

# Diabetes, Distress, and Depression

*[Announcer] This program is presented by the Centers for Disease Control and Prevention.*

[Alexis] Welcome everyone, on behalf of the National Diabetes Education Program to today's webinar. Today we're joined by Adeola Akindana who will be moderating a conversation with Dr. Larry Fisher. Adeola is a diabetes educator with the Joslin Diabetes Center in Maryland, and Dr. Fisher is with the Department of Family and Community Medicine and Psychiatry at the University of California, San Francisco. What they have decided to do today is have a conversation around the questions that you all submitted in advance of this webinar, to really touch on what seems to be the most pressing needs for people working in this area and trying to address this important topic. So without further ado, I'm going to turn it over to Adeola and Dr. Fisher. Thank you.

[Adeola Akindana] Thank you very much Alexis. Good afternoon everyone, my name is Adeola and it's a pleasure to present today with Dr. Fisher. So we hope we're going to learn a thing or two about how to better help our patients navigate with their disease. Some of the goals that we're going to cover today is to provide an overview of emotional health and chronic disease to understand the impact of diabetes on mental health and distress and depression on diabetes management, identify the signs and symptoms of distress and depression in patients with diabetes and discuss the role of the diabetes care provider in identification and treatment of the emotional health issues. Before we continue I just want you to know that we have quite a robust deck of slides. We might not go through every single one of them but Dr. Fisher has been gracious enough to provide that for your resource for later if you need to refer back to any information. We are going to try to make today's webinar as conversational as possible so that it's real practical examples that will be given to you. So today's conversation would include; what are distress and depression, when should you be concerned, what are the signs and symptoms of mental health issues, the relationship between diabetes management and emotional health and again like I said before, what is your role as a diabetes healthcare provider? So with no further ado I'm going to hand off to Dr. Fisher. Welcome Dr. Fisher and please talk to us a little bit about this information.

[Dr. Fisher] Well good morning. It might be good to begin by clarifying what we mean when we're talking about distress and depression, because these terms get bandied about a bit and it probably a good idea to kind of define them so that we're all kind of on the same page as we go through this. Let's start with depression because that's a word that's used in a lot of different contexts. There are basically two different definitions for the word depression. One of them is descriptive like, you know, "I saw my brother yesterday and he looked a little depressed to me." It's more descriptive, it has kind of a tone of how someone might be feeling at the time. And I think we use it colloquially quite easily and it's a commonly used term. But there's another use of the word depression and that is as a psychiatric diagnosis. It is really important to make a distinction between these two. For someone to be considered depressed clinically and the term we use is clinical depression or major depressive disorder, they must fit the criteria the DSM, that's the diagnosis and statistical manual, that's the bible for diagnosis. That individual must fit the statistical diagnosis for major depression disorder.

What is major depressive disorder? It's really important I think we understand what it is and what it isn't because we often apply to it things that really don't fit the diagnosis. So let's go through it very, very quickly. The diagnosis of major depressive disorder or clinical depression is really quite simple. It is achieving five—a minimum of five of nine symptoms and that is, if you go into the manual, they will list all of the symptoms down—we're pretty familiar you know, people are not sleeping, gaining weight, feeling hopeless, down, depressed and blue, these kinds of things. But they're very well defined. An individual, to receive that diagnosis, must have a minimum of five of these nine for a minimum of two weeks and they must be of sufficient severity to be of concern. That's it. That's the entire definition of major depressive disorder.

What's really important to understand about this definition is it's arguably one of the only diagnoses in the entire medical nomenclature that doesn't include a cause or a process. So like, for example, if we have a cold one day and we have all of the symptoms, you know, runny nose and eyes and feeling pretty lousy, we can pretty much conclude what that's about. It is probably caused by a virus that we picked up that worked in the body, led to the symptoms and probably four or five days the process will tell us that the body will overcome the virus and the symptoms will disappear and we'll feel fine. Notice that's really different from this diagnosis of major depressive disorder. Because major depressive disorder is only a bunch of symptoms, there is no implication for cause or context and that really gets problematic when we're working with patients with diabetes because that provides a context that's not brought into the picture when we're talking about true depressive disorder. So major depressive disorder as a friend once told me, it's almost like there is no there there, it is just a collection of symptoms that lasts for two weeks, that is the major diagnosis and the major definition for this diagnosis. It's a simple count of symptoms and if you look at it the more symptoms you have the more severe you experience it. So what we have with a definition of major depressive disorder is it is measure of severity of emotional distress. And that's really important to keep in mind. It's not a thing like a diagnosis of COPD or asthma or a diagnosis of cancer where there is a whole range of things going on and there's a cause and a process and an outcome. It's just a collection of symptoms. What's important to understand is that these symptoms emerged out of a history of clinical pathology and clinical diagnosis. And we'll draw a distinction between that and where diabetes distress came from because it is very, very different. So in any case, major depressive disorder is exclusively symptom based and it's unanchored, that is it has no context with respect to diabetes.

