

Yale CANCER CENTER

answers

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Cancer Survivorship in 2015

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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 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 it is a conversation about survivorship with Angela Khairallah and Mae Anne Jauk. Angela is a licensed clinical social worker at Smilow Cancer Hospital and Mae is a nurse practitioner at Smilow. Here is Dr. Anees Chagpar.

- Chagpar Maybe we can start by talking about survivorship in general. A lot of the time here on Yale Cancer Center Answers, we talk about cancer treatment, and I guess we are doing a good job in terms of cancer treatment in the sense that now we are talking about survivorship.
- Mae Yes. This is Mae, I am a nurse practitioner in the survivorship clinic here at Yale Cancer Center. Thanks for having us here. Survivors in the US are estimated at this time at 14 million, and by 2020 it is actually estimated that it will go up to about 19 million survivors.
- Chagpar Maybe we can talk a little bit about why we even need to talk about survivors. Isn't it that after your cancer diagnosis, your cancer treatment, you are home free?
- Angela No, and this is Angela Khairallah, the social worker of the Survivorship Clinic, and actually survivorship begins the day that a patient is diagnosed and survivorship really is about living with, through and beyond your cancer. Oftentimes, patients when they are coming to the Survivorship Clinic, they are at a very important transitional and pivotal time, and probably one of the most important times during their cancer journey and it is at that time that they talk about a variety of challenges and concerns that they are now being faced with as they are moving beyond their cancer. They are not only adjusting back to life, they are also adjusting to life now that they have been impacted by cancer and the effects that treatment can have on them.
- Chagpar The Institute of Medicine put out a great paper called *Lost in Transition*. This whole idea of "when I was diagnosed with cancer, I had my cancer surgeon holding my hand. When I had my cancer treatment, my medical oncologist was holding my hand and now I am cancer free and who is holding my hand? Is that where you come in?
- Mae Absolutely. That is exactly what most patients that come to see us say, it is the handholding that is there from diagnosis through treatment, and after treatment, they kind of feel abandoned. It is like, what do I have to do now? They have climbed up this hill, reached the

top of the cliff and it is looking down at the unknown of what to do. This is actually a pivotal time in their lives that they need more support. Both physically because they are still dealing with some of the side effects

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from chemotherapy, from radiation, from surgery and the psychosocial emotional component absolutely starts to creep up because that is part of their life that if anything through treatment was pushed aside.

Chagpar Angela, I find that so interesting because you would think that that would be the time that they would be celebrating, “I am getting back to my life, chemo is done, radiation is done, surgery is done...woohoo!” but maybe not?

Angela That is exactly right Dr. Chagpar. A lot of times what we see happening when a cancer survivor comes to our clinic, they are feeling quite ambivalent. Oftentimes they share with me, you know I am done with treatment, I should be happy, I should be celebrating, but why I am not? And honestly from my perspective what I see happening is often cancer survivors when they are in the active phase of their treatment, they are so busy with all the medical appointments and the radiation and the chemotherapy, it is almost like their brain have not started to process the emotional aspect of what they have gone through until it is behind them. And as they are starting to put their life back into place and as they are trying to put back all those puzzle pieces again and try and make their life gain balance, then they start to feel anxious and some depression. Fear of recurrence is the most common thing that we see among our cancer survivors in our clinic and what cancer survivors need to know is this is a very normal part of the process. Recently, there were some statistics that were released and approximately 30% of cancer survivors have some level of fear of recurrence that is moderate to severe within a year of completing active treatment. Most of the time, the patients that I talk to, they are able to manage this fear of recurrence in a very normal way, it does not impact their life or their functioning. I talk a lot about stress management and relaxation strategies and techniques, but there are some patients, some survivors, who do have anxiety and depression to a severe enough level where it is important for them to seek mental health counseling and treatment. So, referrals to social workers, psychiatrists, psychologists in the community are beneficial at this point. Also, between 30% and 40% of cancer survivors do actually have a mood disorder diagnosis.

Chagpar So it seems like that is normal that you just went through cancer, you are wondering when it is going to strike again, but for a lot of these patients, it may never strike, is that right?

