

Welcome to Yale Cancer Center Answers with Dr. Ed Chu and Dr. Ken Miller. I am Bruce Barber. Dr. Chu is Deputy Director and Chief of Medical oncology at Yale Cancer Center and Dr. Miller is a Medical oncologist specializing in pain and palliative care and he also serves as Director of the Connecticut Challenge Survivorship Clinic. If you would like to join the discussion you can contact the doctors directly at canceranswers@yale.edu or 1-888-234-4YCC. This evening Ed Chu is joined by Judy Grasso.

Chu Why don't we start off by learning a little about your background. How long have you been in the field of oncology nursing?

Grasso I have been in oncology nursing since 1980. I started out at Hartford Hospital and worked there for 15 years. Then I had an opportunity to go New London and help build the cancer center at Lawrence & Memorial Hospital, and then I came to Yale. I have enjoyed every moment.

Chu Clearly you have a great deal of experience, what made you decide to get into the field of cancer nursing?

Grasso I had been an ICU nurse at Hartford Hospital for about 12 years, and I decided everybody went in and out very quickly, I did not know anything about them and I wanted to get to know my patients. I had an interest in a lot of the cancer patients that I had seen with these big traumatic surgeries, and I wanted to see what happened to them and be a part of the piece that helped them get well after they had this initial surgery. This is just a great interest of mine and it is in a field where you keep learning all of the time; I really love that part of oncology.

Chu So you have been in the field now for almost 30 years.

Grasso Right.

Chu You have probably seen the entire field grow and evolve over time.

Grasso When I worked at Hartford Hospital, we would give one drug. I remember we had somebody get off a plane and they were getting Adriamycin for the first time, it was a woman with metastatic breast cancer, and we got it from the NCI. We gave her 50 mg of Adriamycin and she went from being on a stretcher and in a wheelchair, to 2 weeks later feeling much better. It was very exciting and then after that everything just exploded and keeping up with all the new drugs and changes has always been a wonderful, interesting and fascinating thing the more we learn about oncology.

Chu From the physician side, again over this 25-30 year period, we have seen such an explosion of treatment options that we have available now to offer patients. It is tremendous for us and for our patients.

Grasso I worked from 1980 to 1990, when we really did not have much supportive care. Then Zofran and Neupogen came out, things to prevent nausea and vomiting, and those are truly miracle drugs to me as well as the oncology drugs.

Chu Let's hold off on that and talk more about it in the next segment. What are the main roles of oncology nurses vis-à-vis the overall treatment of the cancer patients?

Grasso The nurses really walk side by side with the patients when they are on treatment. They are there to get them through the first treatment because they are frightened. Everybody always comes in wondering what these drugs are going to do to them. The nurse explains all of that and then administers the drug. They explain everything while they are doing it and then help patients manage symptoms afterwards.

Chu You folks on the nursing side really do play a lucky role in helping to educate, guide and kind of keep the patients grounded if you will.

Grasso We are the link. The doctors are busy. We are fortunate that they are doing research and other things, but the

