

Yale CANCER
CENTER
answers

WNPR Connecticut Public Radio



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Prostate Cancer Surveillance and
Survivorship

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Yale Cancer Center Answers

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Welcome to Yale Cancer Center Answers with Drs. Ed Chu and Francine Foss, I am Bruce Barber. Dr. Chu is Deputy Director and Chief of Medical Oncology at Yale Cancer Center and Dr. Foss is a Professor of Medical Oncology and Dermatology specializing in the treatment of 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 evening, Francine welcomes Dr. Meredith Wallace. Dr. Wallace is an Associate Professor at Yale University School of Nursing and she joins Dr. Foss this evening to talk about prostate cancer and the recent changes in the field of cancer survivorship.

Foss How have things changed over the last couple of years?

Wallace One of the things about cancer that's very interesting is we have seen a change with the rising older adult population. Cancer used to be thought of as a more deadly disease where people used to be diagnosed and there were not a lot of treatments available and people would pass away soon after diagnosis, but as people have continued to age and the cancer treatments have continued to evolve, people are living a long period of time with cancer and we can actually think of cancer more in a chronic illness framework than we ever have before.

Foss Meredith, we have talked to some other guests on the show that have talked about survivorship, particularly the survivorship program at Yale. Can you tell us a little bit about your background and how you got interested in this whole field of survivorship?

Wallace Well I am a nurse and I have advanced practice nursing certification and licensure and in one of my clinical roles I used to do a lot of prostate cancer screening. I would find that I would screen all these men for prostate cancer and then I would call and give them the results and many of them had positive results, and many of them were going for very aggressive treatments that were not clinically indicated at that time. The aggressive treatments for prostate cancer, while very appropriate for some patients, often result in some adverse effects. Given that some of these men were not appropriate for these treatments those adverse effects could have been avoided. So, it made me question why men were going towards more aggressive treatments when in fact they could be living successfully and surviving with prostate cancer without aggressive treatments.

Foss When you talk about these aggressive treatments, are you talking about the surgeries primarily?

Wallace Sure, radical prostatectomy is the surgery for prostate cancer and then also radiation therapy via external beam radiation or brachytherapy; which is radiation seeds.

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- Foss Prostate cancer is a unique disease because patients are not necessarily treated immediately, in some cases it is watchful waiting, and this is a difficult concept for some patients. Can you talk a little bit about that whole concept and how difficult it is for patients to deal with that idea that maybe they are not going to get treated for their cancer?
- Wallace Absolutely, it is very difficult to be diagnosed with prostate cancer and then not be directed immediately towards treatment. In fact, I did a focus group with some men who were diagnosed with prostate cancer and they said prostate cancers, or cancer in general, is very closely associated with death in their minds and I think that's the way a lot of people think about cancer. So to be told, well lets just watch and see how it progresses, is often very difficult for some patients. Watchful waiting is really very appropriate for men with prostate cancer who fit a certain clinical profile and entails a course of going to the urologist or physician every six months to have the PSA evaluated, and perhaps to have some repeat biopsies and clinical examinations to determine if the cancer is progressive. And prostate cancer is unique in that its a very slow growing cancer and many of the prostate cancer tumors that are diagnosed through a routine PSA are actually very indolent and don't require immediate treatment, and these patients would benefit very well from that period of active surveillance, or watchful waiting.
- Foss Do patients ask questions about watch and wait after they are given the diagnosis, or do you think that most patients don't really know that this is an option?
- Wallace I think that most urologists and medical oncologists who diagnose patients with prostate cancer do present all of the options for the patients, but in fact, it is a difficult option for the patients to understand because it doesn't actually require them to do anything. When men are diagnosed with prostate cancer and their families are dealing with this diagnosis with them, they want to do something, they want to take control of it and in some cases just get rid of it. That's why active surveillance isn't always well thought of in terms of a reasonable management option.
- Foss Can you step back a little bit and tell our audience about the whole process of prostate cancer screening, what is done, in what population of men, and how often?
- Wallace We are very fortunate to have what we call a prostate specific antigen, which is a biomarker for prostate cancer, abbreviated as PSA, and it's a very inexpensive blood test that is routinely done on men, usually through the annual physical exams over the age of 50. In men who are in high risk categories like African-American men, or men who have a first generation relative, a brother or father who had prostate cancer, the screening may began at an earlier age such as 40. Generally we like PSA to be below 4, and men who are above 4 are

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at risk for prostate cancer and the progress of the PSA is really something that we have been looking at. Sometimes men will have a PSA of 4 but it remains 4 for a long period of time and that shows that the activity in the prostate gland is not progressing, but we are looking at what we call PSA velocity, or the speed with which the PSA changes, to determine if the prostate cancer is progressing. The PSA is a marker of the activity within the prostate gland. It doesn't necessarily mean that the man has prostate cancer, so in fact the PSA could be elevated in a man who has benign prostate disease as well.

