we as oncologists do is manage very expensive resources that include drugs and radiation techniques and we have to be very careful that we are using those judiciously, especially as the cost of healthcare continues to rise in the United States.

Foss You mentioned issues of trying to decide what the right treatment is and I know that Dana-Farber is a comprehensive cancer center. Can you go over for folks who do not understand that concept, what a comprehensive cancer center is and then down the line how do you ultimately go about ensuring that the patients are getting the right treatment?

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Jacobson There are approximately 40 comprehensive cancer centers scattered across the United States and these are designated by the National Cancer Institute in Bethesda. Comprehensive cancer centers need to of course, first and foremost, provide very good care to their patients, so this is all about delivering the patient care, but they also have a mission that is somewhat broader. It includes a requirement to do research and to obtain research grants, and to identify opportunities for new treatments for patients. All comprehensive cancer centers have a commitment to serving their local communities to be sure that the patients who face disparities have good access to cancer care when they need it and they are provided services to make screening possible and management of cancer possible. Comprehensive cancer centers also tend to provide a variety of other services including screening, which I have just mentioned, but also opportunities for identifying the patients at higher risk for cancer, those who have genetic predispositions, for example, comprehensive cancer centers tend to have additional services around palliative care, the patient's navigation, survivorship, and other services to treat the whole patient.

Foss As you talk about cancer delivery and cancer care, it seems to me that you are not just talking about chemotherapy and radiotherapy, but that you have a much broader picture of what cancer care is in this setting?

Jacobson Yes, I think that is absolutely true. Cancer is always a devastating diagnosis to patients, their families, friends, and other loved ones, and the management of cancer has to take into account the patient and the fact that they are experiencing new fears and new anxieties that often come out of the blue, the diagnosis of cancer is often reached rather suddenly. It may be based on a symptom or a sign that leads to an x-ray that suddenly raises the specter of cancer. So the patient and family needs to be embraced at the very beginning to be reassured that others have gone through the very same condition and there are systems in place to guarantee their safety and that they will be treated respectfully and offered the opportunity to be involved in decision making at each step as the diagnosis is established and staging is done and treatment is outlined and instituted. We treat our patients specially and recognize that even after treatment is completed they need to feel connected often to the cancer systems so we at Dana-Farber and at Smilow Cancer Hospital continue to provide to the patients after their treatment is completed through survivorship programs, formal programs to be sure the patients still feel like they have something to hold on to in the healthcare system after their therapy is just one thing that we offer to patients, but I guess what I am saying is that cancer care needs to be holistic, not just as written words on a page, but truly what the patient experiences.

Foss It is interesting because from a patient's point of view, they may recognize their oncologist or their nurse, or their radiation therapist, but they may not actually step back and look at the whole picture of integrated care as you describe it. So how can we bring that more to the forefront in terms of the patient recognizing that? You mentioned at one point that there were navigator services available. How does that help us to integrate this whole process across all these different disciplines?

Jacobson Navigators offer that opportunity for some patients. Most centers cannot offer navigators for all

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diseases but for many cancer programs, navigators are present for patients, for example, with breast cancer, and they become safe guides for patients by making sure that they are communicating with patients assuring any barriers to getting timely care are broken down, but that is just one of the components, and every cancer center is different. Dana-Farber, for example, has a very strong commitment to supporting patients and their families. We have a large and fertile patient and family advisory group, and so the patients and family members do make themselves available to patients within our organization and are there to help, but back to your broader question, how does the patient understand the full scope of services, today there is the opportunity for the patients who have access to the internet to go and read deeply into the organization. I think when patients come to their visit, especially their first visit to a cancer program, it is always good to bring a family member and have that family member bring a notebook and write down questions in advance, first of all, but also write down questions at that time of the visit and make sure that those are answered, not necessarily by the physician who may have limited time during that first visit, but by others who should be available within the center so that those questions are answered and this global question of, how does the center look after me, I think can be addressed and I think patients are often quite struck once they learn the full scope of what is available to support them through very tough times often.

Foss Do you think a patient can actually prepare in advance and do you recommend a patient say that has a new patient appointment at a cancer center do anything in advance research wise, research the center, research the disease, or do you feel that it is better for them to just come in, be welcomed and hear about what that center has to offer and then ask the questions after that.