nurses are there everyday. They can get phone calls and field things in triage and help patients manage simple symptoms or call the physicians and get some assistance with managing symptoms if they think they need some. Chu Have you noticed any difference in terms of the role of the oncology nurse here at Yale Cancer Center as opposed to how it was when you were at Hartford Hospital and then New London Lawrence & Memorial Hospital, are they pretty much the same? Grasso At the smaller places you deal with all types of cancer; you treat lymphoma, you treat breast cancer. Here we are trying to put the nurses into disease teams and become experts. You have such huge volumes of patients, and I am finding that here at Yale, the patients are often referred to us after being treated elsewhere and they are sicker. We also have phase 1 and phase 2 trials open and a lot of patients are coming to us after months of treatment or referrals for the phase 1 trials. That piece is very, very exciting for the nurses to learn about the clinic trials, very different then the other institutions that just are not offering the phase I trials. So that whole process of giving a drug for the first time and not knowing what is going to happen, and being the nurse there assessing and watching that person and helping to define with the physicians what the toxicities of this drug are, and how to manage it, becomes very exciting for our nurses here at Yale. Chu I was just looking at some of the latest numbers of patients going into various clinical trials, and you probably would not be surprised to hear that more than 50% of the patients we put on clinical trials are in fact going on to these novel first-in-man phase 1 clinical trials. We are really testing completely new treatments, but with the hope of having a positive impact on the patient's cancer. Grasso Dr. Sznol, with the ipilumimab trial, has got a large number of patients because it is 1 of 5 sites in the United States. People from the entire East Coast are coming to get this drug here. Our nurses are getting very seasoned and experienced at helping to manage symptoms tightly, which is critical for getting these patients through the drug. Chu In fact, you told me that you and your colleagues had put together some abstracts for your oncology nursing society. Grasso We got accepted. I went to the oncology nursing society and presented the poster and it was exciting because melanoma is a disease that there are not a lot of options and treatments for. Also, the people were very interested that there is another drug out there that might really show some benefit to patients. Chu And you discussing our experience here at Yale with all the symptoms and how we might be able to manage them really can be very helpful to others out there in the country. Grasso We did, it was great. People take your card and we have a conversation. We need to do more of that, it was a great experience. Chu The other thing you just mentioned was the issue of having a more disease-oriented approach. The whole field has so rapidly evolved even within a particular disease. The treatment options have become much more complex in breast cancer, and in my own field of colorectal cancer, and this is from the physician's side. It does seem that there is a greater emphasis on the nursing side as well... Grasso Absolutely. Chu ...to focus and specialize. Grasso When we have someone like Dr. Saif who has a lot of patients on trials on a lot of different drugs, its great to have the same group of nurses taking care of those patients, because they learn how to manage those patients

and do a great job with it. With drugs like Erbitux and Avastin, we have a lot of rashes associated with them. The nurses did a little project where they looked at all skin products in the literature to see what patients should be using, and then looked at what was available in the area and made up a teaching sheet that tells patients exactly what is available in Connecticut, at CVS etc. We are trying to develop the nurses to become symptom management experts in the symptoms they are dealing with. We looked at our Press Ganey and we went up five points on management of skin in one quarter just from having the nurses do this little project. They were thrilled because they were actually able to make solid recommendations to the patients. ChuHow does that work, is it when patients come back to the clinic once they have started treatment? Do the nurses then actually sit down with them and discuss what they have experienced over the past week or 2 weeks? GrassoYeah, the patients come in and everybody gets an initial assessment. In fact, it is a huge requirement of all the joint commissions that there is a full assessment and documentation prior to the patient even beginning the chemotherapy. We want to make sure that when they start they are in the best possible shape. We're now putting some nurses in the practice so that we can teach new patients before they get treated. We are still teaching the greater majority on the first day of treatment, but with that said, I think with developing more specific teaching tools as nurses work in these disease teams and get more experience, we are going to be able to help the patients better. For example, with rashes now, they get the teaching sheet upfront the day they start, so they know to start using moisturizers and what to use right away. We give it to them before the rash starts. ChuIf a rash should start and they start on the treatment guidelines, are the patients told to call the nurse or physician first, how does that typically work? GrassoThey get a sheet when they initially come in outlining certain types of things such as, a fever over 100.4 or prolonged nausea and vomiting, where they should call and ask for the physician, but there is whole list of things that they can call and ask the nurses will triage them. There are nurses that triage on the practice side and then nurses that triage on the treatment side. The patients call where they are most comfortable, and most times they start with the treating nurses and the nurses refer back to the physicians. ChuGoing back to the whole issue of oncology nursing, and this might be helpful for the listeners, do oncology nurses have to go through specialized training above and beyond what a typical nurse would have to undergo? GrassoYeah, anybody coming to work at Yale has to go through the Oncology Chemotherapy and Biotherapy course. It's a specific course from ONS. I teach it along with Joe Moore and Lisa Barber, we are the three CNS's. We teach it 4 times a year and give them a chemoprovider card that says they have a basic knowledge and understanding of chemotherapy. After that we arrange a clinical preceptorship for the inpatient nurses, or for nurses from the MICU that are doing a little bit of chemo and want to learn. They come to our outpatient clinic areas to learn. Our nurses go on because they are really going to be doing a lot of management of patients. They are on orientation for 3 to 5 months to assure that they really can be out there and understand the critical assessment pieces and the critical management pieces for

