

## Kessler Foundation Podcast Transcript: Cancer-Related Fatigue Part 2 of 5: Screening

Recorded August 2019. [Listen to it here.](#)

- LINDA SCHMIDT: 00:05 [music] You need objective data. Cancer-related fatigue is the most common side effect of cancer treatment. Being able to accurately screen will improve access to multi-disciplinary interventions.
- ANNOUNCER: 00:18 Welcome to the 2019 third annual cancer conference Beyond Rest, a rehabilitative approach to managing cancer-related fatigue. Sponsored by Kessler Institute for Rehabilitation and Kessler Foundation. Cancer-related fatigue is an issue that often develops during treatment and can last for months or even years. The conference podcasts will focus on the impact, screening, and management of the physical, physiological, emotional, and cognitive sequelae. Listeners will gain understanding of the various evidence-based therapeutic interventions and the overall benefits of a multi professional approach. Topics to be discussed will include current research and practice guidelines as well as the unique role that rehabilitation can play in managing and reducing signs of cancer-related fatigue. This presentation was recorded, produced, and edited by John Bank Smith, creative producer for Kessler Foundation, on Thursday, August 8th, 2019 at the Kessler Institute for Rehabilitation, West Orange campus, New Jersey. Be sure and check out the conference playlist to listen to all of the other session podcasts. The link to the playlist is in the show notes. In this session, nurse clinician Linda Schmidt, from the John Theurer Cancer Center at Hackensack University Medical Center presented screening for cancer-related fatigue.
- SCHMIDT: 01:49 I am truly honored to be here because we need your help in the oncology field and for our patients because they do need the rehab because this is a chronic disease and there are side effects of chemotherapy and just cancer in general that need, over time, the assistance and help. So I thank you for helping our group. I will say that the physical therapy for cancer therapy has been-- there's been some deficits in the community and I'm glad for the ReVital program because they really made a difference to our patients that we've been referring to your program. And I'm here to talk to you about the cancer-related fatigue screening and here we go. Cancer screening, you have to recognize the importance of screening for compliance, quality, and value-based care, recognize the role of multi-disciplinary team and screening for cancer-related fatigue, and identify the tools for the use of screening in fatigue and introduce clinical practice guidelines for screening. Fatigue is a subjective experience that should be systematically assessed using self-reporting in other sources of data. How do we measure and make evidence-based interventions if this is a subjective experience? We need objective data. Cancer-related fatigue is the most common side effect of cancer treatment. Being able to accurately screen will improve access to multi-disciplinary interventions.
- SCHMIDT: 03:47 This is my favorite slide. Okay. These are the most common symptoms of chronic cancer-related fatigue. We have stress, attention deficit, mental fatigue, nausea, short-term memory loss, physical pain, lack of concentration, and physical fatigue. Screening for the treatment of cancer-related fatigue during therapy and during the period of cancer survivorship has become a major focus for supportive care in oncology and is the subject of guidelines from several expert groups, including ASCO, The American Society of Clinical Oncologists, and the NCCN. We also have formal

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diagnostic criteria outlined as the ICD code 10 are not wide-spread used. But I use the ICD code R53.83, that's fatigue, quite often in my practice to help us get the referrals that we need to make you guys happen. Patients do not necessarily need to have a minimum number of criteria to receive a clinical diagnosis of cancer-related fatigue and their use is not recommended in guidelines for screening and assessment for cancer-related fatigue from expert groups, including the NCCN Network. So how do we screen? Patients should be screened for the presence of the severity of fatigue at their initial clinical visit at regular intervals during and following cancer treatment. And as clinically indicated, this should be happening every time you see the patient. That patient could be just walking down the hallway and your eyes have to be on.