Jacobson Yes, I think patients should know where they are going and the websites for those individual centers are powerful starting points. I also think that patients should look towards trusted internet sites that may also guide them. Examples are the American Cancer Society which has abundant resources for patients. The American Society of Clinical Oncology has a specific Patient Portal that is really quite powerful, The National Cancer Institute does as well, I think through their PDQ program, those are places where patients can go and The National Comprehensive Cancer Network is another, but I worry sometimes that patients can find themselves at a less trusted site where they could find information that is not only inaccurate but sometimes alarming and unnecessarily so, but a prepared patient in my mind is the very best patient to meet. Those who come with a list of questions are always welcomed and some of the sites that I mentioned offer a resources checklist that the patients can actually bring with them, and they are scripted with questions that should be answered at the time of that first visit.

Foss You mentioned the issue of disparities and I wanted to know how you would handle patients say who do not speak the language, so perhaps culturally there are barriers to them being able to come in and understand all of what you presenting to them, and also the patients who are at a financial disadvantage, coming into your center. Do you approach those questions and those issues with the patient as they step in the front door and how do you actually get them in the front door?

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Jacobson Let me address your last question first, how do you find the patients? I think one responsibility that cancer centers have, especially the comprehensive cancer centers, is to be sure that those patients who should be screened for cancer are actually getting that screening. At Dana-Farber, we have a mammography van that travels to communities where we know there are low rates of screening for breast cancer. That is a starting point. We have resources as well to care for patients at a site beyond our main campus. Ours is called Whittier Street. It is a community clinic that we staff with medical oncologists who are there to triage to help assure that the patients will get expedited workup of new suspicions for cancer or staging for patients with a new diagnosis of cancer.

Foss Joe, we are going to have to stop for a quick medical minute. Please stay tuned to learn more about cancer care with Dr. Joseph Jacobson.

Medical

Minute The American Cancer Society estimates that over 1000 patients will be diagnosed with melanoma in Connecticut each year and while melanoma accounts for only about 4% of skin cancer cases it causes the most skin cancer deaths. When detected early melanoma is easily treated and highly curable and new treatment options and surgical techniques are giving melanoma survivors more hope than they have ever had before. Clinical trials are currently underway at Yale Cancer Center Connecticut's federally designated comprehensive cancer center to test innovative new treatments for melanoma. The specialized programs of research excellence in skin cancer grant at Yale also known as the SPORE Grant will help establish national guidelines on modifying behavior and on prevention as well as identification of new drug targets. This has been a medial minute brought to you as a public service by Yale Cancer Center. More information is available at yalecancercenter.org. You are listening to the WNPR Connecticut's public media source for news and ideas.

Foss Welcome back to Yale Cancer Center Answers. This is Dr. Francine Foss and I am joined today by my guest Dr. Joseph Jacobson who is here from the Dana-Farber Cancer Institute. Today we are discussing the value of cancer care and quality improvement. Joe, we went through some of the things that you do in your job, but I am wondering if you could tell us what you mean by quality improvement. What are the different components of quality improvement that you address and which one is the most important to you?

Jacobson Many years ago the Institute of Medicine defined six elements of quality of care. Those were not specific to cancer care, but they are relevant and they fall into the following areas. The first is safety, and the second is effectiveness. The third is that the care should be patient centered. The fourth is around efficiency of care, the patient should not be kept waiting, and the fifth is around equity guarantying that all patients have access to the care that they need, and the final one is around timeliness. So that is a starting point. I will speak more personally, when I was a teenager, my mother was being managed with advanced ovarian cancer and this was many years ago in the early 1970s, before there was effective therapy, and I recognized at the time that she had a serious diagnosis and I was aware of the suffering that she experienced and as I thought about it, the

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Foss My next question is around how you are actually measuring that and how you actually know whether you are delivering what the patient wants, and you alluded to Press Ganey. I know some of our patients are getting the Press Ganey surveys in the mail. Can you tell us what that is and how you actually use that information?

Jacobson There are several companies in the United States that are in the business of tracking down patients who received care in hospitals or even in outpatient settings and asking them about their experience, and the one that we use is called Press Ganey and this is through a contract with our hospital. Press Ganey sends out surveys to the patients, or contacts them by phone after they have

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been in the hospital or have been in our ambulatory cancer center, and they have a set of structured questions they go through and from that they generate information for many patients and generate a pretty good snap shot of what a patient's experience is in your hospital system. It is always enlightening. We have always learned things from those surveys and I would argue that hospitals and clinics that are most successful take that information every month and dissect it and understand what can be learned. The patients are also allowed to provide free responses, free text and those turn out often to be the most important and from those we learn and we continuously improve.

Foss A lot of patients feel that if they have a complaint or something did not go right that nobody is really going to answer them or care about what they say or they do not even know who to say it to. How do you provide those avenues for the patients and how do you make them understand that everything that happens to them and their opinions about everything are important, important to the organization and to you as the quality officer?