our patients. Chu Once the nurses have been certified, is there ongoing training to maintain? Grasso We encourage everybody to then become certified as oncology nurses. They are certified chemoprotectors, but there is a second certification for oncology nursing. When I came here I think it was about 3%, and we are up to 48% of nurses that are now being certified. We are running classes to teach them how to take the test and how to prepare for the test. We encourage it and have tripled our staff. You have to have one thousand hours in oncology at least every year to even sit for the test. Once they get that, then we start helping them study what to look for, because we think it is a great way and we are trying to develop budgets so we can send more nurses to the conferences. There is nothing better than going to a conference and seeing what other people are doing and getting some ideas and bringing them back for your own center. Chu How many nurses do we presently have in the chemotherapy and fusion center here at Yale? Grasso I think about 26 right now, 26 or 27. Chu This is just for medical oncology? Grasso Right. Chu And you also have oncology nursing specialists who are in the other fields of oncology. Grasso Lisa, Joan and I also do work for the hospital and outpatient because we are trying to make sure care is equal at both places and that the same standards are held at both places. There are over 95 oncology nurses in the institution. Chu Okay, terrific. We would like to remind you to e-mail your questions to canceranswers@yale.edu or call 188-234-4YCC. At this time we are going to take a short break for medical minute. Please stay tuned to learn more about oncology nursing with my special guest Judy Grasso from the Yale Cancer Center. Medical Minute Breast cancer is the second most common cancer in women. About 3000 women in Connecticut will be diagnosed with breast cancer this year, but earlier detection, noninvasive treatments and new therapies are providing more options for breast cancer patients and more women are able to live with breast cancer than ever before. Beginning at age 40, every woman should schedule an annual mammogram and you should start even sooner if you have a risk factor associated with breast cancer. Screening, early detection, and a healthy lifestyle are the most important factors in defeating breast cancer. Clinical trials are currently underway at federally designated comprehensive cancer centers such as the Yale Cancer Center to make new treatments not yet approved by the Food and Drug Administration available to patients. This has been a medical minute, and you will find more information at www.yalecancercenter.org You are listening to the WNPR Health Forum from Connecticut Public Radio. Grasso Welcome back to Yale Cancer Center Answers. This is Dr. Ed Chu, and I am here in the studio this evening with my special guest Judy Grasso from Yale Cancer Center. This evening's program is focused on discussing the role of the oncology nurse with respect to taking care of cancer patients. Over the last few months we have received quite a number of e-mail inquiries. Why don't we go ahead and take a couple, if that is okay. Grasso Sure. Chu This one comes from a woman in Stanford, Connecticut. She says, "My husband is currently receiving chemotherapy and I am pregnant with our first child. Is it dangerous for me to be with my husband during this period while he is receiving therapy?" Grasso It is not dangerous to be with her husband. The only recommendation I might make is a conservative

one. There is not a lot of evidence to support this, but we tell people to flush the toilet twice for a couple of days after receiving chemotherapy, because that is the average time it takes for most drugs to clear from the body, but there are no other safety concerns for him to worry about, just maybe an infection for her. If she is sick she might want to stay away from him and not pass anything back and forth like that, but other than that there is no risk I know of. Chu Do you get the question of whether or not cancer is contagious a lot? Grasso Oh God! We get that question a lot, and no, there is no evidence to support that cancer is contagious, but we do get that question a lot and people worry about that. Chu This is an email from a listener in Orange, Connecticut. "What symptoms should I be aware of and call my doctor to discuss? This is a woman who has colorectal cancer. Grasso Certainly if she had any kind of fever, we would tell her to call immediately and take their temperature in the afternoon. If it is over 100.4 then they should call. Someone with colorectal cancer might be at risk for diarrhea. If they are experiencing anything twice as much as normal, so if they normally have 1 or 2 bowel movements a day and are up to 2 to 4 days, they should start letting somebody know that is going on so we can get them on some medication for that early on. If they have any extended problems with nausea they should call us immediately. We do not want anybody home vomiting, even 24 hours afterwards. If they have any trouble, they should call us because we have ways to manage that nowadays. The other thing you might get with some of the drugs for treating colorectal cancer is mucositis, so if they have mouth sores they should let us know about that. Chu The main take home message may be, if anyone experiences symptoms that seem out of the ordinary, call immediately. Grasso Call. No question is ever stupid. We want to hear about things because we can help people to feel better. We can get them seen by the physician if they need to, so please call early. Chu One of the things that I have noticed is that sometimes patients feel very reluctant to call because they do not want to bother the staff. Grasso Right. Chu But really the key is to call immediately. If there is something that we need to do in terms of intervention, we can get to it immediately. Grasso If they are feeling very weak and tired, sometimes they just need some hydration. They think they have been drinking enough, but they really have not been drinking enough for those two days after the chemo. We bring them in and give them hydration and they feel 100% better. So it is very simple thing sometimes. Chu We have a question from Jim in Mystic, Connecticut. He says, "Many days I feel depressed. Is this a normal reaction to a cancer diagnosis?" Grasso It can be a normal reaction to a cancer diagnosis, but it does not mean we should not be doing something about it. People should let us know when they are feeling that way. I was just at ONS at a great conference, where they were talking about illness syndromes with cancer, and depression was one of them. They talked about how it is probably a factor of some of the chemistry from the disease and from the treatment going on. Patients feeling this way should tell their healthcare providers so we can try to help them with that and get them on medications, or give them some practical ways to manage their fatigue. Chu One question that I always get relates to whether or not we as the healthcare providers ever get depressed or burned out because obviously,