Mae Correct. Especially with innovative ways of screening and surveillance and early pickup and early detection and treatment that they receive, the rate of recurrence is absolutely less than what it used to be. Also, we try to promote healthy behaviors, which are absolutely vital when we see our patients, making sure that their nutrition, physical activity and emotional well-being are addressed as a whole because it does have an effect. Sometimes, if the emotional well-being is not addressed, it manifests in physical symptoms like fatigue, insomnia, pain, and it is hard to decipher until we start to see the patients and talk to them one-on-one to figure out what is going on. And it is vital that we work together when we see our patients and communicate what needs to be done to help this patient move along.

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Chagpar Talk a little bit more about that Angela, because I think that you will see people who often would be tired and trying to sort out, are you tired because you just got off of chemotherapy and radiation which can make you tired, or are you tired because you are so emotionally drained from this harrowing experience? Or are you tired because now you are getting back to your three kids, your job and your dog, which would make anybody tired.

Angela Quite often it is actually a combination of everything that you just pointed out and that is really part of my role. My role is to really help the survivor examine how they are feeling, how they are thinking, the different physical signs and symptoms that they are having and help them sort that out. Is it because of treatment, is something impacting my emotional well-being that is coming out physically? And then helping provide them with the appropriate resources and services. We have a variety of services available that we can refer patients to. We have over 20 different support groups available at Smilow and throughout our care centers for a variety of different types of cancer. I actually co-facilitate 4 different support groups; an early stage breast cancer, metastatic breast cancer, and a kidney cancer support group as well as a young adult cancer support group, and I am pleased to say that the young adult cancer support group is actually a group that was started by a cancer survivor and is co-facilitated by a cancer survivor and that is open to any patient between the ages of 18 and 40 with any type of cancer diagnosis. I believe we have smoking cessation available; we have a clinic at Yale called SIMS, it stands for sexual intimacy and menopause issues, that is a clinic that we do in fact refer women who have gone through breast or different gynecological cancers to. We have referred patients as well to the Yale Stress Center, where again the focus is treating the person as a whole. They provide mindfulness workshops, acupuncture, yoga. We promote this type of treatment to help address and improve their emotional well-being, not to mention physical therapy as well as dietary.

Chagpar Because I can imagine that all of these issues play such a big role after you have gone through cancer. For many of us, we struggle with our weight, we need to get to the gym more often, we know that we need to reduce our stress – that is part of normal living, but I can see how that would be so much more accentuated in a cancer survivor. Tell us a little bit more about some tips that you may have for cancer survivors in terms of their nutrition. There is not a day that goes by that somebody does not ask me, “well, was it something that I ate that caused cancer, what should I be eating now, what should I not be eating” what are the rules?

Mae Unfortunately, there is no vital rule that we tell patients. We do have a nutritionist who does a one-on-one session and addresses all these questions. She is not with us today, but these are the common questions that patients come when they see us. Number one, I ate something in my lifetime that caused this cancer, now I am in fear of what I am going to eat. Should I avoid soy products altogether, supplements, etc. and all of these are things that our nutritionist, Maura Harrigan, addresses all the time. It is really a balance of healthy nutritious meals. She always talks about the rainbow of colors, and that is what should be on your plate, which is obviously getting you nutrition from natural products that are available. When patients do come with

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supplements and a list of them, Maura and I review to make sure that there is no interaction with any of their medications, especially for breast cancer patients on endocrine therapy treatment. It is not an easy one session done-deal discussion and that is why when they come and see us, we offer a follow-up visit about 8-10 weeks later to see how they are doing. If our recommendations, the tools that we gave them are something that they were able to use, do we need to fine tune some of that, and again, after a second visit, we keep an open door policy and they can always come back anytime.

Chagpar Getting a balanced healthy nutrition diet is the same that we would recommend for just about anybody and cancer survivors need to hear that message. What about physical activity? I can imagine that that is another issue that might be a burning topic for many survivors. How much activity can I do, should I do, should I not do? What do you tell survivors about that?

Angela Our physical therapist, Scott Capozza, is the person that we work with and this is exactly the question that he addresses. He first makes a baseline assessment of what the patient is currently doing and from there learns their daily routine and actually tries to incorporate within that daily activity physical activity or exercise. The recommendation for cancer survivors is exercise 30 minutes, 5 days a week, 3-5 days a week, so really 150 minutes a week. That could be divided into whatever that is convenient for the patient. We always tell

patients to start slow and go in increments of 5-10 minutes and then gradually increase every few days to reach the goal.

Chagpar It sounds like the recommendations are pretty much the same across the board. We are going to talk more about survivorship and issues concerning survivorship when we take a break after a medical minute.