Jacobson It is such an important question. I was hospitalized a couple of times in the fall. So first of all I got to fill out my Press Ganey survey, but I also for the first time in my life experienced the vulnerability of being a patient and one of the things that I recognized right away and I have heard from patients in the past is that I was afraid to talk about parts of my care that I thought were imperfect because I did not want to alienate my caregivers. I recognize that everyone worries about that, but the reality is that hospitals are set up in a way that patients' worries can be kept confidential and that includes me as a recent patient who needed to be reminded that the only way that we can improve care is to understand what is wrong. Almost all hospitals have something equivalent to a patient's family relations department and if you call the switchboard of your hospital and ask for that sometimes it is called the hospital ombudsman, you can be connected with someone who can hear your complaint, respond to it and all others should be encouraged to reach out to the patient and family relations department. At Dana-Farber, our group provides monthly reports to my department summarizing the complaints and breaking them into categories. So some of those are very simple fixes, some are much more significant, but the patient should be reassured that it is safe to report their concerns and it is really vital for us that they do it.

Foss Even if they are at Smilow I can say that we do get that feedback when patients present various complaints about the process or providers, particular situations, and we definitely get that feedback and there is discussion about how that situation can be remedied. So it definitely goes both ways.

Jacobson Absolutely, and given the mission of Smilow and the Dana-Farber to provide the very best care to all patients with a diagnosis of cancer, by the very nature of that commitment it is patient centered care that we are providing and if we do not get the feedback from the patients everyone loses.

Foss Can we talk globally for a minute, about the whole concept of these academic cancer centers? A lot of what you do and what you are talking about isn't directly funded in any way. It has to come

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out of a general operating fund for that cancer center and as the healthcare is changing and we are hearing a lot about some of these changes now, can you tell us what the major threats are to the academic cancer centers?

Jacobson think this is a really important question especially as we move towards needed healthcare reform. What I think many people do not understand is that academic medical centers like Yale-New Haven Hospital, like the

Dana-Faber Cancer Institute, have several missions. The principle mission for all of these centers for academic medical centers and comprehensive cancer centers is to provide the very best patient care. That is what gets everyone out of bed in the morning and that is why they come to work. But, in addition, they have other missions, one is critical and that is to extend the field forward and that is by doing basic science research to understand the causes of cancer better and there have been absolutely extraordinary breakthroughs in the last decade. They need to develop the new drugs. They need to test the new drugs. They need to study populations of patients and also many medical centers, academic medical centers and comprehensive cancer centers, have a commitment to the community. Those missions are very expensive and the cost of providing care is always going to be a little bit higher at these academic medical centers and comprehensive cancer centers. So they are all at risk of competitors and these competitors would come in the form of private practices of cancer care that has a single mission which is providing care for the next patient in front of them. It is a laudable mission, but it is very different from that of the larger centers. So if our centers are to survive, especially in the middle of Federal Sequestration and with declining funding for research, it is going to be vital for these academic centers and comprehensive centers to demonstrate their value and they can do that I think only by having the conversations that we are having today showing that what they do is beyond taking care of the needs of an individual patient, but thinking forward to how care can be better five years from now. How cancer can be prevented based on advances in our understanding of predisposition to cancer. For example, how to come up with newer drugs that are less toxic and more effective.

Foss So, basically what you are saying, and I think a lot of us realize this, is that in order for these cancer centers to make these advances, patient's need to come in, they need you, as a patient, to come to the front door because you can participate in the research and help move the field forward.

Jacobson That is right, and sometimes I use this term that quantity drives quality, and that it is vital for the large cancer programs like Smilow and Dana-Farber to continue to have enough patients so that we can understand the basic principles of cancer, test the new therapies, and implement them. Without centers like Smilow and Dana-Farber, the risk is that progress in cancer care will stagnate.

Dr. Joseph Jacobson is Chief Quality Officer at Dana-Farber Cancer Institute. We invite you to share your questions and comments with doctors Foss and Chagpar and you can send them to canceranswers@yale.edu or leave a voicemail message at 888-234-4YCC. As an additional resource archived programs from 2006 through the present are available in both audio and written versions at yalecancercenter.org. We would like to thank the Yale Cancer Center for providing production support as part of the connecting our communities initiative from Connecticut Public Broadcasting. I am Bruce Barber hoping you will join us again next Sunday for another edition of Yale Cancer Center Answers here at WNPR Connecticut's Public Media Source for news and ideas.