Okay, so let's switch now and talk a little bit about diabetes distress which comes from a totally different background. This one comes from a, an area of research, and stress and coping and emotional regulation. Totally different from major depressive disorder, and it reflects a much broader range of emotional experience than just clinical depression. In addition—and here's the crucial distinction. It focuses on specific situational context or sources of emotional distress. So if you look at the items in the scales that are used to assess diabetes distress, like [inaudible] or problem areas in diabetes or the diabetes distress scale, you'll see items that say "I am distressed about managing my diabetes" "I'm really feeling hopeless about controlling my weight" "The numbers coming from my meter about blood glucose really scare me" or "I'm really worried and concerned about the possibility of complications." These items suggest that diabetes distress has a situational context, and that context is diabetes.

So if we put all of this together we can see that major depressive disorder focuses almost exclusively with the severity of emotional distress. Whereas diabetes distress focuses almost exclusively with the source of the distress—of emotional distress. And basically what we need to do, as clinicians working with patients with diabetes, is it seems to me, we've got to pay attention to both. Severity without source makes little clinical sense, and source without severity, likewise, makes little clinical sense. We really need both of these together to be able to work with patients struggling with the emotional distress associated with diabetes.

[Adeola Akindana] Dr. Fisher when you finish that sentence I really do want to ask you then an important question related to what you are explaining

[Dr. Fisher] Sure, go ahead.

[Adeola Akindana] So, based on what you're telling us, I hear that a lot of times patients and those depression items when they are filling out their forms based on stressful diabetes experiences and you reported that has been a contamination—not able to identify really between them being in distress versus them having true depression. So someone wrote here that while seeing patients I first got the hint that a diabetes specific emotional state exists. So this is new information for many of us. We were really struck by the number of folks reporting high level of stress and depressive symptoms who weren't even close to reaching major depressive disorder. If patients weren't clinically depressive then what were they dealing with? The answer was that they were experiencing unique emotional issues directly related to the burden or worries of living with a chronic disease, which is somewhere where you were going. So help us understand how we could really identify and make a demarcation, even though you did talk about the nine symptoms, but make a demarcation during those visits to be able to pick up very quickly the importance of that emotional well-being for that patient and how it affects them in terms of managing their diabetes and improve their clinical outcomes.

[Dr. Fisher] Wow, that's a long question. That's a complicated question. Let me provide a little framework for doing that. because that's a question that comes up all the time, because every—let's put it this way – almost every patient I have worked with who has diabetes exhibits some level of distress and concern around their diabetes. It's kind of like expected; you'd expect this to happen. And so it's ubiquitous in diabetes, folks are worried about this disease and it's appropriate they are. It's almost expected that they would. And that's an important distinction to make with psychopathology and that's why I want to really make it very clear.

Diabetes distress is something that goes along with diabetes. Psychopathology does not necessarily go along with diabetes. That is an important distinction. If we put both of these dimensions together, the source of distress and the severity of distress, we come up with a simple little matrix and, if we'll switch over to that slide that's at the end, I think it was in the original one, number 23. Is that little matrix there? Did someone move that along? That's it, number 24, okay, that's good. Okay, on the top you see the severity of emotional distress where you go all the way out to the end and that's severe major depressive disorder. And on the left hand side you see the sources of distress. And I really think this is getting closer to your question Adeola. There are three general sources of distress for folks with diabetes. The first is diabetes, all of the

worries and concerns around this disorder as we've spoken about. The other—you know people with diabetes also have other life stressors, it's not just diabetes. You know they may have economic problems, problems at home, they have financial problems, all kinds of things so you have that whole bucket of stressors. And then there are other factors people have like they may have problems with alcoholism or substance use. They may have problems with anger control. These are the more long term kind of problems that people have.