Foss In addition to the PSA when a man is screened, do all of them undergo the digital rectal exam, which is probably not the most pleasant thing but certainly part of the whole process?

Wallace Yes, not at all pleasant, but it is recommended that men go through the digital rectal exam and we also want to look at their symptomatology; are they having any problems with urination? That's one of the main key factors that shows that there might be some growth in the prostate gland.

Foss Do you find that most men are sensitive to these changes that they are undergoing with respect to the urination, or like the rest of us do a lot of men try to deny these things as they get older?

Wallace Well, the problem is that the two major areas that are impacted by prostate cancer are sexual function and urinary function, and both of those things change as the process of ageing continues. So, it is very easy to attribute changes in urination or changes in sexual function to the ageing process and not think in terms of, "Oh my, I might have something going on with my prostate gland."

Foss So for most men over the age of 50, should they expect that their doctor during a routine exam is going to check these things, or should patients be alerted to ask about this and start thinking about this?

Wallace It's always smart for patients to be their own advocate, but yes, it is the clinical practice guideline to screen men for prostate cancer, so most physicians will go ahead and independently do that with their annual blood work.

Foss So once the patient has a PSA over 4, you mentioned that it is possible to watch and wait or possibly do additional testing at that time to determine whether that's important, or whether it needs to be followed. Can you talk a little bit about that process, once a man has a PSA elevated?

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Wallace Once a man has an elevated PSA, we would refer him to a urologist to have further evaluation of that, and that would generally entail a biopsy of the prostate gland where they would look at specific areas in the prostate gland to see if there is cancer activity going on there. And so, men would proceed with that process fairly immediately after an elevated PSA would be found.

Foss And then after the biopsy, say the biopsy shows prostate cancer, the patient will then have a discussion with regard to what the treatment possibilities are?

Wallace Right, so the urologist would probably sit down with the patient and give all of the options, and depending on a number of factors that were found with the biopsy as well as what the PSA level is and how the PSA level has been changing over time, some options would be more appropriate than others. So, if the PSA were changing rapidly, if the patient had very aggressive prostate cancer within the gland, then they would probably be recommended for fairly aggressive treatment immediately. If the prostate gland showed that it was not aggressive cancer, if the PSA level has remained stable over a period of time, or if the man is of advanced age, generally over the age of 65 or 70, then the patient may be a very good candidate for active surveillance or watchful waiting.

Foss And is it true that not every man with an enlarged prostate who has symptoms with respect to urination necessarily has to worry about prostate cancer in that gland?

Wallace Absolutely, because that could actually be very symptomatic of benign prostate disease, which is also common as people age.

Foss Some men have concerns about some of the medications that they are taking, particularly medications that men are taking now for sexual dysfunction and whether those possibly could lead to prostate cancer or affect the course of prostate cancer. Can you comment about that?

Wallace There is no evidence that I am aware of that has shown that the oral erectile agents are increasing the risk of prostate cancer.

Foss I guess that's a relief for a lot of us out there.

Wallace Yes.