every day we are dealing with cancer patients and issues of death and dying. From the oncology nurse perspective, do you see these issues and if so, how do you deal with them?GrassoI think some of the nurses, because we are working in these disease teams and they tend to see the same patients over and over again, they get very attached to them. So yes, when somebody isn't doing well they do feel it. We are fortunate to have a fulltime chaplain in our clinic now that has just started doing monthly remembrances of patients who have died. He also does support groups for the nurses, and I am finding this to be very helpful for everybody. Having him around is very helpful to the patients as well because he is one person there who says, "I have time to talk to you." He's busy all day long. People know that they at least have one person who has time. I think he has helped to move a lot of people to deal with a lot of issues. We are very fortunate.ChuAre there any other supports services that are available to patients?GrassoThere is. We have social work services, we have nutrition services, and we have care coordination. There are support groups for all of the different disease management types. There are lots of ways that patients and families can find some support.ChuEarlier, you were talking about how our ability to treat symptoms has dramatically improved over the last 10 to 20 years. Let's talk a little bit more about the nurses' direct involvement in trying to identify and then treat these side effects associated with treatment.GrassoFor example, you may have somebody who had a cisplatin regimen and when they come back the next time they have not called or complained. They went home and had the antiemetics, but when they come in they are saying, "You know, I had a terrible time for 3-5 days afterwards." The nurse will review what the patient took for medications and call the physician and have a discussion. The physician is probably going to see the patient, and they will put their heads together and come up with something. There are innovative things we can do nowadays like giving Aloxi at the beginning of the treatment and then on day 5 give them another IV dose of Aloxi. That will carry them over for those 3-5 days afterwards when they are home. We have a wonderful pharmacy staff that will tell us if something will work or not and if it's okay. With the nursing staff input, we have been able to come up with some innovative strategies. It is pretty remarkable. I remember when I was fellow back at the National Cancer Institute in the mid 1980s, we did not have a whole lot of medicines that could help prevent nausea and vomiting, and in some cases that was really a big problem, but now it is dramatic in terms of the numbers and types of medicines that can prevent nausea and vomiting from happening.GrassoBecause we are doing so well with nausea and vomiting, the oncology nursing society now says that fatigue is the biggest symptom most patients are complaining about. That is kind of interesting, and now there are lots of small workgroups throughout oncology, working on fatigue and trying to figure out how to manage that better.ChuAnd what are some of the ways that we can get a patient through this fatigue issue?GrassoThe fatigue issue can be related to anemia, so we pay attention to anemia. But we used to tell everybody to be couch potatoes, lay down and rest, do not do anything more, just take care of yourself. Now, we have several nurse researchers that have proven, mostly through research done with breast cancer women, that exercise

is a much better way to go. We have to explain the exercises, walking up and down their driveway until their stamina gets better, or taking a walk around the block. They do not have to be marathon runners, but just get out and walk. Short periods of activity and short periods of rest seem to work much better for patients.

Chu: Yes, in fact one of those researchers is Tish Knobf from the School of Nursing who has focused a great deal of her research efforts looking at this issue of exercise, physiology, and breast cancer, during treatment and after treatment. We also have a number of other folks who really believe that exercise, just making sure that they keep active, is really important.