So when working—and this is where we'll narrow down to your question. When working with a patient or meeting a patient clinically with diabetes, we really have two tasks. The first is to assess the level of emotional distress they're experiencing across the top as you see, little or none, all the way up to severe. And the second we have is to identify the source of distress. Is it diabetes related? Much of it will be but it doesn't have to be exclusively. If not, what else is going on in their lives that would lead to a level of emotional distress? And the—it's really important to try to identify with the patient what's going on with them because, as you know, other life stressors can really influence how one manages their diabetes. You know if they're undergoing, if they've just been laid off from work and finances are a real problem, it is not the greatest time to start a diet with these patients. So the question is how now do you assess this? How do you determine, one, what the level is and what the source is. And I think that's actually pretty easy to do. It's simply having a conversation. "What's been going on in your life? How are things going?" And they'll begin to tell you if there is trust and a good interaction going on about well this is going on and that's going on and during the course of this, some of the things we can do is to begin labeling some of the feelings they may be having. "It sounds like you have been feeling upset about this or this is really stressing you out, is that true and how strong—what's the level of distress you're feeling right now about that?" Is it strong, is it heavy, is—and doing it in a very culturally appropriate way, doing it in a gender appropriate way and doing it in an age related appropriate way can really engage a patient and have them begin telling you more and more, without opening up a Pandora's box, but telling you more and more about what their level and source of emotional distress is. Is that kind of the question you were asking?

[Adeola Akindana] Yes, very much so. Thank you very much. So what I'm understanding that you're saying is, for us as educators and providers, we need to assess the level of emotional distress and also identify the cause of the distress. And this again happens from asking the appropriate questions.

One of the follow-up questions I have here is, "how do you we understand what is going on with the patient, from the patients' point of view?" I think that is really related and I could talk about that a little bit. As the educator is you have to meet the patient where they are and understand what is their problem, if it's understanding the instructions that has been given to them or is it the financial issue, as mentioned by Dr. Fisher, that is standing in the way of them being able to follow instructions, that or even by their medications and different things like that. If that is not the issue then we need to kind of dig a little bit deeper and what I would ask Dr. Fisher is, where will be it appropriate to maybe refer the patient for maybe an additional evaluation to really understand if the issue is just distress from the diabetes, or if this patient is experiencing depression.

[Dr. Fisher] Again, that's a really good question. Before I get into it, I want to ask you one, because you brought up a really good point and that is you were saying that you really need to dig a little bit and engage in a conversation with the patient. And you and I both see a lot of patients so we've got some experience, but I was really curious, from your point of view Adeola, what kinds of things do you think occur among clinicians that make it difficult for them to engage in that kind of a conversation with a patient?

[Adeola Akindana] From working with my peers and from my own personal experience, I think sometimes we need to remove ourselves and don't just look at the situation in front of us from our own lens, but rather look from the patient's perspective. Recently I had a patient—he's actually not a patient in my clinic but he did walk into my clinic asking for help and so we were asking him why didn't he go to his primary care provider and he said "Well I was just driving by and I saw the clinic. I usually come to this hospital so I said I should stop in." So the further we dug in, the short of the story was, he felt really sick to the point where we felt compelled that we should take him across the street to the emergency room. So on our way there I said to him "How have you been managing your diabetes?" He says, "I've been doing well." "Do you check your blood sugar?" You know, the normal spiel. "Do you take your medications?" "Did you eat?" And things like that. And the more he answered the question I was a little bit perplexed and I said to him "So what changed? What changed in your situation? How is it all of a sudden that you don't have a grasp on managing your diabetes on a day to day basis when it appears that you've been doing that?" And his response was that his whole family had left him. He had some kind of family issue, and he's in the house by himself, but he needs to move out, and he hadn't eaten. So he actually took his insulin that morning but didn't eat anything. He said "Well, I ate a slice of bread and that was it." So, when I got to the ER, that was the first thing that I told him that basically he might be having hypoglycemia and definitely he is hungry. I mean, it sounds so simple but we really—I mean for me at that point my first instinct was not to judge him that he wasn't doing what he was supposed to do. But let him tell me what was different, what changed in his situation and all of a sudden he has this sense of desperation that he was losing control.