SCHMIDT: 05:45

You look at them and say, "Are they walking straight? Are they walking in a chair? Are they holding on to the wall? Are they looking up, are they looking down? Can they walk heel toe?" These are things that we have to look at as soon as they walk in the door. In our practice, this is vital for us and says a lot. Let me see. There are the importance of-- the multi-disciplinary team is important for the importance of screening and it's every visit, every time. It's responsible for all providers using reliable and vital tools. When our patients come into our clinic, what happens is we get the vital signs downstairs from our-- in the John Theurer Cancer Center and they come up to us and we see just a vital sign of blood pressure, a heart rate, a respiratory rate, and a weight. And that's basically what we see and the CBC. So there we have some basic information and now we have to decide, "Okay. Has there been any changes?" So that's where it starts. But then again, it's when they come in the door. And what we looked at was-- here the NCCN guidelines have provided us a basic fatigue score. It's 0 to 10. How simple can you get than that? Okay? You have 0 is one, 1 through 3 is mild, 4 to 6 is moderated, and then severe is 7 to 10. I like easy because you need something that patients understand, that they are able to use to make sure that they are able to communicate what their fatigue level is.

SCHMIDT: 07:35

Now, I know the print is small, this is the NCCN guidelines that are available as a reference. It goes into how you screen for fatigue. I'm sorry the print is really small. So they will go into the most-- they're using the 1 through 10. So for children, it goes until 5 is you're tired or you're not tired, for 7 to 10 they use as a severity of one to five, not tired to worse. And for adults, 0 to 10. And there's an easy way-- what's good is when you look at this, you say, "Okay. You're validating that 1 to 10 is actually a good idea because when you have fatigue between 3 to 10, you have to start looking at primary evaluation." I know the physician prior to her talked about primary evaluation. And when we look over, when anyone is diagnosed with cancer, they're already tired. The actual diagnostic process of them being diagnosed with cancer has been exhausting, okay? The stress level is quite high. So when we look at the primary evaluation, look at the management of underlined conditions. They look at anemia, medical comorbidities but many times these patients don't realize that they're anemic and that they're tired because they're anemic. So they're already come in with comorbidities. So if you look at the primary evaluation as if they have no precipitating conditions identified, well, you can evaluate for energy conservation, psycho social support, exercise, sleep, pharmacological agents which are heard about in complementary medicine.

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SCHMIDT: 09:34

But what is concerning to us is that we do have to be able to manage it and there is recommendations for screening of assessment and management. And this is all about quality of life. All about quality of life. So if you look at energy conservation, I will be talking to you about how we look at what is the patient doing, how are they managing their medicines, when are they taking their medications, when is their fatigue happening. Is it in the morning, is it in the afternoon? Are they sleeping? Are they not sleeping? Can they exercise? Are they exercising? When are they exercising? And sleeping is another issue because many of our patients don't know when to sleep, how to sleep or is it their sleep restful, have they earned their sleep is really important for their quality of life. And that's what we are working on right now because since cancer is a chronic disease, people are living longer. In 1984, I lost a lot of young men to testicular cancer and now it's curable. And I still get-- I just got a Christmas card, last Christmas, to a gentleman I took care of in 1984 who's now a grandfather. So here we are, somebody who's living with cancer for decades now. Okay. So we now have the focus history. We have a disease status and treatment. Now, understand you have the patients that are being diagnosed, initial diagnosis, you also have them during their treatment, during their induction therapy, during their consolidated therapy, during their relapse therapy, and their chronic therapy.

S1: 11:35

It's not unusual for patients to have not just one line of therapy, to 15 lines of therapy over a course of five years, three years, 25 years. So we have to keep focused all the time on what is their disease status and their treatment plan. We have to do the review of their systems, in depth fatigue history, the onset, the pattern of duration, change over time, associated alleviating factors, impact on function, their social support and caregivers. Do they have one? Do they have a family member? Do they have a significant other? Do they have the support of a community? Are they a member of a support group? I'm also the medical liaison for the myeloma support group. Do they have somebody that can help them get through the treatment plan or during the course of the disease, whether it's initial diagnosis, in remission, out of remission, end of life? Also their economic status and their resources that they use for support. Money is a big issue. Medication. Lenalidomide is \$14,000 a month. So if you have somebody who's on this for 100 cycles, that's \$14,000 a month if they don't have insurance. But if they do have insurance, they have copay. So it puts a big burden on their family. So that would make me tired.

