

Transcript Details

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Improving Diabetes Care with Positive Experience & Peer Support

Dr. Anderson:

In the United States alone, an estimated 34.2 million patients live with diabetes. Current treatment strategies for these patients focus on behavioral and clinical targets alone, but can incorporating shared positive experiences and peer support lead to improved care?

Welcome to *Diabetes Discourse* on ReachMD. I'm Dr. John Anderson and joining me today to share her recent study on positive experiences for patients living with type 1 or type 2 diabetes is Dr. Elizabeth Beverly, an Associate Professor in the Department of Family Medicine at the Ohio University Heritage College of Osteopathic Medicine.

Dr. Beverly, thanks for being here today.

Dr. Beverly:

Thank you so much for having me.

Dr. Anderson:

Just to start us off, Dr. Beverly, can you tell us about your background and how you became interested in diabetes management?

Dr. Beverly:

My path to finding diabetes as a career choice took a little bit an unexpected turn. So I actually went to graduate school at Penn State, planning to study cognitive aging, and I wanted to study Alzheimer's because Alzheimer's runs in my family, and it just so happened that I signed on with a program, and my advisor just happened to get a grant in type 2 diabetes. And if you know the research world, you know that when you have grant funding, you tend to study what's funded, and so, for me, I was a new grad student in the lab and we had a type 2 diabetes grant, so I was going to be doing diabetes research for the next 4 years. And it just so happened that the first study was a mixed method study focusing on couples where one person had diabetes and the other person—we were trying to learn the experiences of how they managed the diabetes together, and I fell in love with doing the qualitative research, and I fell in love with the storytelling and how people together managed the disease because it's not a disease that you manage in isolation. And so that's sort of the path that I took, but it was like a happenstance. And then looking back, reflecting, diabetes runs in my family, two of my best friends have type 1 diabetes, so all along the way I feel like the signs were pointing me to study diabetes. It just took a while for me to figure that one out.

Dr. Anderson:

You know, one of the things we talk about at the American Diabetes Association, when somebody in the family is diagnosed with diabetes, the whole family gets diabetes, and I think you found that out in your research, didn't you?

Dr. Beverly:

I did. That's exactly what happened. And not only did I have to hear it from others and hearing their stories, but it also was reflected in my life with having, you know, grandparents diagnosed with type 2 diabetes and then just befriending others, you know, and having close friends living with type 1 diabetes.

Dr. Anderson:

Right. So all these patients that you're talking about, they often utilize Diabetes Self-Management Education and Support programs, or DSMES programs. Can you tell us how these programs typically work? And do they have any limitations?

Dr. Beverly:

Sure. So, Diabetes Self-Management Education and Support is critical, and it's recommended for anyone who has diabetes. It's

important that people also have refresher courses for diabetes education because it's possible that you might have had diabetes education 20 years ago, but things get updated over time, and it's also quite possible to forget what you learned, so having the diabetes education—there are several domains to study on, but it's really important, despite what you know or what you think you know about diabetes, to enroll in these classes because it tells you what you need to know about diet, it tells you what you need to know about physical activity and blood glucose monitoring, but some of the things that people aren't as aware about is it focuses on problem-solving, it focuses on coping skills, and some of those things are the things that I would say people with diabetes need the most, and those are the things that we're not necessarily born with. We're not necessarily born with the ability to solve all problems or the ability to cope with challenges, and that's one of the strengths that comes with Diabetes Self-Management Education and Support.

Dr. Anderson:

It really is, as you said, about teaching the patients to do the problem-solving and to manage their disease because it really is their disease. I also liked what you said, is that, you know—especially in type 2 diabetes, it's a journey, and the disease progresses. You may be progressing to your first basal insulin or to your basal bolus insulin for the very first time in your life, and that really does require special education, doesn't it?

Dr. Beverly:

Oh, it does. And even think about the technology. The technology when I started studying diabetes, and then I'm looking at it now, and I have to do education myself to stay up-to-date on what's going on, and I have to take these courses, and I need to make sure that I'm learning from my friends. So, if I'm constantly trying to stay up-to-date with what's going on in new medications, with Diabetes Self-Management Education and Support, with new interventions that are evidence-based but even with the technology—which I feel the technology evolves on a daily basis if not minute by minute, so thinking about it that way, you know, if you're diagnosed with diabetes 20 years ago, there are new technology options, there's new medication options, and why not do Diabetes Self-Management Education and Support where you can learn about those things in the comfort of either a group environment or one-on-one individual environment, and you can figure out which one's best for you.