[Dr. Fisher] Yes, that's a beautiful illustration of how setting aside all of our lenses and just having a normal conversation with another human being really brings out what's going on and helps us kind of channel what the best route for handling it is. You know one of the things you mentioned which I didn't—and I didn't think of mentioning it until you just said that – was many of the symptoms of clinical depression are diabetes related. If you think about someone with very low blood sugar or very high blood sugar, they are often irritable, they're moody, they don't feel well, they don't sleep well. Those are some of the symptoms of depression so you get this kind of merging of symptoms where it's hard to tease out what's going on. And what you did was just a wonderful illustration of saying, "Okay, let's set aside some of this and let's just find out what's going on with this person". And all of a sudden you know you begin to realize, oh my god, this person hasn't eaten, he's in a really difficult situation. Now it kind of makes sense why this guy is feeling the way he's feeling, and it helps to direct what you needed to do clinically. And I think that's a great example and that's what I'm arguing for here, so to speak, assessing the severity, which you did and assessing the source or where this stuff is coming from in a very humane and patient-centered way.

[Adeola Akindana] Thank you very much. Okay so another good question here says, “What are appropriate intervention and support for these patients?”

[Dr. Fisher] For the patient we were talking about just now or—

[Adeola Akindana] Maybe not this particular patient but patients in general with diabetes—you know that are experiencing distress.

[Dr. Fisher] Okay, really good question and I’ll preface my comment by saying it’s a bias. It’s my view, I think there is good data to support it, but I know lots of other people who may see things differently. So with that said, I would suggest that having some level of diabetes distress is almost ubiquitous among folks with diabetes. In a study we just completed—it hasn’t been published yet, it is actually in review now – we assessed 400 adults with Type 1 diabetes, and the level of moderate to high distress was over 40 percent and if you drop it down into other slightly lower levels you are up to 60 and 65 percent. In a study we did about five years ago with Type 2 adults, and these were a mixture here in the Bay Area of folks from different backgrounds, the rates of high, very high diabetes distress, 25 percent. And if you drop that down into somewhat lower levels, the kind you would see in general clinical settings, you are over 50 percent. So it’s probably safe to say that you know, at some point along a diabetes career, you know most folks with diabetes are going to be feeling pretty distressed and it’s kind of like underlying a lot of what we see. So the question is how should we deal with it? What kinds of programs should we have clinically? How should it be addressed if it’s this ubiquitous; how should we think about it?

So here’s what I would suggest. I suggest there are basically three levels of intervention. The first is that dealing with the emotional side of diabetes should be included in all aspects of clinical care, from education to you name it. Everything we do, there should be an emotional component, and by that I’m simply meaning to bring how one feels into the picture. So for starting someone on a new medication, you know we might anticipate how someone is feeling by saying “Gee, I wonder whether you’re feeling like you failed in the past because we’re now starting a new medication” or starting insulin for example or the fears around complications, just bringing this stuff up and making it public. The reasons that’s useful it provides labels for the feeling in a culturally appropriate way, and it helps people anticipate that they might feel some this or that later on and, if they do, it’s normalized so it takes the feeling out of the context of being something bad and unexpected into the expected and part of the process of having this chronic, very demanding disease. So the first level of care, in my view, we should be looking at individuals blood glucose numbers and looking at individuals feelings at the same time, for everybody, broaden clinical care, generally and throughout education.

Now, for some people, the second level of intervention you know around critical areas we’re going to see spikes in distress. As I said, starting new medications, emergence of a complication, you know something is going on with the disease. In those situations within the clinical care setting we need to bring it up and deal with it directly. I don’t think—since this is a normal reaction to a chronic disease we need to be considering, at this level at least, referral. We should be able to handle it internally. Doing so I think really is helpful for patients. They don’t feel like this is something unusual or crazy or wrong, and they have to be referred out, away from their

care program. They trust people that they are seeing regularly on an ongoing basis so there is no kind of—there is no pause while they reestablish a new relationship. It's kind of all part of the same context.

