

WEBVTT

NOTE duration:"00:20:01.0050000"

NOTE language:en-us

NOTE Confidence: 0.864410281181335

00:00:00.030 --> 00:00:11.410 About his patients uhm I would go to him an I learned a lot here, too. I'm going to pull up my slides here. I'm sorry. I was a little bit late my husband.

NOTE Confidence: 0.886842131614685

00:00:11.920 --> 00:00:30.770 Is a surgeon here and he had a promotions reception so I was there and I'm really excited to end my night with you. An I you know survivorship always goes last so I know how to stay on time. My name is Terra stamped. I see some familiar faces in the crowd. I'm the director of the survivorship program here.

NOTE Confidence: 0.919427096843719

00:00:31.390 --> 00:01:03.640 Um and you know, many of you in this room. I've heard these words and when you're told you have cancer. My guess is your reaction is as unique as you are depending on where you are in your life and circumstances that are happening to you. I've been here for almost 10 years and I've been able to meet many survivors in my clinics. You might recognize Robin Roberts. She was one of our speakers, and her cancer diagnosis really called on her spirituality to get her through.

NOTE Confidence: 0.930403590202332

00:01:04.600 --> 00:01:20.180 And this is a woman who won a contest choose a photographer, she goes across the world. Photographing people who've had cancer in her, her big issue was about food and what should I eat to avoid recurrence or what do I need to avoid so my cancer doesn't come back?

NOTE Confidence: 0.897243857383728

00:01:20.760 --> 00:01:52.430 Um and this is the patient a deer patient of mine who actually had metastatic disease. For many, many years, an really did not want cancer to define her an part of that was riding 100 miles in our bike ride. She rode for farther than I did that year and so these are all just some common themes that we hear but recognizing that not everybody is comfortable with the term survivor. It's something that we've sort of decided on as an umbrella term but really it's just about.

NOTE Confidence: 0.917702555656433

00:01:52.430 --> 00:01:56.900 Supporting the whole person in meeting them where they are, and helping them meet their goals.

NOTE Confidence: 0.930129706859589

00:01:58.410 --> 00:02:09.860 So you know with that just to be clear, um survivors are anyone who's been diagnosed with cancer and it spans from the time of diagnosis throughout the balance of his or her life.

NOTE Confidence: 0.940411806106567

00:02:10.950 --> 00:02:41.480 There are millions of survivors right now because of better detection and better treatments. I'm sure you've heard about these things tonight and people are able to survive. The treatments and live longer. You know, such that there is 17,000,000 cancer survivors in the United States. Today this is going to grow exponentially and for the vast majority of our breast cancer patients they are still alive. Many years after diagnosis and these this is all stages.

NOTE Confidence: 0.900694370269775

00:02:41.480 --> 00:02:43.400 So really, and includes everyone.

NOTE Confidence: 0.915224075317383

00:02:44.870 --> 00:03:00.660 In that context. We think of it in sort of 3 big categories. This is an old article from a Doctor Who also is a cancer survivor and went on to publish in the New England Journal decades ago, now about these sort of 3 phases of survivorship.

NOTE Confidence: 0.913511097431183

00:03:01.240 --> 00:03:20.070 I'll just point out that most of our programs kind of are in these last 2 phases, so briefly the acute phase of survivorship starts at diagnosis and it goes throughout your diagnostic process and your treatment plan. This is you know sort of the Rapids going over the waterfall.

NOTE Confidence: 0.935993194580078

00:03:20.860 --> 00:03:37.860 It does happen to be a time where there is a lot of support. So so places like here. We have a lot of networks and support systems in place to help you hopefully Shepherd you through this treatment process and also communities are built to help people get through their treatment.

NOTE Confidence: 0.926310658454895

00:03:38.670 --> 00:04:12.950 After active treatment ends this is where the extended survivorship starts in and this is where I feel like what we do is really important in survivorship clinic because this is a time of really high uncertainty. The treatments over an we hear from a lot of patients that are doing just fine. In some patients feel like? Why don't I feel happier or when am I going to get back to what I was doing before this is taking longer than I thought so the idea here is you're doing better, but you don't know what's coming around the bend or what might be lurking behind you.

NOTE Confidence: 0.899676144123077

00:04:14.310 --> 00:04:43.870 Extended or long term survivorship is many years later, where the risk of recurrence really goes down dramatically. But the long and Lee effects long term in Lee defects can creep up as the reminder and you know this is where like long term survivorship programs mostly focus on surveillance and kind of keeping you healthy come into play. But you know it's something that people deal with still on a daily basis, sometimes.

