

Tish Knobf, New Research for Cancer Survivors August 3, 2008 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 the 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 Tish Knobf, the American Cancer Society Professor of Oncology Nursing at Yale University School of Nursing. Tish has focused much of her career in research on cancer survivorship and is a recipient of the Lance Armstrong Foundation Grant.

Chu Tish, we are going to be talking for the most part today about your research efforts in the field of cancer survivorship. But I thought we could start off with some definitions for our listeners, specifically the definition of a cancer survivor, which I understand has evolved a little bit. There was a strict definition, and now there is a broader definition. Could you help us define survivorship?

Knobf A survivor I think is how one individually appreciates it, but basically the broad definition is anyone from the time of diagnosis; anyone who has been diagnosed with cancer can be perceived as a survivor. It has gotten more well-defined in terms of how we deliver care to survivors, there are acute survivors, who are patients in treatment, and then there is a recovery rehabilitation phase for survivors who have been treated and who do not have any evidence of their cancer. We need to try and help them recover. Then there is extended survival, and that can patients who live for years without the cancer coming back. There are survivors for whom the cancer does come back, and who are receiving treatment and/or palliative care.

Chu In the 20 to 25 years that I have been in the field, and you obviously also have had great experience in this field of cancer treatment, but our ability to have the patient survive their cancer diagnosis has dramatically improved.

Knobf I think right now it is about 65% of all cancer patients live longer than 5 years. There has been a real focus in the last 2 to 3 years on helping people transition who have finished therapy; transition into life after cancer treatment and that is the focus of my research, helping people to live a healthy life after the cancer treatment is over.

Chu How did you make the decision to focus in on that area for your own research career?

Knobf For most of my clinical and research career I worked with women with breast cancer. I then became interested in how they deal with the symptoms during treatment, and doing that research opened my eyes to what it was like for them when treatment ended. The reality is that the symptoms do not go away when you get your last treatment, but, in fact, they persist for several months, if not, for some patients, years. That got me very interested in trying to understand what life was like after treatment and what could we do to make that life better.

Chu That is a nice segway into the grant that you recently received from the Lance Armstrong Foundation. Can you tell our listeners what that proposal is all about?

Knobf Lance Armstrong, as most listeners probably know, is very interested in cancer survivors and recovery both physically and psychologically after treatment. This past grant cycle for the Lance Armstrong Foundation, they were very interested in programs that

would help people recover, and they were particularly interested in programs that would help minority populations or underserved populations. We have been working for about 3 to 4 years with a group of women of color in the New Haven area trying to look at some of their unique needs and what we could be doing as providers to help minority populations manage the effects of cancer, and how they cope with that in their individual lives and in their culture. This was really the foundation for Lance Armstrong, to develop a program that would look at physical activity and healthy eating choices in a population of women of color who were cancer survivors.

Chu There has been a great deal of research looking into the barriers that women of color, and all minorities and underserved populations, have with respect to say, Caucasians, in terms of access to care and response to care. Are there also differences in terms of the issue of cancer survivorship and how women of color and other minority populations do once the cancer treatment has been completed?

Knobf The unique aspect that we discovered in our Connecting Sisters project was the influence of their culture and how they grew up. There is a very, very strong sisterhood bond and a very strong relationship between how they cope with illness, particularly cancer, and their faith. Not necessarily their alliance to a particular church, but they have a very strong faith bond and they have a very strong need to be connected with other women of color. This project helped us identify support groups that were specifically for women of color, because they have a smaller incidence of breast cancer than the larger Caucasian population, so it is a little more challenging to help them network with other women of color. That is what the project, and also the Lance Armstrong Foundation program, is going to do; help network them and empower them in terms of healthy lifestyle choices.

Chu And what are some of those healthy lifestyle choices that you are focusing on?

