Podcast 50: Diabetes Distress

Dr. Rita Kalyani, MD: Welcome to Diabetes Deconstructed, a podcast for people interested in learning more about diabetes. I'm your host, Dr. Rita Kalyani, at Johns Hopkins. We developed this podcast as a companion to our patient guide to diabetes website. If you want a trusted and easy to understand resource for diabetes or to listen to previous podcasts, please visit hopkinsdiabetesinfo.org.

Today we are thrilled to welcome Katie Lacy, who will be talking with us about diabetes distress and burnout. Katie is a Registered Nurse RN) and Certified Diabetes Care and Education Specialist (CDCES) at the Johns Hopkins School of Medicine Division of Endocrinology, Diabetes and Metabolism. After earning a Bachelor of Science (BS) degree in psychology, she began working in the field of diabetes management in 2017 and graduated in 2022 from Johns Hopkins School of Nursing with a Master of Science in Nursing (MSN).

She's currently pursuing her Adult-Gerontological Primary Care Nurse Practitioner Doctorate at Johns Hopkins University School of Nursing, reflecting her commitment to expand her expertise and advance her practice. She currently practices in an outpatient clinical setting, focusing on education, optimization of diabetes technology, and promoting emotional wellbeing while navigating life with diabetes.

Welcome, Katie.

Katie Lacy, MSN, RN, CDCES: Thank you so much for having me.

RK: We are so thrilled to have you here to talk about this topic, which I think is so important to discuss, but probably is not addressed as much as it should be, and that is a topic of diabetes distress and diabetes burnout. Could you start off by telling us — What is diabetes distress and what is diabetes burnout?

KL: Diabetes distress refers to the emotional and psychosocial burden of living with and managing diabetes. It can involve feelings of stress, frustration, even fear. The fear could be related to, fear of complications or concern that maybe you will be judged in the medical setting based off what your diabetes looks like. It is really personalized to you, as to what is causing that stress in relation to your diagnosis.

Diabetes burnout is when you reach the state of exhaustion of either physical or emotional exhaustion from stress. You could feel powerless or hopeless to the point that you start to disengage from self-care activities. Maybe you miss appointments, start making unhealthy choices with eating or uncontrolled eating due to the state of exhaustion from the stress.

RK: Wow. It is a spectrum then between diabetes to stress, perhaps more common in people with diabetes to the point of diabetes burnout where there's exhaustion and it sounds like impairment in activities of daily living. How common is diabetes distress?

Does everyone with diabetes experience this?

KL: It is pretty common, but not everyone experiences diabetes distress. If you look at statistics, they can vary. For someone with type 1, it could be anywhere from 22 to 42%, and then if you have type 2 some statistics show that it's over 60%. So most likely while you are waiting for your appointment, somebody else in the waiting room has also experienced this type of stress. It is definitely something that I see in varying levels every day in practice. It does not always have a label to it. I think that it is something we as providers can do a better job acknowledging that we are asking you to do a lot of things that can contribute to stress.

For example, if we asked you to check your blood sugar before each meal, there are multiple steps:

1. You have to wash your hands or maybe you are using an alcohol pad.
2. You have to get a lancet or lancing device, the glucometer, test strip.
3. You have to make sure you line everything up in the right way.
4. Then you have to make a decision off of that number.

That is one thing that we are asking you to do, and we ask you to do it multiple times. Being stressed in relation to doing some of those tasks is perfectly reasonable. It is estimated that people with diabetes can spend upwards of four to five hours a day engaging in self-care activities. It is natural that it can be overwhelming. I think the numbers do not always reflect what everyone is experiencing, because we are not always screening for it. If we do not screen for it, you as a patient have to have the skill and the ability to say, this is a lot and this is stressful for me.

RK: That is a lot of time for someone to spend managing a chronic disease such as diabetes at home, four to five hours a day. You can see how it can place stress or additional burden on the person living with the disease. As you were talking, I heard you talk about things such as stress, and it almost seemed like feeling overwhelmed as well. Is diabetes distress an umbrella term for having those feelings or, is what we are talking about here, really that feeling of being stressed and overwhelmed with having a disease such as diabetes?

KL: It is specific to diabetes as a diagnosis. That feeling of stress and overwhelm is related to your diagnosis of diabetes, but it definitely encompasses varying levels. That is where we mentioned diabetes burnout — as that stress accumulates and maybe gets worse and is harder to manage, that is where you can see that burnout occur.

