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Cancer Survivorship

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Yale Cancer Center Answers

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Welcome to Yale Cancer Center Answers with doctors Francine Foss and Lynn Wilson. Dr. Foss is a Professor of Medical Oncology and Dermatology, specializing in the treatment of lymphomas. Dr. Wilson is a Professor of Therapeutic Radiology and an expert in the use of radiation to treat lung cancers and cutaneous lymphomas. If you would like to join the conversation, you can contact the doctors directly. The address is canceranswers@yale.edu and the phone number is 1888-234-4YCC. This week, Francine and Lynn welcome Dr. Ruth McCorkle for a conversation about cancer survivorship. Dr. McCorkle is Florence Schorske Wald Professor of Nursing at the Yale School of Public Health. Here is Francine Foss.

Foss Let us start off by having you tell us a little bit about your role here and what you do?

McCorkle I have been a nurse for almost 50 years and have a program of research where I study advanced practices nurses and how they have specific outcomes with patients and family members. Last year I was appointed to be Director of Psychosocial Oncology at Yale Cancer Center, so my charge right now is trying to develop a psychosocial program at Smilow Cancer Hospital.

Wilson Ruth, how did you become interested in these topics?

McCorkle I am also personally a survivor. I had breast cancer over 22 years ago. My father died of lymphoma, so as with most people, we have lots of personal and family experiences, but I studied to become an oncology nurse in 1967, after I got out of Air Evac with Vietnam and I thought cancer would really give me an opportunity to establish relationships with patients. I had learned how to break bad news and had gotten, actually, too good at it unfortunately, so it gave me that personal connection with patients and cancer allowed me the opportunity to grow and learn.

Foss Ruth, you mentioned that you are involved with advanced practice nurses, could you let our audience know the difference between a regular nurse and an advanced practice nurse?

McCorkle Sure, that is a great question. Nursing actually is very confusing because nurses take the same degree, the same licensure to get their RN, and most nurses now can be two year. There are also some schools that have diploma schools and there are educations with bachelors. I work with nurses that have a master's degree and they specialize in oncology. So they have extensive education in order to practice somewhat independently under a physician's supervision.

Foss Is it relatively recently that we have had advanced practice nurses working with us?

McCorkle It came out about in the mid sixties, a nurse practitioner out of Rochester, and Yale has actually been very committed to advanced practice since they started their school because we are

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only a master's program. We do not have an undergraduate, so that actually was one of the reasons why I came to Yale 12 years ago.

Wilson Ruth, I think people have a general sense or idea what survivorship means, but tell us what it means to you. What is it really all about?

McCorkle For a number of years, survivorship was only thought about as those people who had a diagnosis and finished their treatment and then after they completed their treatment, they were called a survivor because it is a tough road to go through, cancer treatment, but we have had a number of Institute of Medicine reports and out of those the common perception now is that a cancer patient at the time of diagnosis is a cancer survivor. Because the goal is to help them survive the experience and live the best they can. I think that is a good definition and the general population I do not think has that understanding and I think it gives people hope to realize that we are all working on the same team to help them to survive.

Foss How would you differentiate the kinds of challenges that a cancer patient faces say from getting their treatment versus when they are finished with their treatment?

McCorkle Well we know there are particular times in the course of an illness in which people have more psychological distress than at other times, and these are usually at the time of diagnosis and the time when treatment starts, but it is equally difficult when the treatment stops because during the treatment the patients and families have a lot of concentrated time with the providers and after that stops you will not see them as much and some are free of their cancer and they are sort of encouraged to go back to their primary care doctor and only see their physician maybe every six months or every year, and here they have been seeing them every week or every couple of weeks, and in radiation you will see them daily for six weeks, and so it is also very difficult and you need to really plan for it. During the treatment you have a lot of people helping you, you have the physician, you have the nurses, you have social workers, so you have a lots of support and after the treatment, sometimes it is important to be plugged into systems like support groups and maybe even private counseling just to get back into work because one of the devastating side effects from cancer, no matter what your diagnosis, no matter what your treatment, is fatigue, and when you get really bone tired sometimes you get depressed and you do not know whether you are going to get better or not, but it does get better and often you just need encouragement to tell you that in fact you are going to get better.

Wilson I will be interested in your experience with this, some of the patients I have treated who have done well, things went very well during their treatment course and they got through it well and their side

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effects were not too bad, but then when things were done and we had very high chance of a cure for that patient, that survivor, some patients actually have a tremendous amount of anxiety that is much more significant after the treatment is over than actually during the treatment program. I think this might be a little bit along the lines of what you said that all of the sudden they are not coming to the team on a daily basis and I think there is a lot of concern for the patients regarding, is my cancer going to come back, what is your plan for monitoring me, and that sort of thing, have you seen that sort of experience?