Knobf What we will do in the Lance Armstrong Foundation Program is provide a 6-week program that is based on the concepts of sisterhood and social support, that is using the women to support each other, and we will be giving them information on types of physical activity, community resources and how they can use community resources in order to develop a daily program of physical activity. They will each be developing an individual sheet that looks at what is going to prevent them from exercising everyday, and what is going to help them and encourage them to identify a partner, and develop a program that they can do at home in their own neighborhood that will work for them. We will also be giving them a cook book and will have 2 classes with a dietician to help them make better choices for healthy eating.

Chu Will they interface at all with an exercise physiologist or physical therapists?

Knobf Yes, we will have a physical therapist present at the classes who will help them understand the exercises and they will all get pedometers which will help them count their steps. The national guideline is 10,000 steps a day, which I do not know how many people have worn a pedometer, it is pretty challenging to get 10,000 steps.

Chu 10,000 steps, how far is that?

Knobf I am not sure, but you start where ever you are, so if you have to start at 2000, then you will be encouraged to keep a chart and see if you can increase the number of steps per day. Cancer treatment takes its toll on patients and they often do not keep up with their normal activities. Many cancer patients

during treatment become de-conditioned so you have to start where they are and help them gradually increase. Chu This program will be here at Yale-New Haven Hospital, Bridgeport Hospital? Where will the centers be? Knobf Lance Armstrong Foundation is very committed to community programs and so this particular grant mechanism was meant to have a program that would be in more than one community. We have partnered with Bridgeport Hospital and we have strong support from a program called The Witness Project, which is African American Women who go out and get the message to their sisters about early detection and mammography. They are very interested in participating with us and offering this program to women of color in Bridgeport. We will be doing these programs in both cities, New Haven and Bridgeport. Chu Terrific. How good are women of color in terms of seeking followup for their care? In terms of making sure that the cancer has not come back and the usual ongoing routine health assessments. Knobf That is a difficult question, all of the research that has been done so far speaks to educational and economic issues, and the ability to get to the doctor's appointments. Women of color who are well educated and have financial means probably have followup that is identical to any other group of women. They are very concerned about breast cancer risk to their other family members, and to their daughters, and they are very avid about their followup. The populations that we need to help make sure get to their followup appointments are those who have less means in order to do it. Those people that have competing life demands is the population we need to help. Chu How does this support system work to help women during their cancer treatment, not only for women of color, but for any woman with breast cancer? What are the different types of support systems that are available to them? Knobf During treatment women are very well supported. They see their oncology nurses all the time, they talk to their oncologist all the time, they are going to a health care facility where they perceive that they are getting treatment to keep the cancer either away, or in order to put it into remission. There are also social workers and other providers who provide support during treatment. It is when the treatment ends that we need to be developing interventions, because our medical system normally sees cancer patients every 3-6 months, so all of the support that was there seems to disappear once the treatment ends. That is where we need to develop programs or interventions to help people during those vulnerable 6 to 9 months after treatment when they begin to think about the consequences of the diagnosis and the treatment. They are still living with feeling tired and they may have other symptoms that have not gone away. They need some help dealing with their anxieties, uncertainty and their physical symptoms as well. Chu It is interesting because both women patients and male patients feel like they are part of the family when they come to the clinic setting, but once that treatment ends, it is sometimes like they have been abandoned and they feel lost. Knobf There is an article called "Cast Adrift" because patients feel like they are sent out in this little rowboat by themselves once treatment has ended. Their family wants them to get better, their friends want them to get better, their coworkers want them to come back to work if they've taken time off, their hair starts growing back and they look healthier, but psychologically,