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- Foss The other question is, with respect to hormone use, because men are now starting to use testosterone replacement therapy, is that a risk?
- Wallace Not that I am aware of at this point in time, but I think that there needs to be further testing on that.
- Foss With respect to other things that you talk to men about when they have an elevated PSA, are there other lifestyle issues or other things that men are concerned about that we need to talk about?
- Wallace Again, the research is still forthcoming in that area. We know that prostate cancer is very high in this country as opposed to other countries. So, there is some concern about the high fat in the US diet that certainly should be considered, and one thing that medical oncologists and people who work with cancer will always say, what's good for your heart is also good for your prostate gland. So, low fat diets, exercise, a lower amount of alcohol or moderate amount of alcohol intake, and smoking cessation are things that we can all do to improve our health that most likely will impact the risk of prostate cancer.
- Foss And all of these supplements that we see advertised on TV that supposedly improve prostate health, are they of any benefit?
- Wallace Again, we just don't have any research to show that they are at this point in time, but hopefully, they'll be some further research that gives us a better indication of whether they are beneficial or not.
- Foss Once you have a man with an elevated PSA, and a man who has say low-grade prostate cancer, that man is going to go on what you call active surveillance.
- Wallace If the man, with his family and his oncologist or urologist, decide that that's appropriate, a period of active surveillance would probably be very beneficial for this patient. What we do know now is if patients fit that clinical profile, even delaying prostate cancer treatment for a few years is not going to impact their overall survival.
- Foss What about the role of imaging studies like PET scans and bone scans at this point early on?
- Wallace Well there would probably be no indication of needing to do that early on if the prostate biopsy and the PSA levels are fairly low and show that it's not aggressive disease. The likelihood that it would have gotten into the bones is not very likely.

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Foss And you are monitoring the PSA how often as you are following these men, is it once a year or is it more often than that?

Wallace About every six months or so.

Foss And as you mentioned there is no need to do any imaging studies after that as long as there are no symptoms?

Wallace Right, different patients differ in terms of their symptomatology so an individual urologist might suggest that, but overall, if they are able to evaluate the growth of the prostate gland through the PSA that would not be necessary.

Foss Can you talk to us a little bit more now specifically about your work and your involvement with these patients?

Wallace Sure, so knowing that men may be very appropriate for active surveillance clinically, but maybe very hesitant to do that because it is so very difficult to live with prostate cancer, myself and some other urologists, as well as cancer researchers, have developed a website that we hope will help men to manage the uncertainty associated with living with cancer as a chronic illness. And the website focuses on two specific areas; number one is changing the way we think about cancer and looking at it as a chronic illness as opposed to an instant killer. We do that through looking at the way we think about different things and looking at cancer maybe as an opportunity as opposed to a danger. The second thing the website focuses on is self management, which is some of those things we talked about earlier; diet and exercise.

Foss Meredith, I would like to talk a little bit more about this website when we return after the break. You are listening to Yale Cancer Center Answers and we are here discussing active surveillance in prostate cancer with Dr. Meredith Wallace.

*Medical
Minute*

The American Cancer Society estimates that in 2009 there will be over 62,000 new cases of melanoma in this country and about 2400 patients will be diagnosed here in Connecticut alone. While melanoma accounts for only about 4% of skin cancer cases, it causes the most skin cancer deaths, but when detected early, melanoma is easily treated and highly curable. Clinical trials are underway at federally designated comprehensive cancer centers such as Yale Cancer Center to test innovative new treatments for melanoma. Patients enrolled in these trails are given access to newly available medicines which have not yet been approved by the Food and Drug Administration. This has been a medical minute and you will find

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more information at [yalecancercenter.org](http://www.yalecancercenter.org). You are listening to the WNPR Health Forum from Connecticut Public Radio.

Foss Meredith, we were talking earlier in this show about the whole process of the diagnosis of prostate cancer by elevated PSA and the fact that a lot of men are actually followed and not treated for this. You have done some research in this area looking at that whole process of how men feel about this, could you talk a little bit about that?

Wallace Sure, so the diagnosis of prostate cancer is obviously very disconcerting for men and they have talked to me a lot about their feelings when they are diagnosed. Some are just shocked, some just feel like they have been punched in the stomach, hit over the head, and it really shakes your whole concept of life and makes you look at your mortality more closely than anybody really ever had wanted to. It also affects the man's family who is all of a sudden dealing with perhaps a life-threatening illness and so it is very difficult for men to have to understand this diagnosis and then make treatment decisions and then live with the aftermath of the disease.

Foss There is the whole issue of uncertainty I would imagine when dealing with these patients, uncertainty about the disease, uncertainty about the outcomes in the future, and you specifically focused on this uncertainty issue in your study.

Wallace Yes.

Foss Can you talk to us about that?

Wallace I discussed earlier how I had originally been involved with screening men and couldn't understand why so many men who were appropriate for active surveillance were undergoing aggressive treatment, and one of the things that I found through my early work that really played an important factor is that the level of uncertainty after diagnosis with prostate cancer is very high and very similar to the level of uncertainty with many other illnesses. That's one thing that I think we as nurses could focus on, to help men to deal with that uncertainty so that the decision making process is made more consciously and not influenced by that uncertainty.