NOTE Confidence: 0.918676137924194

00:04:44.540 --> 00:05:12.410 So with that in mind, I just have kind of 3 brief objectives number one. What are the agreed upon tenants of survivorship care and if you've heard of survivorship care plans uhm you know they're in the news. Sometimes and what is the evolution of those and that movement and then I wanted to just end with the survivorship clinic here and talk a little bit about what we do, and some initiatives that we have in place to sort of expand the reach.

NOTE Confidence: 0.923315763473511

00:05:14.780 --> 00:05:41.860 So the agreed upon tenants are for things number one surveillance make sure that the cancer isn't coming back or you don't develop new cancers #2 prevention and this focuses mostly on healthy behaviors and lifestyles. So we talk a lot about managing weight. Combating obesity physical inactivity. Managing stress and course smoking cessation number one thing you can do to prevent cancer.

NOTE Confidence: 0.922829508781433

00:05:42.720 --> 00:05:50.750 We talk about assessments and treatments for late in long term affects and coordination of care and make sure you know who's in charge.

NOTE Confidence: 0.915369808673859

00:05:51.660 --> 00:06:22.110 This is there's many guidelines out there, although very few that are dedicated to survivorship. This is our national comprehensive cancer network, which is a set of guidelines that all of us are held to in how we practice. I'm fortunate to be a vice chair of this guideline annetts professionally very gratifying once a year we get together for 2 days. A bunch of survivorship specialists in a room and try to talk about how we can meet meet those tenants of survivorship care.

NOTE Confidence: 0.917367875576019

00:06:22.110 --> 00:06:36.610 There are patient forward facing materials as well, but this is what our guidelines ended up looking like and we're trying to hit all those main tenants and have some some language that all providers can understand.

NOTE Confidence: 0.918220996856689

00:06:38.740 --> 00:07:11.470 So if some common themes to survivorship fear of recurrence almost universal an independent of your actual risk of recurrence fatigue again almost universal, especially patients who received chemotherapy or radiation therapy report a lot of cancer related fatigue different than being tired. It doesn't go away with rest. And it can persist sometimes longer than a year but but on average. It can take up to a full year to really feel.

NOTE Confidence: 0.923919379711151

00:07:11.470 --> 00:07:39.510 Better and then I put in here sexual dysfunction because I feel like we don't talk about it enough and we need to start talking about it more and I know that there's some supporters of that in the room, but it's the 3rd most common concern of many, many cancer survivors men and women in all different types. And despite this, you know less than half of patients with this concern seek treatment. So we really need to make these issues able to be talked about in addressed.

NOTE Confidence: 0.925224006175995

00:07:41.770 --> 00:08:03.310 Again, I'm healthy lifestyle is really important, he ran. It's important to survivors. The vast majority want us to address in activity weight issues and I. A quality but we also know there's a merging evidence that healthy behaviors matter in terms of reducing risk of recurrence and mortality.

NOTE Confidence: 0.928873240947723

00:08:04.080 --> 00:08:34.550 I included this slide because it shows in the black circles on the left hand side that physical activity. Both before diagnosis. That's the Top section and after diagnosis is the bottom section improves breast cancer death and death from all causes what I love about this slide is the second section. Because these are all patients who did not exercise before their diagnosis.

NOTE Confidence: 0.916860818862915

00:08:34.550 --> 00:08:57.880 And even with that, starting after their cancer. They were able to show that exercise impacts recurrence and mortality. So is really never too late to start and I think it's just our mission to talk more about you know, we're not talking about marathon running were just talking about adopting some simple exercise habits.

NOTE Confidence: 0.914768695831299

00:08:59.090 --> 00:09:30.320 So you know, let's move on to survivorship care plans. I don't know if any of you have heard of these before over 10 years ago. There was a Commission Institute of Medicine report here. It's not a survivorship talk if you don't include this picture called lost in transition. It got a lot of press and in that they recommended that patients receive a survivorship care plan and the idea. Here was like if you were discharged from a hospital. You get a discharge summary. So when you're done with cancer care.

NOTE Confidence: 0.926623523235321

00:09:30.320 --> 00:09:44.900 You should get a survivorship care plan. It makes so much sense. It really includes a record of what you were diagnosed with what you were treated with what your plan is going forward and make sure that you know like all the different referrals that can be made for you.

NOTE Confidence: 0.896209061145782

00:09:45.970 --> 00:10:13.970 This is important because um survivors don't really remember all the details right. They were going over the waterfall so a lot of things were missed, and just last week. You know impatient under Stage 2 or stage 3. I really confused about what was told to me. Why am I an endocrine therapy? What is endocrine therapy right so the you think as a provider explaining all these things but in the midst of all this information. A lot is not sinking in.