McCorkle I have and it does not happen to everybody, but we do know that posttraumatic stress syndrome does occur for people that have been away from the clinic and just walking through the double doors will bring back all of those fears and anxiety and so those people really want to not go around and so often I think returning to work, if people look different, if they have tracheostomies or if they have lost their hair, for myself I had lymphedema, and you have to really learn how to protect yourself from raking, shoveling snow, etc. Any little thing can upset you and it is a matter of really learning what we call 'self management' and it is an area where we have to teach people to reorganize. I am working with people with ostomies right now in a clinical trial, and it is really fascinating to work with them, they want to travel and you have to help them figure out where to drive, where the bathrooms are in they have an accident and they have incredible problem solving abilities, but it is just helping them join in a partnership to think out what their day is like so they are not embarrassed and then they're willing to take those risks.

Foss Ruth, when we see patients in the clinic, Lynn and I or other oncologists, and we are starting treatment on the patient, is there anything special that we should be doing to screen patients to try to identify patients who perhaps might become more anxious during the course of treatment or even after treatment?

McCorkle There is a battery of psychological instruments. The National Cancer Network Group came out with the guideline to use the emotional distress thermometer which goes from 0 to 10 and has a list of problems along it and their recommendation is that you give this to people at every visit. Well, it is difficult because you have limited resources for people to check it. We are implementing this at Smilow Cancer Hospital now, and using it in some clinics, we are actually doing it in the bone marrow area where you work Francine, and we are doing in the breast clinic and we are doing it in the GI clinic, and what we are trying to figure out right now is how frequently to give it and who should be looking at it and how to make the referrals to make sure that we have adequate resources. Our social workers at Smilow are phenomenal at responding to peoples' needs. The majority of the patients and families get through cancer pretty well and they have the resources with just a little bit of our help, because nurses and physicians are extremely skilled in supporting

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people, but there are groups of patients who are at risk for problems and if you have had psychiatric problems before, cancer is not going to help it. So those people are at high risk if you have genes that are in the family, the BRCA gene for either breast or ovarian. We also know those women are often hypervigilant about it and they monitor themselves and then they get cancer and they feel like it is unfair, and so we know who some of these people are, but we do not know who they all are. So we all just have to be aware that people need assistance and you have to ask them.

Foss One of the things that actually came out of one of the little surveys that we did was that patients say that we're not asking them often enough whether or not they are depressed. I think that is a key point and it is true that we get busy and are tending to the physical aspects of what is going on, and perhaps we do forget to ask often enough about the emotional aspects of the patient.

McCorkle And I also think that sometimes the patients do not want to tell us. They have that stiff upper lip, and so I think the family member is sometimes the best informant in saying how has this person been. We see people on a daily basis, and sometimes we get used to them and we do not see the changes, but when they come back at the three month visit it becomes very apparent that they have changed. And I think that is true with family members, they often do not realize how people are deteriorating, and they need our help in seeing some of those cues.

Wilson I think another advantage to the teams we have at Smilow in the multidisciplinary clinics, and I do not just mean different types of doctors tending to a patient, but I mean social workers, nurses, and dietitians, is that a lot of times, Francine as you mentioned, the patient may be depressed and it is something because I am bogged in the hands on real medical aspects of their care, but one of my team members will bring something to my attention that I either did not notice or was too focused on other things to pick up on, and so I think that is important and it is one of the nice things we have here at Yale for the patients. There are a lot of different specialists associated with each team who are always trying to evaluate the patient from their area of expertise. It can be very helpful and a great advantage for patients.

McCorkle That is why I like nursing, because I always feel like the nurse can be the hub and really help to coordinate all those services.

Foss Can you talk a little bit also about some of the physical challenges? We talked about the psychological issues, but there are certainly a lot of physical challenges for survivors as well.

McCorkle In my experience, patients do not have as much pain as we think they will afterwards and the patients are fearful of pain, and generally pain is overrated I think, but when a patient has pain,

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I think we need to really be sensitive to it, but as I said before, it is the fatigue. Women with breast cancer often are really out of sorts because they are gaining weight and they are doing everything they can and they feel like they are not eating and yet here they are and it really has to do with the metabolism and in understanding that we have a couple really good trials going on with Tish Knobf and Melinda Irwin on the role of exercise in these women, and we know that exercise is really healthy and beneficial, and is not only effective in breast cancer patients, but other patients. We also have a really strong program to help people with smoking cessation and we know that if people make an effort to stop smoking while they are getting treatment, it will increase their appearance, it will increase their energy, and it will increase their breathing. I mean just overall, and their family is glad that they are doing that.