RK: It sounds like identifying diabetes distress is important to prevent it from eventually progressing to burnout. Is that right?

KL: Yes, I think it is a very important step because we can always get overwhelmed at times. I also think that knowledge is power. Looking at how you are managing your diabetes, there may be ways that we can make it easier for you, to prevent that accumulation of stress related to the disease.

RK: While we are talking about that, I wonder if you could go into a little bit more detail and how would someone know if they are having diabetes distress? How would a healthcare provider screen for it? Are there certain signs or symptoms or ways that an individual with diabetes could know if they are experiencing this?

KL: There are some validated scales that providers can use. One is called the Diabetes Distress Scale, and the Problem Areas In Diabetes (PAID) scale, and those both identify symptoms of diabetes as well as aiming to help identify what the root cause of the distress is. But it can also often be identified by reported symptoms. Some of these symptoms could be overwhelming thoughts about your food choices or worrying about having a low blood sugar. You might be disappointed that you are not getting the support from your provider or from your family members, and so those are some of the symptoms. You could also self-administer the scale online; it is available online for free. If you notice some of these symptoms or maybe there's a change to your normal routine and you're noticing high blood sugar, that could be an opportunity to step back and reflect if any of those emotions or experiences are applicable to how you're feeling.

RK: That is great to hear about the different scales that might be available, but also the different symptoms and signs that someone could be aware of. Are there certain time-points in a lifetime of having diabetes that someone is more likely to experience diabetes distress. Is it more common when people are diagnosed, when there is a major life event or change in regimen? Or it just occurs anytime. What would you say?

KL: You are exactly right. You are more likely to experience signs of diabetes distress at diagnosis, and at times where maybe you have had a change in your regimen — something is new or maybe you were taking, one pill a day and now we have asked you to add insulin. That creates a lot more steps and a lot more self-care tasks that we are asking you to engage in. Other times you may be more at risk for distress if you have had recent low blood sugar, as well as if you have any complications such as retinopathy or problems with your vision. A lack of family support can also be a risk factor that can contribute to more likely developing diabetes distress at that time.

RK: That is good to know, especially around times when we might have changes in therapeutic regimen, like you said, going from pills to insulin, for instance, or change in a support system that this could be a time when an individual could be more likely to experience distress. Just being aware of that and being educated about that seems like it is very important.

We talk a lot about these other psychosocial conditions associated with diabetes; depression and anxiety, which are also really important to identify, but we do not often talk about diabetes distress and burnout in that same conversation. Do you think we should be talking about it more? How are the conditions we are talking about today, distress and burnout, different from those medical conditions, anxiety and depression?

KL: I think that is a great question. First, yes, the symptoms can look similar between diabetes distress and depression or anxiety, some of the symptoms may overlap with diabetes distress. The emotional response varies. You may just experience one symptom, maybe lack of motivation towards diabetes tasks or fear of a complication versus depression and anxiety which have very specific criteria that need to be present for a certain period of time to meet a clinical diagnosis.

Now they can definitely coexist, you can have depression or anxiety as well as diabetes distress. Depending on what type of diabetes you have you can be anywhere from two to three times more likely to have a diagnosis of depression. I would say one, if you are not sure whether what you are experiencing is stress related to the illness specifically, or depression, that is when talking with your healthcare provider can be beneficial.

Then to the other question, yes, I think it is something that we should be screening for more and something that we should be having conversations with your patients. I personally like to start off my visits by asking, “What is your main goal for today? "and “What about diabetes right now is hard for you?” By asking those two questions, I think we get at what is making this stress build up and it helps us focus and identify what is important to you and what matters most.

RK: That is so important to hear what you are describing. I really like how you approach that to ask, “What is really troublesome for you right now?” or “What challenges are you encountering?” Do you find in your practice that individuals are hesitant to share the difficulties they are experiencing? Is this in any way, a reflection of the ability to cope with the disease or what do you tell your patients who may feel like “I should have this under check. Why don’t I have a better feel on this? Is this normal to experience?”