NOTE Confidence: 0.913659632205963

00:10:14.590 --> 00:10:28.080 Not only that, but our follow-up care is really chaotic and there is evidence that we under adhere to some guidelines. But over prescribe unnecessary testing an survivors are not always sure who's running the show.

NOTE Confidence: 0.904047906398773

00:10:28.740 --> 00:11:01.590 Um these survivorship care plans have been very hard to operationalize their mandated by these governing bodies that decide if you're a comprehensive Cancer Center or not the effort was good. It was Noble to try to get survivors. The care that meet those for tenants. But the truth is, it's very hard to give pieces of paper to people and change their life. So this is hot off the press just last week, one of the standards has changed to better reflect.

NOTE Confidence: 0.951633155345917

00:11:01.590 --> 00:11:15.730 What I think is really important which is a comprehensive survivorship program that provides services to patients and Taylors? What they need and make sure they are plugged in with their individual preferences.

NOTE Confidence: 0.909669280052185

00:11:16.360 --> 00:11:31.970 And this is the Commission on cancer is newstandard, saying, You need to have a survivorship program. An you need to have at least 3 services so I think we're evolving to make sure that meaningful care is accessible to all survivors.

NOTE Confidence: 0.905132234096527

00:11:32.680 --> 00:12:06.830 And just this week, so just Tuesday. What are we this is Wednesday so just yesterday the patient brought me this Washington

Post article from? I think the week before an it's talking about survivorship and you know what's interesting is I just kind of highlighted that sidebar there. The Top 5 concerns. These are actually not elements that are in a survivorship care plans, so again illustrating that while our intentions are good with those. I think that we're falling short a little bit with meaning our patients needs.

NOTE Confidence: 0.90315854549408

00:12:08.660 --> 00:12:16.500 So let me tell you a little bit about the survivorship clinic here what we do an then what some future steps are.

NOTE Confidence: 0.928167581558228

00:12:18.080 --> 00:12:34.430 So we are a multidisciplinary clinic and we were founded in 2006 by a cancer survivor who said, I wish that I had had this when I was diagnosed and going through my treatment and in that sort of extended phase of follow up.

NOTE Confidence: 0.899444401264191

00:12:35.130 --> 00:12:54.080 Uh it's the only multidisciplinary clinic in Connecticut, an it's a 2 hour sort of highly personalized visit 1 on one, not a group session each patient meets 30 minutes with each provider and you walk away with what I call a highly personalized survivorship care plan.

NOTE Confidence: 0.91167777767181

00:12:54.610 --> 00:13:02.470 We have a medical person so it's myself and there's also a physicians assistant who makes the plans and we share the visits.

NOTE Confidence: 0.891875386238098

00:13:03.090 --> 00:13:26.800 We go over like those questions like? What is the diagnosis? What was the stage? What was the treatment. We see patients of all different types of over half are breast cancer survivors. But we see everyone an we go over you know what are? What are the side effects you're having now are they going to get better are they going to be chronic? What's your health scenario who's in charge of web thing.

NOTE Confidence: 0.918578565120697

00:13:27.380 --> 00:13:57.540 The social worker is also a trained provider of cognitive behavioral therapy. She also facilitates a meaning centered therapy group and also the adolescent and young adults support group, so she's got this wide net that she can speak to with her expertise and she talks. A lot about fear of recurrence, which again almost universal. She also has many resources to address the financial toxicity that cancer comes with.

NOTE Confidence: 0.912066340446472

00:13:58.240 --> 00:14:25.740 Our physical therapist is survivor himself and he helps right the board exam for oncology rehab and his main focus is on personalized exercise program so he sees people who used to be triathletes, but

he sees a lot of people have never been in a gym and never want to be in a gym and so really meeting. The patient where they are, and what is the scenario that can get them to meet their functional goals.

NOTE Confidence: 0.923264861106873

00:14:27.450 --> 00:14:44.960 And then our dietitian, she has spent decades counseling survivors. She's been involved in multiple R 01 level. Studies looking at healthy diet and exercise in cancer breast cancer survivors specifically she talks about weight.

NOTE Confidence: 0.914696574211121

00:14:45.490 --> 00:15:04.320 Changes in weight goals eating habits and she does a lot of myth busting so everybody's like. Oh, sugar feeds cancer or if I just take these supplements you know everything will be good and so she. She really spends a lot of time addressing things like that, and I learned a lot from her.