The third level of care is when that severity level really increases dramatically and begins to approach or does approach the criteria for major depressive disorder or a similar diagnosis and then, depending on the clinic, where some clinics have you know, mental health professionals internally, some you have to make referrals and then to initiate that process if indeed you've reached that level of severity. So the three levels in some—incorporated into all aspects of care is part of education and treatment. When it increases around expected diabetes events, deal with it internally and not make referrals. Deal with it as part of the regular care process which is it, and then, if it does pop way up into the domain of major depressive disorder or something similar, then specialty care might be an appropriate way to go.

[Adeola Akindana] We have a couple of questions that have come in from the audience related to this. One is, "How can this apply or does it apply in a group education setting and related to that, what do you think is the role of the community health worker?"

[Dr. Fisher] Well let's go to the first one. Group settings are absolutely wonderful because they normalize the feelings. So many of these patients won't even—first of all, many patients don't even have the language to describe what they're feeling. And, if they did, they may be very embarrassed and uncomfortable to bring it up because a lot of folks feel they are the only people that ever felt this way. So, in a group setting, bringing this up, normalizing, providing words to describe it in a culturally appropriate way—and that is going to vary from culture to culture, gender to gender and also by age interestingly. Older folks may use different language than younger folks but being in a group setting is a wonderful place. I think a lot of folks on the clinical side are afraid to bring this stuff up because they are afraid to—it's going to open up a Pandora's Box that they won't be able to close. And I think that's—you know I can understand them feeling that way but I don't think that's a good reason for avoiding it. I think it often underlies so much of what we do and just mentioning it and bringing it into context could be very helpful clinically. So group settings, ideal places for doing this.

Regarding the community health worker, absolutely. Part of the dialogue with the patient is, you know, "are you eating well, do you have your medications, how have you been feeling?" Those are the kinds of—you can bring this up "looks like you are upset today" "it looks like you're doing well, you're smiling a lot, I'm glad to see you're—you seem to be pretty good today, tell me about it." Bringing the emotional side of diabetes into the same discussions we have with patients around all of the other aspects of care.

[Adeola Akindana] Thank you, Dr. Fisher, and I have to piggyback on exactly what you said in terms of the emotions and addressing those emotions and before you answered that question you said something that was really very important and kind of strike a chord with me. You said looking at the individual blood glucose and also addressing the patient's feelings. And even though we are in a public forum, I also have Type 2 diabetes and not too long ago I was trying to learn how to use a new CGM, which is a continuous glucose monitoring device. So I had it on

for about six days and of course I could see my readings and how my body was reacting to the meals and different choices that I was making, and even, though I did know better, it was very distressful for me just to see the response from my blood sugars, from whatever it is the choice that the thing I chose to eat and things like that and I had to come back to my office and talk to my colleagues about that. So it is important, as health providers, that we address those issues and, again, from personal experience I would say paying attention to what is not said as much as what the patients do tell you. A lot of times they are either quiet, they appear thoughtful or distant and just as Dr. Fisher had said, maybe they are finding it difficult to express. They might be ashamed, number one, that they are disappointing us, or don't even know how to put whatever they are feeling into words. So one of the questions I would ask based on you talking about different cultural groups and the need to address emotional well-being, how do we then address the stigma that is associated with you know emotional distress. So if people come from a culture where they are not open to talk about it, you have done some research with different groups, how do you kind of address those, or what advice do you have for us to address the stigma so that we begin to break down some of these barriers and be able to have a candid dialogue with our patients.

[Dr. Fisher] Yeah, that's another good—boy you're raising good questions today. That's another beautiful question, and that's why I like the idea of diabetes distress because it doesn't imply pathology. Having diabetes distress is part of having diabetes. They go together. It's not something that—that only a few people have and when they have it it's—it's "bad" or it indicates a weakness in them or it indicates some kind of pathological process. It's part of the spectrum of having diabetes and, if it's cast in that way, we kind of give permission for people to begin to verbalize it and to acknowledge it. And if we acknowledge it as a part of the spectrum then they will. If we see it as normal, then they will as well.