Foss How do you actually deal with uncertainty?

Wallace The intervention that we have put on the website is what we called an uncertainty management intervention, and it has been around for quite a few years and was originally developed by Dr. Merle Mishel at the UNC, University of North Carolina in Chapel Hill, and

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she really focused on what we call cognitive refraining, or rethinking, about cancer as a chronic illness. What that allows us to do is examine our individual feelings that are automatic once we are diagnosed with a particular disease, particularly prostate cancer, and see if we could perhaps think about those things in a different way. It goes through this kind of systematic process of re-thinking the way that we have traditionally imaged prostate cancer.

Foss Is this a process where the patient undergoes a number of different steps, or is this kind of a one-time analysis?

Wallace It's kind of between both of those things. There is not actually a series of steps that they have to go through. It's kind of self-directed in terms of where the man starts with on the uncertainty management and where he might feel like he ends up, but one of the key components that's involved is a close relationship with a healthcare provider that you trust, and in this case on the website we really want men to interact with nurses and to ask questions and voice their feelings associated with a prostate cancer diagnosis, and then get the answers and the support that they need to go ahead and resolve those feelings of uncertainty.

Foss Meredith, this is an excellent time to get into a really important question, which is to try to define the role of the different health care providers in caring for these men. Certainly, there is the urologist who may or may not be involved, there is the medical oncologist, but also now the nurses are playing a much larger role, particularly the advanced practice nurses. Also, just in oncology practice some of the nurses are there all the time interacting with patients, so can you talk a little bit about your role as a nurse and how that's different than the role of the other providers?

Wallace I think it's actually truly unfortunate in some cases that prostate cancer patients can go through their whole prostate cancer diagnosis process without ever encountering a nurse if that particular urology practice doesn't have a nurse who is working within there, but I think as you said, more and more urology practices and more and more medical oncology practices are employing nurses to help with that diagnostic and education process. I think it's going to be very helpful for men as we go through the future, because nurses are traditionally very good teachers and advanced practice nurses are very well educated to work with patients throughout all the disease trajectories.

Foss Also, patients often times feel more free to discuss things with the nurse than with their physician.

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Wallace Yeah, and in fact, doing some of this early work, I was hesitant because I am a women and obviously prostate cancer is a disease of men, and thought men would not be comfortable talking about that with me, but that has not been the case at all, men are often very comfortable to sit and talk with a nurse about all their uncertainties and ask a lot of questions and get the answers that they need, which make the whole disease trajectory a little less painful for them.

Foss Meredith, are you involved at all in training other nurses to do what you do?

Wallace Yeah. My associate professorship at Yale obviously is highly focused on teaching. I teach in the adult and gerontological nurse practitioners speciality and we do clinical education and didactic education with nurses in these specialty programs, so hopefully they will be well prepared to help patients.

Foss Great, and your website you eluded to that has this uncertainty tool, can you talk a little bit more about that?

Wallace This is a website we have developed over the last couple of years. We have taken this traditional uncertainty management intervention and we have developed it into a website. There are a couple of reasons why we decided to do that. First of all, because we know men with prostate cancer need a lot of support and a lot of education, but often are not comfortable initially either going to support groups or asking those questions. So, this was an opportunity for men to anonymously access the information and support that they would need. We felt that this was a really great format in which to provide the uncertainty management intervention. What it does is it focuses and gives a lot of prostate cancer information, a lot of information about active surveillance and has a few pages devoted specifically to cognitive reframing, which is rethinking prostate cancer in a chronic illness framework. It also has several pages on self-management, diet, exercise, smoking cessation, and alcohol reduction and where to get resources on all of those things with direct links to the American Cancer Society web pages. There is also a number of links to some prostate cancer sites, which men who assisted in the development of the site felt were really very helpful.

Foss How does a patient access this website?

Wallace Right now it is still under research, so it's not open in the free web framework, but at this point you have to be a member of my study to actually be a part of it, to access the website.

Foss When the website is opened up to the public, will it be opened up through Yale or through another organization?

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Wallace Yeah, I think we will probably open up through Yale Cancer Center.

Foss And as you mentioned, there will be links to the American Cancer Society website, will there be links from their website back to this website?