SCHMIDT: 13:15

We also assess treatable factors. We have medications and their side effects. The backbone for oncology care is steroids. Dexamethasone. Dexamethasone is a big-- causes steroid myopathy, the big muscles in their thighs and their butt. Okay. They have trouble getting up. They have trouble sitting. They have trouble standing. They get tired because they can't go up and down the stairs. So you have to find out, "How many stairs do you have? How many to get into your house? Where's your bedroom? Do we need to move your bedroom?" So steroid myopathy is a big issue. Other medication side effects, we have other toxins that can cause peripheral neuropathy that sometimes doesn't go away. So that's why we need people in the rehab department to help them adjust to the peripheral neuropathy. Can they button their buttons? Can they tie their shoes? We have to work on that. Do they have pain? What kind of pain do they have? But what I have noticed is that there's less narcotics being

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prescribed. We're using other agents to help with pain and discomfort. It's not like it used to be. There is a study that looked at narcotics utilizes the same pathway as cancer cells. So we're trying to just move away from the narcotics. So then you don't have those peaks and valleys with pain regimen. Emotional distress. We already talked about how difficult just being diagnosed with cancer can be.

SCHMIDT: 15:05

Anemia. Many patients are anemic. They usually come in as anemic or the chemotherapy is so mildly suppressive that they are anemic and they can't function during the day or they can't do the things that they want to do. There's sleep disturbances. When are they sleeping? Are they earning their sleep? When did they take their dexamethasone? Because we know that, for hours later, they're going to be awake. So if you take dexamethasone in the morning, you're going to be great. You're going to be fired-up. But what happens is come later on, you're going to crash. In our therapies that we use for multiple myeloma, we know that two days after they receive their steroid, they're going to crash. So we tell patients, "Please, use your exercise. Do your activities during your up time because know that you can potentially in bed, not able to do two to three days later." Nutritional status. That's also a big one as well. Are they eating well? We have nutritionists that look at weight. So we have height, we have weight, we have blood pressure, we have heart rate and we ask for the changes in the weights. "What is going on? Are you drinking your fluids? Are you getting enough energy to get through your day, to help battle the cancer so you'll be on the winning side?" Functional status, "Are you sitting in bed? Are you in your chair or recliner all day long? Can you take part in your daily activities? Can you go to the supermarket? When do you go to the supermarket?" One of the things that we do do is we tell our patients to, "Please, if you're going to go to the supermarket, go first thing in the morning. Wipe down the cart. Do your food shopping then so you're away from people because if you're anemic, most likely your white count is low as well. So you're more susceptible to infections and every flu virus out there is on a shopping cart."

S1: 17:04

"If you're going to go to the movies, make sure you go to the first showing. If you're going to go out to dinner, go on the first dinner of the day, okay? Be the first one and don't go to an all you can eat buffet because everyone is using those spoons, okay? Everybody. You just have to watch. If you go to Wegmans, look at them. Everybody is using the same spoon. So please protect yourself." And tell your patients to be mindful. And the comorbidities for cancer treatment, because of the steroids, we regularly predispose our patients to a diabetes and we have to watch our patients with their blood sugars and make sure that they're taking the meds that they should or they may have to double up on their antidiabetic medication on the days that they get dexamethasone. But also remind them, "Please watch your sugars two days later because you may be crashing." Some of the other tools that we use for cancer-related fatigue are unidimensional measures and multidimensional measures. So the tools that we use that are unidimensional are the height, the weight, just the nuts and the bolts before you see a patient. I see the multidimensional as the ones that you see like, "What do they look like? How are they feeling?" And this is all of these here. These are all the tools that the NCCN guidelines have reviewed. There's 14 commonly used tools that were reviewed by the NCCN using a Likert scale that's using like a one

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to five to agree, to disagree, most likely, yes, almost, that kind of thing. So there's 14 of these. I'm sorry.