NOTE Confidence: 0.914483070373535

00:15:06.190 --> 00:15:34.750 So how does it work we do a very extensive intake and we ask patients just free free right in your Top two concerns an when we started this part of the intake. We weren't sure like we'll have to see what they are, and see if we can address them and the good news is after the first 300 or so people filled this out. We had a student go through and categorize them and lo and behold, they really do did fit into what the providers expertise was so we feel good about that.

NOTE Confidence: 0.925134301185608

00:15:35.250 --> 00:16:05.440 We've also had a student come through and do some observations in her chart review and she found that there were 75 unique referrals that were made in the course of her observations so these include ordered referrals that will help you get the long term care that you need through our system, but also our group knows about the programs and they know about your community and and we have all kinds of websites in apps and so I really do think it's a personalized approach.

NOTE Confidence: 0.882694602012634

00:16:05.440 --> 00:16:09.270 An and everybody comes out with something.

NOTE Confidence: 0.908337712287903

00:16:10.760 --> 00:16:41.910 So one of our successes been we've shown that we do decrease distress after our visits in this is we showed that it's still low at the eight week follow up which is nice. We have very high patient satisfaction and those are the 2 most important things to me. Fortunately, we've been a model program. For many different National Cancer centers and we've been able to help train future survivorship providers coming out of Mayo Clinic and.

NOTE Confidence: 0.848501026630402

00:16:41.910 --> 00:16:44.840 And supported through our Asko Foundation.

NOTE Confidence: 0.929266154766083

00:16:45.890 --> 00:17:05.700 Just today, we launched a like a telemedicine train. The trainer program and this was actually a national group and we had 18 people on the call 18 sites and these are multidisciplinary programs that want to learn more about how to sort of work together to get survivorship care to their patients.

NOTE Confidence: 0.917743325233459

00:17:06.690 --> 00:17:17.540 We have very nice comments and this is what I go to and I've had a bad day because I feel that we're really servicing our patients in a positive way.

NOTE Confidence: 0.922829627990723

00:17:19.770 --> 00:17:50.340 So again you know cancer is a teachable moment for many people. It's kind of a time in your life as an adult where you're ready to make some changes and so I feel like if we can talk about that and try to help you meet your goals. That's what we're here to do, but oncologists in general don't get a lot of training and how to talk about healthy diet and exercise. And so we don't do a lot of that kind of talk and survivors don't really remember being counseled on it, so we need to.

NOTE Confidence: 0.917015552520752

00:17:50.340 --> 00:17:55.890 To sort of help make those messages easy for us to learn an easy for you to hear.

NOTE Confidence: 0.923716008663177

00:17:57.220 --> 00:18:15.360 Survivorship clinics are important because oncologists are not able to multiply fast enough to meet that demand in terms of the number of survivors so this is a really unhurried type of visit where you can get that kind of counseling rather than in like a general follow-up clinic.

NOTE Confidence: 0.906290411949158

00:18:16.870 --> 00:18:21.020 So, in the last minute, you know what are we doing next?

NOTE Confidence: 0.906130373477936

00:18:21.750 --> 00:18:56.500 Right now we have a study that's funded to start at diagnosis and we're instituting a healthy diet and exercise program to try to combat some of those negative affects before they ever start. So to maintain weight to help prevent side affects an to hopefully help chemotherapy be completed easier so that on the backside. There's not so many survivorship issues.



We also have um NCI funded study looking at resilience trajectories as patients transition from that.

NOTE Confidence: 0.898302853107452

00:18:56.500 --> 00:18:59.610 Acute Phase 2 extended phases.

NOTE Confidence: 0.91408109664917

00:19:00.530 --> 00:19:31.160 We I'm very proud to announce that our physical therapist has been hired full time as an oncology rehabilitation specialist so he is out there doing Prehab and trying to get people ready for their surgery. Once there, diagnosed and all the way to seeing patients. You know long term throughout their rehab needs and then like I said the survivorship echo that we're doing is a national program. We're also launching one lokoli to try to help our own providers.

NOTE Confidence: 0.909918546676636

00:19:31.160 --> 00:19:37.240 Get the messaging to patients and meet them where they are in the care centers and beyond.

NOTE Confidence: 0.92289400100708

00:19:38.700 --> 00:20:01.010 So, In conclusion survivorship is a huge umbrella and all survivors should have access to prevention management of latent long term effects and opportunities to maximize their health a tailored comprehensive approach is necessary and certainly one size does not fit all, so I will stop here, an I thank you so much for you.