Dr. Anderson:

That's great. It's about tailoring the education to the patient's needs. So let's take a look at your study. Dr. Beverly, what can you tell us about the study design? And what were some of your primary goals?

Dr. Beverly:

Sure. So, I'll tell you a little bit of a background for how this even came to be. So I study diabetes for a living. I focus on behavioral diabetes. I'm really focused on the psychosocial impact of diabetes. And so I happened to be giving a guest lecture to a group of students in a Health Professions class at the university. And afterwards, a couple of the students came up to me talking about how excited they were that I was talking about diabetes, and then they also, of course, wanted to know if I had any openings in my research lab, which of course I did. And then I brought someone in to do some research with, and she talked to me about, 'You know, when people talk about diabetes'—And I'll note this, that this individual has type 1 diabetes herself. She mentioned that, 'You know, listening to all these lectures'—and when she has her peers listen to these lectures—'all these lectures are negative about all the horrible complications and the terrible things that can happen with diabetes, but it's not all that bad, and maybe it would be nice if other people heard about positive stories.' And so that was really like the impetus for what we thought about, like let's plan this study. And we searched the literature. There really is not much out there on what could be positive about living with diabetes.

And by no means are we trying to say that this is an amazing thing that could happen to you. We recognize how hard it is to live with the constant daily demands. It's very difficult. And, of course, there are lots of things to be worried and concerned about, and the quality of medical care, the costs of care, there are a lot of issues with it, but there are some positive aspects about living with diabetes that we could reflect on, and so that's what led us to this study. Considering there's no research on it, we thought the best way to do this is let's talk to people and hear about their stories, and that's what led us to the qualitative research design.

Dr. Anderson:

For those just tuning in, you're listening to *Diabetes Discourse* on ReachMD. I'm Dr. John Anderson, and today I'm speaking with Dr. Elizabeth Beverly about her study on positive experiences associated with diabetes.

So, Dr. Beverly, this is fascinating. What do you hope to do, and what is the methodology of your study?

Dr. Beverly:

Sure. So the overall aim was really to listen to individual stories. One of the things that I think is most powerful—and when you look back on human nature—it's storytelling, and I think it's really important for anyone to tell their story, and so the thing that I wanted to focus on with this is I wanted to give individuals living with diabetes an opportunity to tell their stories, and if they had positive experiences, to share them with me, and that's something that we could share then to a wider audience. I personally as I young child was diagnosed

with an endocrine condition, so if someone had ever shared with me positive stories about living with that, it would have meant the world to me, because when I was little, I just thought, 'Oh, there's something wrong with me. There's something broken inside me.' And had I known that you can live with this, it will make you better, it will make you stronger, that would have meant all the difference. And I think that's kind of the point behind this study is this is something where you can share these findings. Right now in a research study, that's not necessarily something I'd pass on to a young child diagnosed with type 1 diabetes, but I could see a diabetes educator taking this information and sharing some of the messages in this with the young child and the family or the physician, the endocrinologist, who's talking with the young child and sharing this with the parents so that you see that there's hope for the future, and hope is always the key.

Dr. Anderson:

So let's talk a little bit about some of the key results of the study. What did you find?

Dr. Beverly:

So some of the key results are some of the things that you might expect. So all of the participants really focused on that the support that they got from people, and a lot of times they focused on—They didn't expect some of the support. So they expected support from family members and friends and peers. So a lot was said about peers with diabetes, particularly from the type 1 diabetes community and the online community. There's this huge support on the diabetes online community, and it's a wonderful resource for the type 1 diabetes community, and so just hearing about the, the support groups and the individuals, it was just a real connection for people. People said that they met some of their best friends at diabetes summer camp, or it was just a major connection when they saw someone else walking down the street with an insulin pump. It opened doors for them.

Another positive experience is all of them commented on how it improved their health behaviors, and so it was a built-in reminder for them to take care of their health and how they were healthier now because of having diabetes. And then a lot of the individuals also reflected on how being diagnosed with diabetes, regardless of the age or type of diabetes, it made them grow as an individual, so it led to personal growth, and it also led to them being more empathetic and more compassionate towards others because they had that personal experience themselves.