So, for example, your example with CGM, I've actually worked with a couple of the CGM makers and have urged them to put in their materials that they—that patients who first use this device will most likely feel very distressed and upset when they see the variability in blood glucose levels and feel like they are totally overwhelmed with all these numbers, because there's a sense of them not being able to control their disease when you look at this incredible volume of data coming out. That's not—wasn't even considered when they issued these new devices and wrote all of these instructions and pamphlets and what not for patients. I urged them, "How about dealing with the emotional side of this, because that's what happens when they come in?" When folks come in trying a CGM for the first time they (nine out of ten) report exactly what you did. Why can't we anticipate this beforehand so the patients say "Oh my god you were right, I am distressed, and I can see why?" It's almost normal, "They told me I would feel this way." It takes the tinge off. And it takes the—it takes the stigma off as well and I think that's really a crucial thing. Group settings, by the way, are very good for doing that. And comments you can make with your patients, "You know, if I were in your shoes, I think I would feel exactly the same way" or "I was in your shoes a little bit ago, and I did feel exactly like that." Or "The last four patients I saw told me exactly the same thing you're telling me." "You know, it's part of having diabetes. I can understand why you feel this way."

[Adeola Akindana] We're getting a lot of questions from the audience. On a sort of practical note is "How would a clinic—as we're thinking in terms of treating distress – how do you bill for



that? Is there a DSM diagnosis that could be used, is that an appropriate way to go in order to provide therapeutic services?”

[Dr. Fisher] Well I don't think we need to provide therapeutic services, billed separately or documented separately for distress. If it's part of diabetes, it's part of the care we need to deliver. Now, if the severity goes so far up that we need specialty care, then the—the billing and the referral kind of arrangements can be made. What I'm arguing for is—is this is not an added burden to us clinicians in dealing with the emotional side of diabetes. It's part of the care we deliver generally to folks with diabetes. And that's a very different perspective and some people may argue and say “No, that's not our role,” but I think it is our role. I think our role really does include dealing with the whole person, not just with blood glucose levels.

[Adeola Akindana] So, related to that, another question came in regarding this idea about referral to mental health professionals and the suggestion that you wait until it escalates. Is that what you're suggesting that you wait until it is severe or at what point do you say “Okay, now we need to refer this patient on to a mental health professional” especially if it is someone who could intervene and prevent symptoms from progressing to a more severe state?

[Dr. Fisher] Well again, that's a good question. It's going to vary from practice to practice and from patient to patient. I am not saying don't do anything until it goes all the way up and, you know, it—just wait until it escalates and then make a referral. What I am saying is we should be dealing with the emotional side of diabetes throughout diabetes care. For some people, it will increase and, at that point, you know, if we can predict who's going to demonstrate, you know, in one year a high level of severity, that would be wonderful. I don't think we can do that very well. But, if we introduce the emotional side of diabetes into general diabetes care, looks at the preventive aspects right there. We're helping people anticipate it. We're helping people verbalize it before it gets too high. We're helping people understand that's part of the whole construct of diabetes, the whole broad syndrome of diabetes. It's to be expected. Yes, some—a small number—a relatively small number will reach criteria that need to be—that indicate a referral is required and obviously those individuals, if we didn't kind of predict that beforehand, that's great or when they do, we should be referring them into some kind of special program. But we're talking here (if we look at the prevalence statistics nationally) we're talking about relatively small numbers who really should be referred. Relatively few patients really get so far up that they do need specialty care and the prevalence levels are probably for Type 2 diabetes nationally, they're probably between 10 and 15 percent. Now that's not to say that only 10 to 15 percent are—are—need to be referred, that's to say—or let me put it another way. That doesn't say the 10 to 15 percent aren't distressed. A lot more are. Many more are and those are the folks we can deal with in regular clinical care. The 10 to 15 percent probably will require some kind of referral or some kind of integrated care in which there is a behavioral specialist integrated with the diabetes care team. But I think I'm emphasizing the preventive aspects, the normalization process and the—the ability of us as clinicians to call attention to the emotional side of diabetes with not only among patients but among staff members as well, so it's integrated fully into care.

[Adeola Akindana] Thank you. I have another question for you. And that is, “How does diabetes distress affect the compliance with therapy?” And another question that was submitted actually

said, “How do we help patients achieve self-efficacy?” I really think that is one of the things that you are driving on. So, based on your practice and what you have seen, how do we begin to move patients into that role for self-efficacy and again, like I said, how would you think this affects the compliance with therapy?