SCHMIDT: 19:04

I'm missing my screen. Okay. So there's 14 of these and what this is actually saying is if you look at the number of items, you see 14 items, 20 items, are your patients going to answer those questions? When you look at them and say there's 20 questions, that's a lot. But the one that we do use is the NCCN problem list which is used as a thermometer. So it actually looks at-- I actually have a picture of it here. We use this at our cancer center and it's just basically a thermometer on a 1 to 10 of what your stress level is. And it goes over like, "Yes, no, childcare, housing, insurance, transportation, work, school, dealing with kids, are you having any of these problems?" And if you're greater than five, we either call the social worker, call the dietitian and say, "Okay. We've got a problem here," Call our transportation expert to make sure-- can you get here for your treatment? So this is one of the good tools that we use at the cancer center in addition to trying to establish the fatigue 1 to 10, which I think is a wonderful thing, okay? And also, the other tool that's not written here, we do clinical trials at the John Theurer Cancer Center if you're an NCCN member. Because we work at research, fatigue is considered a constitutional-- it's called constitutional guideline and they have three. There's only three. So we need to make things simple for our patients. And I think that's what I really wanted to just touch base with everyone is that is important to know that all these tools have been investigated but the best one is making it simple. Because once you start-- if somebody is tired and fatigued, they're not going to fill out a form that says 20 questions on it.

SCHMIDT: 21:05

You want something that's quick and that's easy to deal with. The other part of this is I want to just let you know the patients may not be aware that they are fatigued and that it's negatively affected their life. Family might be more cognizant of the change and of the effect fatigue has. I call the patient the president and I call their family member the chief of staff because sometimes the president doesn't tell you exactly what's going on, it's the chief of staff that does. Whether it's the rolling of the eyes, I'm feeling fine, I'm not tired, I feel well, this is something that you have to defer to family. There was a study done by one of my peers Stewart Goldberg and it looked at a-- it was just published in 2018. And it showed that there was a disparity between what the patient can do and what they wanted to do. So we need to close the gap of either saying, "Okay. Let's bring it up to what they want to do," or help them reconcile to what the new normal is. The way that I try to help our patients is I tell them to start journaling because we need to pin-point before we can make those referrals to physical therapy, occupational therapy, speech, dietary, we need to find out where these things are happening.

SCHMIDT: 22:49

And I had patients that go start journaling with the little black and white marble notebooks - they're on sale for 10 cents now during the school season - and I just say, "Where are you feeling fatigued? How are you feeling? When is it happening? What can we do to make a difference? Can we switch your meds to take it in the morning? Can we switch it to the afternoon? Can we switch it to the evening?" Some medications are better off taken at night. So if you have peripheral neuropathy and say that you're supposed to start on a medication called Elavil, okay? That's being

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given for a long time for neuropathy and people say to take it at night but they can't wake up until 11 o'clock in the morning. They're missing the whole morning. So they have to back up their meds, even though the prescription bottle says, "Take it at nighttime," you may have to switch it and tell them to change the time. But journaling is so important. I have somebody that's been doing journaling now for 20 years. So she can actually pull out a journal and say, "Well, I had this back then. And this worked for me last time. Can we try it again?" So that's why it's just important. So when you see people that are having problems pin-pointing where they are in their therapy or what they're feeling, have them just write it down. Okay. Barriers to screening. Screening is not systematic or effective in many practice settings for a variety of reasons. The patient family, they don't want to bother the clinicians. If somebody is saying to me that-- if they're looking at me and they're saying everything is fine and their body language is telling me is not, I really zone in on that, okay?

SCHMIDT: 24:40

They're worried about their treatment, maybe change because many times the patients are having symptoms, they don't want to say anything because they're going to think, "Well, you're going to delay my treatment." What we usually look at is when the treatment needs to be changed, it's usually because they're more anemic or they're not responding to their growth factor or we need to just alternate their therapy a bit. It's kind of tough because cancer is a chronic illness and they're on therapy for a very long time. Some people don't get off therapy but they just-- we just kind of tweak things along the way so they can live their lives the best that they can, so that they can enjoy their kids, enjoy their grandkids, so they can go on that trip or that wedding or that anniversary or that trip across the world or go on that Viking cruise that they want to go on. They don't want to look like they're complaining but if you're not complaining or there isn't any issues, then we might be missing the mark because we want to make things better. And they also assume they have to live with it. Well, living with something that we can tweak, why not? Let's make it a little bit better. And for clinicians, they may not recognize it as a problem for the patient. They may not be aware that there are effective treatments and that's part of my job, is to make their-- to give an awareness that there are things that we have to recognize so we can make patient's lives better. So we can refer them to programs like ReVital. So I'm getting feedback from my patients because I've been sending people. They say, "Hey, it's really working. I can do things that I couldn't do before."