Wilson We are going to take a short break for a medical minute, please stay tuned and learn more information about cancer survivorship with Dr. Ruth McCorkle.

*Medical
Minute*

This year over 200,000 Americans will be diagnosed with lung cancer and in Connecticut alone there will be over 2000 new cases. More than 85% of lung cancer diagnoses are related to smoking and quitting, even after decades of use, can significantly reduce the risks of developing lung cancer. Each day, the patients with lung cancer are surviving thanks to increased access to advanced therapies and specialized care. New treatment options and surgical techniques are giving lung cancer survivors more help than they have ever had before. Clinical trials are currently underway at federally designated comprehensive cancer centers, like the one at Yale, to test innovative new treatments for lung cancer. An option for lung cancer patients in need of surgery at Yale Cancer Center is a video-assisted thoracoscopic surgery also known as a VATS procedure, which is a minimally invasive technique. This has been a medical minute and more information is available at yalecancercenter.org. You are listening to the WNPR Health Forum on the Connecticut Public Broadcasting Network.

Wilson Welcome back to Yale Cancer Center Answers. This is Dr. Lynn Wilson and I am joined by my co-host Dr. Francine Foss and our guest Dr. Ruth McCorkle, and we are discussing cancer survivorship. Ruth, tell our listeners a bit about what sort of support families receive and how essential it is for family involvement, if possible, to support the cancer patient?

McCorkle Families are neglected, I think, in cancer care. One of the dilemmas is with HIPPA which creates some difficulty with talking to some family members about cancer, but I think it is really important when a patient's diagnosis is given that a family member is present, and I think it is also important that the health care provider who gives the diagnosis asks the patient who else they have to tell,

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because when you are dealing with a diagnosis yourself, whether you have a background in cancer or whether it is new, it is really an existential experience and to have to go home and start calling people to tell them what you are going through when you are trying to cope with it yourself is tremendously burdensome. One of the things I think that is important to families is that we are clear that someone else understands the diagnosis and wants to take on the burden of helping to tell the other members of the family, and I think we have a responsibility for that. It is difficult if the patient does not want anybody else to know, and I know there are always special circumstances, but even in those circumstances, I think the patient needs to be brought back in, in a week or two weeks, or talked to on the phone if that is what the patient wishes. So, once a patient is diagnosed, gets a workup and decided on a treatment plan, no matter what that treatment is, whether it surgery, radiation, or a bone marrow transplant, that person's world is going to be turned upside down, and cancer treatment takes a lot of effort, and if we want it to be successful at home, we have to have family members help the patient, because we are not in the home and most of the time they do not ask for other services like nursing care to come in the home to help them, and most patients and families have no idea what that care is going to entail. So those families, and they are very competent, but because again they too are in an existential crisis, their problem solving skills, everybody's skills are taxed, and so we need to be sure that a family caregiver is capable of providing the care and that we're not sending somebody home to ill people in the family. Often what happens to a person who gets a diagnosis of cancer, about 40% of the time, they are taking care of somebody ill in their own home. If you put an ill patient in a home with an ill caregiver, they both do poorly, and my research shows that they both get admitted quicker, within the 30 days then if you send some help home, whether it is professional help or not. So, you have to find that if a caregiver is willing to provide the care, it is one thing to have a body in the home, but if the person says, you know, I just can do it, you have to have somebody who is healthy, you have to have somebody who is willing, you have to find out if they have any special skills that we can use to capitalize, if they have given medication before, if they know how to give injections, if they're a dietician. A lot of people have skills. Lots of people have taken care of ill people before and we have to make them the captain of the team, it is really boosting them up and teaching them how to do this. You have to let them understand about the long haul of this. If you are going to get six weeks of radiation, it is a daily trip and it is not just adding something to your day, oh I'll stop by for an hour, get my radiation and go on about my day. I tell patients when I work with them, you are going to get this treatment, you have to give something up. It is not an add on, it is not like taking a paper home and reading it, you have to give something during this period of time, and when you talk to them like this, they get it. They really get it and then you have your team in place and both the patient and the family caregiver feel good because they know they are doing something to help the patient.