Grasso: When I was at Lawrence & Memorial, we had Susan Komen grant and we did an exercise group. I had a physical therapist with me every Monday night for 3 years with the breast cancer women, but they all did not come, sometimes they were too tired after treatment, but it was a very positive group. They did not want to go to a support group and discuss, they wanted to be doing something positive and they saw the exercise in that way. It can be a positive in their lives, if they can still do this it helps their emotional feelings about what they are going through.

Chu: What are some of the other major symptoms that you as the oncology nurse want to educate patients about?

Grasso: Nowadays, with the types of drugs we have coming out, peripheral neuropathies are huge for patients. If you have a lot of numbness and tingling in your fingers and toes, and walking is difficult or you are dropping the carton of milk, those are big issues for patients so there is still a lot of work to be done. We do not have clear evidence on what is the best thing to do, but I think we can at least give our patients enough information about the possibility of it happening and how to manage it at home and to be careful so they do not have any injuries related to that.

Chu: One thing that I have heard a lot about is the issue of chemo brain, where patients say they feel foggy sometimes and that their mind is not all that clear. Have you noticed that?

Grasso: Yes, we see that all the time, and the nurses define it for the patient because they will say, "I cannot read a book anymore and I have to flip through magazines." Women will say that they are now channel surfers like their husbands.

Chu: Well, that's not so bad.

Grasso: People seem not to be able to concentrate or remember things so they write notes and stick them all over the place. And we're not sure exactly what it is. People looking at it with breast cancer just see the effects of decreased estrogen, which is a part of the problem with patients. It is a huge factor for a lot of our patients, especially our patients who are trying to work. They really come back and tell you about that, that they have to work very hard to keep track of things at work.

Chu: Have you found any strategies that can help overcome some of that?

Grasso: Getting enough rest and not being tired prior to your activities and having some kind of system to keep track of things really helps. We do not have any easy answers yet.

Chu: We have a good question from Melanie in New Milford, Connecticut. She says, "My doctor does not always answer my questions in a way that I can understand what is going on. How can I get the time I need from him, or from any of the other staff, to review my disease and my treatments? I think that is a very-very good question."

Grasso: A list is a really great thing because if you come in with the list and the doctor is busy and edging out of the door, you can say, "But

I am only on #3 of my list and if we can get through the list quickly, I will have the answers to the questions I need.” I think it is good for physicians to ask the patient if they understand, so that people can have a chance to express what they didn’t understand about what they just said. With the physicians I find they are so focused on the disease and treatment that patients go into this black hole and they will come out of it and not remember half of what was said. As a nurse, I have gone back to the physician and asked what they told the patient. I have been able to go back and reinforce what they have said again and again so that they really understand. Chu That it really important because I have found that even when I think I am explaining things very slowly and carefully, the patients and their family members only get a very small fraction of what we are saying because in large part they are very anxious. Grasso They are anxious, and so many have told me that they heard the word cancer, and they heard their prognosis, but have not heard another word since. The other thing is for family members to bring someone with them to the doctor’s visit and to the initial part of chemotherapy while there is lot of teaching and education going on. If someone else hears it they can write it down and then they have someone at home they can bounce the information off in case they forget something. Chu The key issue to emphasize is that the physician and the oncology nurse really are a team. Grasso Yeah, absolutely. Chu The two need to work hand in hand, and work closely with the patient and family members. Grasso We are lucky we have a nice computer system, and it is used very well by the physicians. I will go in and read the histories and all the background information and then interpret that to the physicians that are there that day. I usually like to know what the physician has explained to them about their options and I find that conversation is best way to go. Chu When should the patient and family member call the nursing staff if they are concerned? Grasso Anytime they are concerned. We have a very good staff and we are fortunate that we have plenty of nurses who will answer your call. They will answer your question and help triage your call where it needs to go. No question is a stupid question. We are there from 7 in the morning until 6 at night and we are very glad to help. Chu Thanks Judy, so much, for being with me this evening on Yale Cancer Center Answers. It has been great to hear about the role of the oncology nurse, and hopefully we will have you back on a future show to get an update. Until next week, this is Dr. Ed Chu from the Yale Cancer Center wishing you a safe and healthy week. If you have questions, comments, or would like to subscribe to our podcast, go to www.yalecancercenter.org where you also find transcripts of past broadcasts in written form. Next week we will talk about blood transfusions and the role of the American Red Cross. I am Bruce Barbar and you are listening to the WNPR Health Forum from Connecticut Public Radio.