SCHMIDT: 26:35

Well, in summary, cancer is a chronic disease. There's a disparity between what patients want to do and what they're able to do. We need to utilize a subjective NCCN fatigue scale, compare with each visit, and document the findings. That's just really important so we know did it make a difference? Because we need to make a difference. Ask questions, assess responses, develop interventions for every patient. Nobody's going to be the same but we can make things a little bit better. Document the findings. So evaluate findings and make changes, advise patients to journal patient symptoms. That's really important. Again, cancer is a chronic disease with fatigue affecting quality of life for patients and their families because we're living with these disease. We don't die of it, we live with it. And that's just basically it but thank you very much.

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- MICHAEL  
STUBBLEFIELD: 27:44 So the bad news is that enjoyed that and it's over. The good news is now you can ask questions for a couple of minutes if you don't mind. We have questions?
- SCHMIDT: 27:54 Yes.
- STUBBLEFIELD: 27:57 Hold on. Raise again. Way in the back, getting my steps in. Hello.
- AUDIENCE: 28:08 You were saying about the steroids, you were saying after four hours, that's when you're going to get the most amount of energy and then two to three days later there's a crash?
- SCHMIDT: 28:19 There's a crash. Yes. So depending on when you take your dexamethasone, for some people, we tell them that they're going to be the most awake for full four hours and that's usually when their energy kicks in and then they're awake. When they tell you you're awake, usually that's the time that they're most anxious, they have lots of energy. Any junk drawer you want to have done, it's going to be done. And that's usually when I tell patient's family members to duck and cover, to let them go, don't worry about it. If they want to straighten out the dishes, go ahead. We have patients that have actually done their TV kind of work or they're trial lawyers and they've scheduled their court dates on days that they get dexamethasone because they're on fire. But don't talk to them two days later, on Tuesday or whatever it is, when they're crashed out in bed because nobody knows that because they're in bed.
- STUBBLEFIELD: 29:24 And I would hazard a guess for those of us doing in-patient, rehab, or who are taking care of fatigue patients in the out-patient setting, helping them time their steroids can be useful. And the physicians and in-patient staff, don't assume they know anything about that. So now you know this little pearl. It's a good way to advise them.
- SCHMIDT: 29:43 And the other thing I did want to say was sometimes when patients go for physical therapy, there's only a certain number of visits and all of a sudden it ends. And then patients come to us and say, "Okay. We're done now. What do I do?" And I'm like, "Well, what did your physical therapist teach you? Let's go over the exercises with you." And they don't have-- usually, I tell patients, "Please, I don't want you to go-- I don't want home PT." Sorry for the people who are doing home PT, "I want you to get out of the house. I want you to get out of the house because it gets you new perspective. You're seeing new people. You're going to meet your physical therapist and I want you to go and do." But when it ends, that's many times when I tell patients, "Okay. Now it's time for you to go to the gym. Take what your physical therapist has taught you, go to a gym. Go first thing in the morning, wipe down the equipment, wipe down the equipment, and go forward into your physical therapy. And just make that as part of your regiment. And as soon as you have another deficit, it's okay. We can submit it to your insurance, they'll send you for another prescription." Because again, we're talking about people getting therapy now for-- chemotherapy for years. So you only have to get physical therapy once. You get it within a certain calendar of a year or I'm sure-- Tiffany is shaking her head. Yeah. You're only allowed certain amounts. So I'm like, "Okay. So now we can for the next time, all right?" In our division, there's three things that for our patients that are our biggest concern, is neuropathy, the risk for falls, and steroid myopathy of the big



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muscle groups. So it's just so important when you see that patient for the first time, look at them.

SCHMIDT: 31:37

How are they walking? Are they holding on to the wall? Are they walking like a duck? Are they walking heel toe? Do they have a pullover shirt? Do you ever see that they don't have buttons? Why don't they have a button? So those are things that I ask patients but I guess I'm kind of old in this business and I ask. So but it's my job and my privilege to have you guys come help our cancer patients because 50% of us are going to have somebody in our family that are going to have cancer. It's just the way it is. So we have to be more proactive and I thank you.

ANNOUNCER: 32:20

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