and sometimes physically too, it takes a much longer time to recover. Chu We would like to remind you to e-mail your questions to canceranswers@yale.edu or call 1-888-234-4YCC. At this time we are going to take a short break for medical minute. Please stay tuned to learn more about the issues of cancer survivorship with my special guest, Tish Knobf. Chu Welcome back to Yale Cancer Center Answers, this is Dr. Ed Chu and I am here in the studio with my special guest, Tish Knobf, the American Cancer Society Professor of Oncology Nursing here at Yale School of Medicine and Yale Cancer Center. Before the break we were talking about Tish's research focused on cancer survivorship in women with breast cancer and the exciting work that she is doing focusing on issues of cancer survivorship for women of color. She recently received an award from the Lance Armstrong Foundation. Tish, for those who did not hear the first segment of the show, could you very quickly, recount what this grant is for the Lance Armstrong Foundation and when is it going to begin? Knobf This is a 6-week program, and it is going to be 2 hours a week. It is for women of color who have survived cancer and it will provide information about breast cancer for women of color. The focus is really going to be on how to develop a plan for daily physical activity and healthy eating choices. We will begin the program in September and we will be offering it in New Haven and Bridgeport. Anyone who is interested can call me directly at (203) 737-2357. We will be providing African American women with exercise physiologists who will be giving them classes on exercise and they will receive cookbooks on how to develop healthy eating meals at home with a dietician who specifically works with women of color. It will be a really fun program, so I hope you join us. Chu This sounds like an extremely important research effort that you are putting together. Obviously you are focusing on women of color, but the issues that you are identifying and dealing with relate to all women with breast cancer, or any other cancer, I would suspect. Knobf Yeah, I think so. Chu You also received a very large grant from the National Institute of Health to study the effects and influence of exercise on cancer survivorship. Can you tell our listeners a little bit more about what that grant project is all about? Knobf That grant project is a year long study, and we know that there are some effects of cancer treatment that persists after cancer treatment is over. There are some effects, which we call late effects, which may be side effects or consequences of the treatment in the long term. One of the things that we are interested in is relatively young, or young midlife women in the 45-55-year-old range, who will be going into menopause either because of the cancer treatment, or just because it is a natural time for them. There is an increased amount of bone loss in the first five years that a woman goes into menopause, and it seems there is a particularly greater risk for women who go into menopause because of cancer treatment. We want to prevent that if possible. Also, we want to help women maintain a healthy weight, because we know that is important in certain cancer diagnoses like breast cancer and colorectal cancer. We want to minimize women's risks for other health risks such as heart disease and diabetes. It is a program aimed at keeping cancer survivors healthy, not only from a cancer coming back, but also from developing other kinds of health risks as they age. This will be a study where

there will be two different types of exercise. It will be supervised exercise at a fitness center, compared to a home-based exercise program. Both groups will get information on nutrition and healthy eating and both groups will also get supplements of vitamin D and calcium; both of which are very important to bone health. Chu I would imagine an expert exercise physiologist is also involved in this project. Knobf Yes, we have two co-investigators who have doctoral degrees in exercise physiology. Our staff also consists of exercise physiologists and our interventionist will be trained in exercise science and monitoring the subjects in this study. Chu So it is not like people have to go out and be able to run 2 or 3 miles or a marathon, but to have daily constant physical activity in order to help prevent all those bad things from recurring. Knobf Right, both groups will get very specific instructions and information about the types of moderate physical activity. The current national guideline is 30 minutes of moderate activity on most days of the week. Moderate activity is something like brisk walking, not casual slow walking, but brisk walking. We will give them examples of moderate activity and the supervised group will get very specific information about which exercises to do and how often. Chu This is probably a good recommendation for anyone, with or without cancer, because this is a part of good healthy living. Knobf It is a part of good healthy living, but if we took a survey of all of our listeners I doubt that most of our listeners are exercising 30 minutes on most days of the week. It is forcing me to become a role model. Chu No need to go to the listeners, I think yours truly has also clearly fallen very short of that national goal. Knobf It is important now in cancer though because we do have 2 or 3 studies with at least initial evidence that even walking 30 minutes on 3 or more days of the week has an association with lower risks of recurrence and a better survival. There were 3 studies in breast and in colorectal cancer patients. Chu How many women do you hope to enroll into this study? Knobf We hope to enroll 150 women. There will be 75 women in each group of the 2 different exercise programs. Chu Will all of these women have been treated here at Yale Cancer Center, or will they come from different communities in the state? Knobf They will come from both Yale Cancer Center and areas throughout probably the greater New Haven area. Chu How will you reach out and identify potential study participants? Knobf We will use both hospitals in New Haven, Yale-New Haven Hospital and the Hospital of St. Raphael. In our previous studies one of the most successful strategies has been making women in the community aware. We will do community announcements in the local papers because it will attract the women who are interested. Providers, physicians and nurses are always willing to help us identify patients, but cancer survivors as individuals are the ones who are most motivated to want to do this. Chu For women who do not join your study, but have had breast cancer and undergone treatment and who are cancer survivors that are scared or anxious about this notion of starting an exercise program at home, what can they do to jump start things and get involved in an exercise program? Knobf The American Cancer Society has a couple of wonderful booklets. One is called "Smart Steps" which gives you lots of ideas of how to slowly begin an exercise program. For cancer patients who have the ability and the financial means, they could certainly