Wallace That's a possibility that we can consider in the future.

Foss In terms of this website, you would envision that men would instead of going say through your study, be able to go directly to the website?

Wallace Right, so what we are in the process of doing right now is we have a number of men enrolled who are looking at the website and going through a period, we calculated a period of about five weeks, that would be helpful on the website and patient's would be able to get all the information they would need at that point in time. We did some pre-testing and will need to do some post-testing with the men to see if it impacts their uncertainty and quality of life levels. We want to wait until we have that data before we roll it out, we think that there might be some changes that we need to make, some additions or taking things out. One of the really great things about the website is that we developed it with active surveillance participants and the website is very reflective of their questions and their concerns and their needs for information and support.

Foss That's terrific. I am sure men were really interested in participating in that.

Wallace Yeah, it was a very gratifying process because when they came they asked all these questions during the focus groups and then we actually used that to develop the frequently asked questions page and then they saw their questions and were like, Oh, that's my question! So, it is wonderful.

Foss Great. What about other support for these patients right now? Do they have support groups?

Wallace Yes, there is a prostate cancer support group through Yale Cancer Center which is easy to access and a number of men have stated that that process has been very beneficial for them and the men in that support group are through all management strategies. Men who have then undergone radical prostatectomies, radiation treatment, hormone treatment, and active surveillance are all a part of this support group.

Foss What about national organizations like we see for breast cancer?

Wallace There are a number of prostate cancer groups as well, Us TOO is one group that men have

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thought was very helpful and I think the American Cancer Society offers local groups as well.

Foss What about the whole issue of patient blogs now? A lot of websites have blogs where patients can communicate with each other around specific diseases, is that something that you can see incorporated into your website at any point?

Wallace I have certainly thought about that and I think my concern with prostate cancer is that there are so many treatment options and there is such variability in terms of who is appropriate for which treatment. Even in my focus groups I found some men trying to talk other men into a particular treatment, which worked for them. My concern with that is that I want men to really be in a good relationship with their healthcare provider so that they are not influenced incorrectly into a particular treatment.

Foss From that point of view, you feel that the actual one-on-one support groups and direct interactions with their providers is where men should get most of there information.

Wallace I really think so, and again, this is a problem specifically to prostate cancer where there is so much treatment variability.

Foss When you talk about your website and your uncertainty tool it makes me wonder whether that would actually be applicable to other cancer situations as well, because there are patients say with low-grade lymphoma that also are watched and waited.

Wallace And the uncertainty management intervention has been used with other cancer populations as well as other chronic illness populations. In fact, it was originally tested in the breast cancer population and we have adapted it for prostate cancer patients.

Foss Have you done anything with men on the flip side of the coin, men who have undergone treatment for prostate cancer and are now extensively cured?

Wallace It's very difficult to actually separate who is in active surveillance as opposed to who has been treated. So, one of the studies that I am just actually finishing up is in men who originally were in active surveillance and converted to treatment. In that particular study, I worked with a number of men who have had radical prostatectomies, radiation, and men who are currently receiving hormone therapy to examine their reasons on why they converted from active surveillance to active treatment.

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Foss Are those men still undergoing a degree of uncertainty about their future, or do you feel that once something definitive has been done, that degree of uncertainty is less?

Wallace That's funny you asked because we actually asked that question, we asked if they have any regrets about their treatment and most men felt very satisfied with the treatment decision they had made and their levels of uncertainty were less after that period of time, but there were some things that came up with the study that were kind of interesting. One particularly being that men felt watchful waiting was a very dangerous thing to do and the other thing being that men had a very sensible clinical tract toward treatment, they had a rising PSA and they had clinical symptomatology that really forced them into treatment.

Foss Meredith, this has been a really enlightening discussion and I think a very valuable discussion with respect to managing this disease that is so prevalent in our population. Thank you very for joining us tonight. You have been listening to Yale Cancer Center Answers and I would like to thank Dr. Meredith Wallace for joining me for this discussion about prostate cancer. From Yale Cancer Center, this is Dr. Francine Foss, wishing you a safe and happy week.

If you have any questions or would like to share your comments, go to yalecancercenter.org where you can also subscribe to our podcast and find written transcripts of past programs. I am Bruce Barber and you are listening to the WNPR Health Forum from Connecticut Public Radio.