KL: Yes, it is normal to have these feelings, and I often encounter patients that do put self-blame on themselves. I think it is an important point to take a step back and say, you are not responsible for your diagnosis of diabetes. There is a huge genetic component when it comes to diabetes. You can have lifestyle factors to help manage your diabetes, but there is no moral failing, there is no lack of care. When you have a chronic illness we know that you want to feel good — no one wants to feel bad, no one wants to have complications, no one wants to have bad glucose numbers, so we definitely acknowledge that. I think that is something that we can do a better job, as providers, of reminding patients that it is not your fault that you have diabetes, and it is not your fault that it is not going well. There are so many things that can influence your blood sugar and not all of that is in our control. You can do the same thing day to day and one day have a great blood sugar number, and then the next day, your blood sugar decides to be high or it decides to be low. You know it is really about building those tools to address that.

RK: Well thanks so much for bringing that up because I think that aspect of self-blame can sometimes underlie the hesitation that individuals might feel before bringing forth challenges they are facing or obstacles that they see ahead. I think one of the time points where sometimes I see this in my practice is at the time when people need insulin. One of the things that we remind individuals is that this is a natural part of the progression of the disease. It doesn't reflect in any way that the management was not optimal or that there was anything that the person with diabetes did that led to this. But having to take injections is more a reflection of the natural history of the disease than a failure to manage it.

I think that in any chronic disease, particularly one such as diabetes, where there is such a large aspect of self-management. It is important to keep that in mind, so thank you for bringing that up.

Since we've talked about, different ways that diabetes distress can present and how people can identify whether they may be at risk or not? Once, once it is identified that someone may have diabetes distress or experiencing feelings that are consistent with distress or burnout, what can they do? What would you recommend and how effective are the approaches that you usually recommend to reduce distress?

KL: I think stress is managed by building resiliency and that resiliency is the ability to find strength and seek support. I tend to encourage patients to identify things that you're doing well. Maybe you never monitored your blood sugar before, now you're checking it once a week or twice a week and that in itself is a win. That is a strength and a sign of resiliency.

Focusing on those small wins is important because each win is going to help you manage your diabetes and feel better doing it. Different lifestyle factors like adequate sleep and nutrition, engaging in activities that you enjoy, such as yoga or music those can act as a buffer to stress and also build resiliency. I think another place to start is identifying what matters most to you as a person and as a person living with diabetes. Maybe one of your biggest hobbies is trying new restaurants or you want to play with your kids more. All of that is an important part of identifying what the next steps are in your management and what steps we need to take together as a team to accomplish that goal. It is important when we are creating those goals that they are unique to you and are realistically able to be achieved.

When I sit down with my patients, especially those who are going through stressful times, I like to use the acronym SMART (Specific, Measurable, Achievable, Relevant, and Time-bound). So, we work on SMART goals. We create something that is specific, something that we can measure so that we know that we are actually achieving it. Something that is attainable and something that is realistic, and then time bound. We will say, "In the next month, I want you to go from checking your blood sugar once a week to checking it twice a week," and I am not going to ask you to go from once a week to three times a day because that is not attainable, it is not realistic. Also, maybe that doesn't matter as much to you. I think that is a good way to approach the goals.

Once we have that goal, I ask you "How confident you are that you're going to make this change on a scale of one to ten," and if the number is low and you are not confident, that tells me that the goal is not right. We need to take a step back and then reevaluate what our goal is.

Then the last thing I would say in relation to that, is looking into connecting with diabetes education group classes or support groups. That can be either online or local, and the chances are you are going to find someone that has a similar struggle to you, or maybe they have been through that before, and they have a solution that has worked for them that may also work for you.

RK: Those sound like great resources and I like the idea of small steps celebrating small wins because over time those can become huge wins. And not only the resources in the healthcare team, but the support group that you mentioned, learning from others who are experiencing similar challenges and may in some ways be able to offer even more support because they are experiencing what you are going through as at the same time.

For the caregiver who has a loved one who is experiencing diabetes distress or burnout, I can imagine it could be challenging at times to know what is the best way to help alleviate the feelings or the distress that the person with diabetes is going through. What would you suggest that caregivers do or need to be educated about to best support the person living with diabetes who might be at risk for undergoing distress?

KL: I think the first thing is looking out for signs — is your loved one disengaging in some of the behaviors that they usually do to manage their diabetes? Such as, skipping medications, not checking their blood sugar, missing appointments. Then really having an open conversation and listening to your loved one to see if they are expressing that they are stressed. Or do they usually share information about their diabetes journey, or how you can help them, and then now they are taking a step back and not willing to share as much information. That may be related to some shame or guilt that comes from the diagnosis of diabetes.