join a fitness center. The other resource would be the Survivorship Clinic at Yale where we have an exercise physiologist who can provide information and consultation. Chu Tish, could you speak a little bit more about the Survivorship Clinic here at Yale and what the different recourses available to cancer survivors are? Knobf At the Survivorship Clinic here there is a comprehensive evaluation, so survivors can get a comprehensive summary of what their treatment has been, what their followup should be and what potential side effects of treatment should be monitored more closely. For instance, if somebody had radiation therapy to the chest, or if they got an anthracycline drug, their cardiac status should be monitored more closely than someone who did not. There are multiple services provided at the Survivorship Clinic. There is a social worker, a dietitian, an exercise physiologist and multiple resources are identified for survivors to help them and their families cope and manage life after cancer treatment. Chu It is a terrific clinic and we have been very, very fortunate to have this philanthropic group, the Connecticut Challenge, led by their founder and spiritual leader, Jeff Keith, to help raise money on behalf of the Survivorship Clinic. Their efforts are now expanded into trying to support research efforts into cancer survivorship. Knobf When you think of a bicyclist, you always think of Lance Armstrong, but what has been most exciting about the Connecticut Challenge is that it has put survivorship on the map, or on the front page of the paper, for survivors. It has increased awareness for people with cancer, and without cancer. For our listeners who do not have a cancer diagnosis, but might be at risk or might have a family member that has cancer, that message of people now surviving for years and years after cancer treatment because of the advances in our treatment is such an important message. Chu Absolutely. Tish, you have been in the field for a long time and have been involved in research, but now your focus is on cancer survivorship, which is a relatively new area of research. Where do you see the field evolving to over the next 5 to 10 years? Knobf I think the focus is going to continue to be on followup after treatment and also long-term followup. There are four major areas of survivorship care identified by the Institute of Medicine. One is prevention; prevention of recurrence of the cancer or a new cancer. The second is surveillance; what kind of guidelines do we have for people who are to have followup, how long should they have followup? Intervention is the third one which is my area of research, which is managing potential or actual side effects of cancer treatment. The fourth and final area in survivorship care is how to coordinate our medical care system. We have so many survivors now; we need to figure out how they are going to be taken care of by their oncologist or by their primary care physician. This is the map that the Institute of Medicine has put out for us to look at in regards to how do we take care of people once they have been diagnosed and treated for cancer? Chu Tish, the time has gone pretty quickly and I would like to thank you for joining me this evening on Yale Cancer Center Answers. Congratulations on receiving those two large grants from the Lance Armstrong Foundation and from the National Institute of Health. We certainly look forward to having you come back to hear the outcomes of your research projects. Until next week, this is Dr. Ed Chu from the Yale Cancer Center wishing you a safe and healthy

week.