Medical Minute

The American Cancer Society estimates that there will be 75,000 new cases of melanoma in the US this year with over 1000 of these patients living in Connecticut. While melanoma accounts for only about 4% of skin cancer cases, it causes the most skin cancer death. Early detection is the key, and when detected early, melanoma is easily treated and highly curable. Clinical trials are currently underway at federally designated comprehensive cancer centers such as Yale Cancer Center and at Smilow Cancer Hospital at Yale-New Haven to test innovative new treatments for melanoma. The goal of the specialized programs of research excellence, SPORE, in Skin Cancer grant is to better understand the biology of skin cancer with a focus on discovering targets that will lead to improved diagnosis and treatment. 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.

Chagpar Welcome back to Yale Cancer Center Answers. This is Dr. Anees Chagpar, and I am joined tonight by my guests, Angela Khairallah and Mae Ann Jauk. We are talking about cancer survivorship. It is a topic that we do not often cover here on Yale Cancer Center Answers because

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we spend so much time talking about treatment and advances in treatment, and the good news is that we have advanced treatment to such a point where 14 million cancer survivors are alive and well right now in the United States and that number is estimated to grow. But still, these cancer survivors face a number of issues and I want to get back to some of those issues. Angela, before the break you mentioned a few issues that cancer survivors face. For example, this whole issue of sexual function, I mean that it is something a lot of people do not think about. Talk more about that.

Angela The fact is, cancer is not just something that impacts your life physically. It can impact it socially, emotionally, spiritually and even sexually, and unfortunately, sometimes it is the sexual issues that are the issues that can be difficult to talk about. Or they are the issues that

oftentimes we do not bring up because we feel uncomfortable. It is very common that once a patient comes to the survivorship clinic that is actually something that is brought to our attention. Oftentimes the sexual issues can be attributed to the variety of treatments that they have gone through; the different types of chemotherapy or radiation. It is pretty common to have men, for example, who have gone through different types of cancer – testicular cancer, prostate cancer as well as women that have gone through breast and different types of gynecological cancers.

Mae That is actually one of the key points that I talk to patients about when it comes to long-term potential side effects based on the treatments you have received. For someone that had ovarian cancer, uterine cancer, breast cancer, there is always the component of sexuality issues, lack of libido, vaginal dryness. It is uncomfortable and the majority of them are females, so female to female, they are able to open up a little bit to me and I have just basic suggestions during the visits, but I do mention the fact that we offer a clinic called the SIMS Clinic and that stands for Sexuality, Intimacy, Menopausal Symptoms Clinic. And I do a lot of referrals to this clinic and patients have given feedback to me that they are helpful.

Angela I think what is very important to emphasize, and that our whole clinic emphasizes is that it is very normal to have sexual side effects related to going through treatment, and it is a relief oftentimes to women and men to hear that they are not alone, that this is normal and this is quite common. Also, besides the physical aspect that Mae talked about, there is also the social and emotional aspect. Oftentimes because there isn't libido women and men feel that their relationship with their significant other, their loved one, their spouse is being impacted in some way, and so that is an opportunity for me to talk about relationship issues that might come up between them. Oftentimes, referral to couples therapy is something that I discuss with them as well. But again, I think just emphasizing that a lot of what they are experiencing and going through is normal and that this is a safe place to talk about it.

Chagpar Right, and that there are suggestions for things that you can do. But getting back to the point that you were just making about the relationships, I can imagine the other thing that cancer does is it puts a strain or perhaps a perceived strain on relationships. It is hard going through cancer. But it

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is also hard supporting somebody going through cancer. What do you talk to families and couples about? Is survivorship just about the survivor or is it about the survivor and their significant other, their family, their community, their loved ones.

Mae When our patients come to our clinic we actually offer if the significant other wants to come, they are absolutely welcome. So when I do my sessions, they are in the same room as the patient is, myself talking to them and it is really a matter of including them in the assessments, making sure that they are also finding ways to find support for themselves aside from taking care of the loved one that is sick, and really the key thing is I connect with Angela to make sure the patient has been talked to and then whatever assessment or referrals you need, I can definitely help in that way.