[Dr. Fisher] Well there’s some very good data out there on that second question, and it’s very interesting. We’ve done a lot of this ourselves, but there are several other laboratories around the world that have really looked at this closely. There is a significant and clinically meaningful association between level of diabetes distress and both glycemic control and disease management. By disease management, I’m talking about medication adherence, diet and exercise. Significantly associated. There is no significant association between clinical depression, glycemic control and disease management, and that really knocks people off. They say “Wait a minute, I always thought depression was heavily linked to this.” Well, actually it isn’t, it’s the diabetes distress portion of the emotional distress I was talking about earlier. So the focus really needs to be on the distress associated with management.

The second part is how do you increase self-efficacy? Well very often, what happens in the sequence of things is that, when people are really burned out with their diabetes, upset about things in general, they don’t manage well and that’s – any clinician knows that from the very beginning. You see that constantly. Very often patients don’t draw that association. They don’t realize that how they feel affects what they do. And let me say that again, that’s really important. How you feel drives what you do. If you’re feeling, you know, just think about getting up in the morning and going for—doing some exercise, going for a walk or swim or whatever you do and if you do it in the morning, you wake up and you are really exhausted, and you’ve had a bad day the day before and you’ve had it you know, getting yourself out of bed to get going is really hard. Okay? Very simple linkage. That plays out with diabetes as well. If you are feeling powerless in controlling your diabetes, and you are beginning to feel “What’s the use” you know “I’m just not getting anywhere,” well you’re not going to do as much as you might otherwise. But that linkage isn’t often clearly established in people’s minds. So one of the things we can do to enhance self-efficacy and there’s—there’s a couple of programs now that have begun to show this and we are actually launching this (a program with Type 1 adults) to actually see whether—to test whether or not this really will have a—a major clinical effect is to help people understand just that, that how they feel and what they believe about diabetes really strongly affects what they do. If they become more aware of how their feelings affect their behavior, then you have a kind of medium around which you can begin to work. Otherwise it’s this hidden stuff about diabetes. It’s this hidden set of feelings that nobody pays attention to, including the patient and it’s like having them deal with managing their diabetes with one arm tied behind their back. Because they are not addressing one of the primary motivators that deal with self-efficacy and with actual behavior.

[Adeola Akindana] Thank you very much. I have a follow-up question to that and actually I do sometimes have a label and I think some of us are familiar with that name—you know calling family members the “diabetes police,” and sometimes patients are very overwhelmed with their family. But then you have some patients that don’t have family support in terms of them trying to change their lifestyle or live a healthier lifestyle and change behavior in order to promote the self-efficacy that we were talking about earlier. How do we begin to guide our patients if they

either have the overly protective family member or friend or co-worker or those who just want the same status quo, I mean for example, I had a patient one time who had lost a lot of weight and she was telling me in the class that her family member were actually asking her if she was sick or does she have HIV because she lost all that weight. So when you have the extreme of both sides where they are either not supportive of the changes you are trying to make, or they are overly protective, how do we help them navigate that system because they still have to live within that community or their family environment.

[Dr. Fisher] Yes, I can understand that. That's a really good issue. It's incredibly complex stuff, and you can expand that culturally. For some cultures, if you don't eat this food or that food, people think there is something wrong with you, because it's such a staple of the diet, and it's loaded with carbohydrates. But you know—so the good care for diabetes emerges in direct conflict with cultural norms, let alone family expectations. It's really complicated business. I don't know whether there is a set thing one should "do" or "not do," but I think having a conversation about it so it's very clear and possibly even bringing family members in. Community health workers can be very, very helpful in this regard. Many family members are not educated about what diabetes is about, they have no idea and many patients don't want their family members educated because they don't want to be intruded upon or what they feel to be intruded upon. And bringing family members into the picture can be very, very helpful. We tried a couple of pilot programs where we would only accept a patient in for diabetes education if they brought at least one significant other into the program within them. That was not only for support but to provide some educational experience for other members of their community. Will that work for every patient? Probably not, but it's something where it may have to go patient to patient. But looking at diabetes within the context in which it is cared for, which is family or community setting, is absolutely crucial, absolutely crucial, and it's a very difficult thing to do well and it can't be done uniformly for everybody. It's got to be kind of patient specific. Group programs are useful. Family group programs are very helpful. There's lots of ways of doing it. It's very hard and sometimes very expensive to do.

[Alexis] We've had some questions about—what about patients who may be reluctant to talk about their feelings? Or if you have some ideas about resources such as online resources or resources where—there are a lot resource questions, resources for veterans, you know. What are some of the things—resources that are available that—to help people who are trying to address this in their practices?