Wilson I am sure you have been in this situation before, but say you are with a patient maybe for the first

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time and they are alone and you talked to them about family or family involvement, and maybe there are family members but for whatever reason the patient is not interested in either talking to them about it or having them there, wants them excluded. Have you been fairly successful in trying to get that patient to talk with their family so that they can have some of the help and advantages when getting through this that you have just reviewed?

McMorkle Some patients are very independent, very private and sometimes they have to struggle. The important thing is to realize you're putting them in that category and that you monitor them carefully. I know when I was ill with my own head and neck cancer, you called me, I had never met you before, you gave me your cell phone number, you told me to call you any time, I never called you, but I still have it in my cell phone on speed dial, but I mean just to have that reassurance to know you were checking in with me, is incredible reassurance that somebody cares.

Foss Ruth, I know that some patients do not have family members, or perhaps they are more comfortable with a friend and there are certainly instances that I have seen where a person has identified a best friend or in some cases, a fellow cancer survivor that they have met through say the American Cancer Society, to come with them to their meetings.

McMorkle Yes, they are very helpful, this buddy network and the rides through the American Cancer Society, but I think the important thing is to use a lot of resources during this period of time. Most people think, well I can get through this, it cannot be that tough, but I think we really have to be more proactive in helping people and usually if they don't have somebody there, as a health care provider you have an understanding that maybe this person may have a difficulty, so you want to bring the nurse in and say let us see if I can coordinate something for this patient.

Foss In terms of that multidisciplinary team, you have the physician and the nurses and also the social workers, are there other people that get involved such as a dietician or the chaplains and other people as well?

McMorkle Again, I was diagnosed with head and neck cancer, I had a lesion on my tongue about three years ago and the nurse manager there at the time, Shelley Jolie, she had my hearing tested, she had me go to a speech therapist, she had me to go to a physical therapist to learn swallowing and preparation. I had to make a decision of what kind of treatment I wanted and whether I was going to do surgery and she really helped me to figure out what the consequences were of the different kinds of treatment before I made a decision, and part of that was understanding what kind of resources I would need afterwards in rehabilitation to get some of the function back.

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Wilson Ruth, could you talk to the listeners a little about some of the challenges and the affects of head and neck cancer treatment?

McMorkle It is a really devastating cancer. For years it has been associated with unhealthy behavior like smoking and drinking, and there are sort of the stereotypes and so when people get this, who do not have those unhealthy behaviors, we now also know that it is associated with some of the viruses, so then you worry about some of your sexual practices, I mean all of these things go through your mind as to why did you get this sort of awful disease. Again, I have been talking about the existential plight about when you get it, am I going to live or die? And we know that lasts for about 100 days in which you sort of get your senses back and realize that this isn't going to kill you, but it is going to make you different than what you are before, and I was very fortunate. We know that people who have cancers that are unusual should ask for second opinions and come to a comprehensive cancer center and we are the only comprehensive cancer center in this state and it is important to get people who do the treatment and understand the diagnosis on every basis, that they do not have a case once a year, but they see people with these kinds of cancer three or four or half a dozen times a week, and my cancer was unusual. I have adenoid cystic, and you think about adenoids and tonsils and it is a very slow growing cancer, so the usual chemotherapy and radiation was not necessarily sensitive to it. I was very fortunate that we have Dr. Roy Decker here and he has an MD and PhD and has done some really groundbreaking research in understanding how to treat my cancer. I went to Seattle and Dana Farber and Iowa to get worked up and I came back here because of his expertise and I chose to have radiation therapy and I have to admit, one of the things that happens with radiation, is they have to devise a technique so you get treated everyday in the exact some spot. So, they have to do a lot of calculation about the tumor in order in keep you in position, they have to put a metal mask over your face and actually clamp it to the table and sometimes that treatment can last 5 to 10 minutes and when you're in that position, it is really quite scary going through it and there are medications for it, Ativan and some other things, but one of the things that I felt was the most helpful to me, was I had a doctoral student at the time who was into meditation and she taught me to meditate and go through my meditation mantras to get through my radiation and between her and Roy and the medication, I really did sail through it. I lost weight and my skin was irritated and I had a sore throat, but I was very lucky to have the team that I did, and right now the cancer is very well controlled and I am very fortunate.

Dr. Ruth McCorkle is Florence Schorske Wald Professor of Nursing at the Yale School of Public Health. If you have questions or would like add your comments, visit yalecancercenter.org, where you can also get the podcast and find written transcripts of past programs. You are listening to the WNPR Health Forum on the Connecticut Public Broadcasting Network.