Angela And you know, the fact is, the definition of survivorship has been expanded to include caregivers, family members, friends as cosurvivors. So the day that a patient is diagnosed with cancer that is when they become a survivor along with family members, friends and caregivers. And so, caregivers are impacted by cancer just like survivors. In fact, oftentimes, the distress that a caregiver feels is more stressful than the stress that a survivor is feeling. There has been research to show that caregivers actually feel higher fear of recurrence as well as uncertainty about the future than the actual cancer survivor does. The other thing is that there is a lot of responsibility and role reversal that the caregiver has to take on. And even when the cancer survivor is transitioning into moving beyond their cancer, the caregiver is still supporting them emotionally, helping them to deal with the side effects of treatment, maybe helping manage medical appointments and finances as well as also trying to balance their own physical and emotional well-being. Caregivers are definitely at risk for emotional distress including anxiety, depression, social isolation, and these are quite common. And again, just like it is important to recommend and suggest that cancer survivors attend a support group, it is also important that caregivers attend a support group. A lot of research supports that when cancer survivors and their caregivers attend support groups, it impacts their emotional well-being in a positive way, to be able to be relating to others who are going through similar circumstances. And actually at Smilow, we do in fact have a caregiver support group that meets twice a month and social work services are not only just available to the patient they are available to the caregiver and the family members as well, and we also have complementary services at the patient and family resource center that are available to support the caregiver along with the cancer survivor.

Chagpar That is so good to know because I think a lot of people when we think about support groups, we really think about the cancer survivor, we do not think about the co-survivors as you put it, who really take on the huge brunt of that whole process. I guess the other issue too that you mentioned was the finances, which is another one of these topics that is often swept under the rug because people think, okay I am surviving cancer, this is a big illness, I just want to save my life. But at the end of the day, it can take a huge toll in terms of medical expenses too. How do you deal with that? Is that an issue that survivors bring up?

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Mae It is absolutely one of the major issues that is also brought up. When patients come to see us first they take a distress thermometer and on one side of it, it asks, on a scale from 0 to 10, how distressed were you in the past week and on the opposite side of the page is a check off list of what caused that distress, and the majority of the time it is always checked off as finances, work and then there are the physical symptoms that come along with it and the fear of recurrence and emotional well-being. And that distress thermometer is a tool for us to guide how we are going to talk to the patient, assess the needs and referrals that they may need and Angela uses this distress thermometer a lot.

Angela Oftentimes, when patients are in the active phase of treatment – surgery, chemo, radiation, they have to take a significant time off of work, maybe cut back their work hours, maybe they quit their job altogether in order to manage what they are going through, and so often as they are completing their active phase of treatment, transitioning back into life, oftentimes you will hear and read in the literature that cancer survivors talk about the new normal, and the new normal really is redefining your life, rebalancing it out after being impacted by cancer, and one of the large things that often is brought up is that the transition back to work can be quite challenging. Oftentimes, it is because you are dealing with the side effects of treatment, fatigue, issues with memory and concentration, difficulty with pain, sleep issues. Those are all things that you are trying to deal with along with trying to get back into your normal work routine. And so, oftentimes, because you have been out of work for a period of time, your monthly bills, your expenses and so forth are still there, you still have to make those payments and so there is a loss of income that results because of that. When I meet with patients it is often just making a variety of referrals to different resources in the community, educating them that they can contact different billing offices for different medical providers and hospitals to negotiate payment plans. Having them talk to their mortgage company letting them know that they have been impacted by a serious illness, a variety of things like that.

Chagpar Do you get a lot of patients who tell you that they are in fear of losing their jobs?

Mae No, I would say not really. In my experience, they actually worry more about if they have a span of time in their resume where no work happened between this time and this time. They worry about if they should tell them that they were diagnosed with cancer, would they hire them knowing about this cancer history and that is actually another component that comes up. And I am pretty sure Angela addresses and gives them tips and information on how to go about that.

Angela There is a lot of wonderful information available through the American Cancer Society and there is a wonderful website out there that talks about the different federal laws and state

laws and regulations that cancer survivors are faced with, it talks about different cancer and careers and things like that and how to address that. So, I definitely refer cancer survivors to the various resources to help guide them through that process. And also, it is important to communicate with your human resource department, your employer. Oftentimes though, cancer survivors are nervous and do not know what to say and do not know what to do about how to address that.

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Angela Khairallah is a licensed clinical social worker at Smilow Cancer Hospital and Mae Anne Jauk is a nurse practitioner at Smilow. 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.