And then finally, the result that I would say was most surprising to me was the amount of advocacy work they were all doing. And so some of them were advocating, you know, down at Washington, D.C. for changes for insulin coverage and cost of insulin, and some of them were also just locally doing advocacy work, you know, for children in schools or doing some mission trips to some other countries where they were helping with diabetes education or sending supplies, for diabetes for children who could not afford them. So there were just some really fantastic results, many that I did not expect to find myself.

Dr. Anderson:

Do you think that really helps both the type 1 and the type 2 patient who's sort of now advocate for their greater collective, brethren, whether it's Safe at School with the American Diabetes Association or participation in summer camps or lobbying Congress, or, JDRF also does a lot of advocacy work. Have you found that that really empowers these people?

Dr. Beverly:

Not only do I find that it really empowers these individuals, but I always think back on when I read things about when people reflect on their life about what will bring you happiness and what's most important, and then they always say 'when you spend time volunteering' or 'when you spend something where you find a purpose and meaning in life' and so I think these individuals found that, and some of them found it very early, which must be incredibly rewarding. So I think that they found that this disease came at a time when they knew that they would be able to help others through their experience, and to them it was a very positive experience.

Dr. Anderson:

So, as we look to the future, Dr. Beverly, how do you think incorporating peer support into care can impact or will impact the diabetes community?

Dr. Beverly:

So there have been a lot of interventions that have looked at peer support, and some of these are just peer support interventions or peer support compared to a control condition or peer support compared to another type of intervention, and the results in the diabetes literature have been fantastic, and they all show that, not only in the type 1 literature as well as the type 2 literature, that peer support is incredibly helpful. And I think what that comes from is, when you're looking at it, to have someone tell you what to do but they're not living in it, that you don't know if they actually know what it feels like to have diabetes, but if you're listening to somebody else who's in those challenges or the daily struggles, you're much more likely to lean on them, to believe them or listen to what they're going to do. Not only that, you have that innate sense of social support, and so that I believe is why it's been so supportive. And then I also think the rise of social media has been a part of it as well, but I really do think there's going to be a surge in peer support interventions.

Dr. Anderson:

One of the things we often talk about here on ReachMD is the impact on primary care providers. And when we say providers, we mean physicians, nurse practitioners, PAs, those who are on the frontline taking care of a lot of these folks with diabetes. What advice would you give them about positive experiences? And how do they incorporate that into their practice perhaps to better impact some of these patients?

Dr. Beverly:

That's a great question. I, myself, am not a primary care provider. I do work with a lot of primary care providers, and so of course, I thank them for all the work that they do because I know that primary care providers provide about 90% of the care to people with diabetes in the United States. And what I would say is the message to take home from this is, yes, diabetes is a very difficult disease to live with, and sometimes just acknowledging that it's very difficult for people to live with, but also, perhaps, reframing some of the comments. So, if somebody talks about 'This is so hard, I'm not able to do this,' but you might be able to cognitively reframe how they said something. So if somebody says that 'This is just so difficult for me to remember to plan my meals over the week, and it's just so hard for me to follow this diet,' you could say, 'I hear what you're saying.' You know, you can use some of your, you know, reflection statements, your motivational interviewing. 'I hear what you're saying. I understand how difficult this is. I do not myself have diabetes, but diabetes itself could be a built-in reminder to really focus on your health, and perhaps this is what it's telling you.' Or you could also provide recommendations for the online support, and there are online support groups and peer support groups that you can find online all across the country, which are critical, especially in rural areas like the one that I live in in rural Athens, Ohio. So I think building on some of those things, focusing on the peer support, the social support, as well as the cognitive reframing.

Dr. Anderson:

Well, I think that is a great thought for those of us who are in primary care to leave with. Dr. Beverly, thanks for joining me, and thanks for sharing your findings on these emotional experiences for patients with diabetes. I mean, it really was eye-opening. It was great speaking with you today.

Dr. Beverly:

Thank you so much for having me.

Dr. Anderson:

For ReachMD, I'm Dr. John Anderson. To access this episode and others from our series, visit ReachMD.com/DiabetesDiscourse, where you can Be Part of the Knowledge. Thanks for listening.