[Dr. Fisher] Well I think you've developed a whole bunch of them.

[Alexis] We've developed some.

[Dr. Fisher] Yeah, I mean I—I've looked through many of them and they are really quite excellent. The ADA has stuff. The juvenile research foundation diabetes research foundation has a whole bunch of stuff on their website. There are a bunch of things online. In fact—and some of the group—the websites out there, where they have chat rooms and there group activities and there are notices and what not, really do attend to these issues and do it well and I think it's emerging more and more. Lots of folks are going online to establish a diabetes community, and I

think that's really important. You know another notion—the group—I think it's called diabetes sisters, is absolutely wonderful. It's just a great group of people get together regularly or get—or have resources online to kind of make public some of these issues and to suggest things. “I handle it this way” or “this happened to me in a very personal way.” All of these things are really very helpful. There's a bunch of stuff out there. I couldn't label many more specifically than that.

[Alexis] And our—the resource we have in New Beginnings tries to address issues related to people not wanting to talk about their—their—their feelings by using stories. So people can talk about the person in the story without having to talk about themselves. It's one of the main reasons we use stories, because it gets people to open up.

[Dr. Fisher] Yeah, it's a very good way of doing it. You know for lots of folks who don't want to, or feel ashamed or embarrassed or just don't have the skills to do it, that doesn't mean they can't listen to other people and profit from it. And that can come from small group programs. It can come from just discussions with a clinician. These things can be extraordinarily helpful. It breaks the ice.

[Adeola Akindana] One of the things that I might add as well is support groups. I believe we all know that that is an important part of ongoing in diabetes management. Even though I facilitate it every other month here I always like to attend and it's just interesting what you will learn from patients and they will learn a lot from each other. And I think Dr. Fisher has kind of eluded to that, that a lot of times they have emotions they are not able to articulate and so being in a support group setting, and you have people who are struggling or people who have you know overcome a lot of barriers and they are sharing their personal experience, I think that also helps to break down some of the stigma and for them to begin to talk more openly about the distresses that are associated with having diabetes and dealing with it on a day to day basis.

As we are winding down, Dr. Fisher, please can you just give us some takeaway message. What I have learned so far listening to you is that diabetes distress is far more common than depression, and our role as healthcare providers is to hone in on what is going on with that patient to really find out—it may be something as simple as their family or even just having a stressful job where they are not able to take lunch breaks or you know—I've heard it all in my practice where they are not allowed to even take their meter into work and things like that. So what is the takeaway message as to how we could continue to move our patient along so that they can have a very positive outcome with diabetes and be able to deal with this diabetes distress that would help us is – what I'm understanding because you said – it is expected and it is common. So they are going to have those moments but the takeaway and how to help them deal with is on a day to day and a regular basis and our role in that.

[Dr. Fisher] Yeah, it's really important. And I think generally speaking our role is to help patients identify, label and anticipate beforehand how they are going to feel and if we can do that then feelings become part of the disease, not something outside it. It becomes part of living and managing and struggling with a very difficult thing. That's the kind of take home message – anticipate, label and verbalize and normalize all of those feelings.

[Adeola Akindana] Thank you very much. So I'm going to pass it over to Alexis, I know you tried to talk a little bit about some of NDEP's products, the New Beginnings. Maybe you could let the listeners know how they could obtain a copy of that for their practice and end use and whatever other resources that we have to help them you know with their patient care.

[Alexis] You can also visit our website, [yourdiabetesinfo.org](http://yourdiabetesinfo.org) to visit our Diabetes Health Sense page for more resources that are available to you. There are so many questions and we haven't been able to get all of them, but we are recording the ones that we haven't been able to get to, and we're going to look at the best way we can start to address these either a follow-up webinar or a podcast or some fact sheets because these are really great questions and they are questions related to the role of social workers and motivational interviewing and resources for how to address grief and how you address underserved populations and populations with different cultural backgrounds. So I'm going to leave the last word for Dr. Fisher.

[Dr. Fisher] The last word, thank you for your interest in this part of managing diabetes. It's just wonderful to see the response that people are interested and concerned in this part of care. It's been neglected in the past and I'm just really pleased and excited to see so many people interested in—in dealing with this in a very overt and straightforward way, so thanks very much for joining us.

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