The biggest thing that you can do as a caregiver is offering to listen. Offering support in the way that's important to your loved one. Asking a question about "How can I help you or will it be helpful if I do X?" You can start with an open-ended question and then you can move to something specific. If they identify that one of their stressors is ,for example, picking out what to eat for their blood sugar. Then offer, "Can I cook dinner?" or "Can I plan the meals for this week?" Allowing them to take a break from the diabetes relationship with food, maybe the relationship with counting carbohydrates, and allowing you to take some of that burden as a caregiver.

RK: I appreciate you going over that because I think that sometimes it could be hard not only as a healthcare professional, but as a caregiver to know how best to support the individual who is experiencing the distress. Having those questions and having those ways to relieve, temporarily, some of the burden during times where there might be more stress could be immensely helpful, in terms of health outcomes and also just self-management.

KL: I think a good reminder to someone that's trying to provide support is that support never has to be perfect. I think sometimes we get overwhelmed as a caregiver or as a provider saying, "I want to have the perfect answer." We do not always have to have the perfect answer or the perfect solution to help you. Just by being present and offering, you as a person, to help can really be encouraging and helpful to the person that is going through this stress.

RK: Katie, thank you so much for talking about something we know it needs to be talked about more and really bringing attention to the importance of being educated on diabetes distress, knowing the signs, knowing the symptoms, knowing the resources that are available, and knowing what can be done both from a healthcare team and a caregiver perspective to help alleviate the distress that an individual with diabetes may experience in order to prevent burnout and prevent impairment in the ability to self-manage the disease at home for people.

For people who may be experiencing these symptoms, but have not had anyone ever ask them about it or pay attention to it, what would you say to them in terms of how they can go about seeking further counseling or further treatment or support for diabetes distress?

KL: One thing I will say is the fact that you are actually listening to this podcast right now is a great sign. That is a sign of resiliency and that you are acknowledging that maybe you or someone that you love is going through this stress. I think first you have already taken a great step towards managing that. The next step with bringing it up with your healthcare provider, I think if you have a relationship with maybe the nurse, medical assistant or support staff it could be helpful to mention it at the beginning of your visit that this is something you want to discuss with the provider.

If you don't have that relationship with them when you go into your visit, I would suggest saying, at the beginning of the visit, "I do want to acknowledge that, I have been feeling overwhelmed and stressed lately. I think it might be related to how I am managing my diabetes." Or you can ask your provider if you can talk about some of the things about your diabetes that is frustrating — share specifics. Let them know that this is the most difficult part about diabetes — maybe it is not checking my blood sugar, but maybe it is actually coming to the appointments. It can also interfere with other things in your life. You could say, "I'm having a hard time concentrating at work, and I think it is because I am focused on, what to choose for lunch or how to take my medication."

Then ask directly for support or guidance. So "I would love to talk about ways to manage my stress around diabetes better. What resources do you recommend?" Then just to give you an idea of what resources are usually recommended — just because you have diabetes distress does not mean that you need to see a mental health professional. It is often managed through diabetes self-management training or DSMT. It has been shown to decrease diabetes related stress and improve quality of life. Another thing that has shown improvements in quality of life is using a continuous glucose monitor (CGM) because it takes away some 25 of the daily tasks that you have to do. If you do have a comorbid condition like depression, anxiety, or there's concern that maybe you need additional skills or services, you may get a referral to a mental health professional. But initially, usually management is going to start with the diabetes education.

RK: Thank you so much, Katie, for sharing all your great experience and expertise and for really bringing to light the aspects of diabetes distress and burnout that we should all pay attention to. This has been such an informative podcast and I'm sure our listeners have learned a lot as well. Thank you so much for being here.

KL: Thank you so much for having me. I appreciate it.

RK: I am Dr. Rita Kalyani, and you've been listening to Diabetes Deconstructed. We developed this podcast as a companion to our Patient Guide to Diabetes website. Our vision is to provide a trusted and reliable resource based on the latest evidence that people affected by diabetes can use to live healthier lives.

For more information, visit hopkinsdiabetesinfo.org.

We love to hear from our listeners. The email address is hopkinsdiabetesinfo@jhmi.edu.

Thanks for listening. Be well and see you next time.