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Strategies for Addressing Diabetes Stigma and Discrimination

Dr. Buse:

Welcome to *Diabetes Discourse* on ReachMD. I'm Dr. John Buse, and joining us to talk about her study focusing on diabetes stigma and discrimination is Dr. Mary de Groot. She's a Professor of Medicine and the Associate Vice Chair for Wellness at Indiana University School of Medicine.

Dr. de Groot, thank you so much for joining me today.

Dr. de Groot:

Thank you so much for having me. This is a delight to join you on this topic.

Dr. Buse:

Yeah, this is a really important but I have to say long paper, so I hope you'll be able to boil it down for our listeners. One of the top lines I took from it was and I'll quote, "Four in five adults with diabetes experience stigma, and one in five experience discrimination like unfair and prejudicial treatment, such as in healthcare, education, and employment." Now I think everyone knows about discrimination, but what should we really know about stigma?

Dr. de Groot:

That's a great question, John. First, let's talk about what stigma is and particularly diabetes stigma, and we define that as negative social judgments, stereotypes, and prejudices about diabetes or about a person or group due to their diabetes that occur typically in the context of a power imbalance, and so there are many variations on a theme here. That can be experienced or enacted stigma, so those are tangible examples of stigma where someone makes a comment or portrays someone in a particular way. There can be perceived stigma where there's a feeling that goes with that. It's a belief or awareness or the existence of diabetes stigma. That might be in the present moment, or that might be a carryover from a past enacted experience. There can be anticipation of stigma, and that sometimes happens in the healthcare setting. There can also be internalized stigma or self-stigma where people have internalized negative messages about diabetes and then apply that to themselves in an ongoing internal narrative that is negative and blaming. And then there's also intersectional stigma. That is diabetes stigma that interacts and converges with other kinds of stigmatized conditions or characteristics. So, for example, obesity or severe mental illness and substance abuse has stigma associated with it as well as a stigma and discrimination that we have in our societies on the basis of race, ethnicity, gender, and other characteristics, so there's many different forms of this.

And as you said, the prevalence of diabetes-related stigma is alarmingly high when we think about prevalence statistics. As you mentioned, four in five adults have reported experiencing some form of diabetes stigma at some point in their lives. Anywhere from 65 to 99 percent of adolescents and young adults with type 1 diabetes in large cross-sectional samples have reported experiencing diabetes stigma frequently from peers who don't understand diabetes or may have aversive reactions to insulin administration or pump technology or other kinds of ways that it interacts. 83 percent of parents of children with type 1 diabetes experience stigma. That can be in the healthcare setting. That can be from other parents arranging overnight visits, or that can be from school systems—children being taken out of class unnecessarily or being treated differently because they need to report to the nurse in order to receive their insulin or to have their pump managed or to manage a low or high blood sugar.

Dr. Buse:

Is there anything easy that healthcare professionals can do to try and reduce the burden of stigma and discrimination in people with diabetes?

Dr. de Groot:

I think the really good news about changing the course of stigma for people with diabetes is that the kinds of things that we can do to make this a better world for people with diabetes are relatively simple. They take a little bit of mind share, a little bit of mindfulness, but they tap into, I think, most of the core values that guide us to careers in healthcare in the first place, right? We care about people, we care about our patients, and we can leverage that caring with a little bit of mindfulness to help create environments in our places of clinical practice to be more inviting for people with diabetes.

So simple things that we can do, such as addressing our language, do we refer to people with diabetes, or do we refer to diabetics? Right? We know that the idea of person-first language has been around for quite some time now as has the concept of patient-centered care. And monitoring our language so that we're not using blaming language or stigmatizing language is very important, and there's multiple statements that have been published around the world in Australia, the UK, and here in the US by the American Diabetes Association. Back in 2017, there was a consensus statement on the use of language, and anyone who might not be familiar with that, I highly recommend taking a look at that paper because it gives some handy tips about terms that they're really passé now, things that we don't need to refer to that actually induce feelings of stigma.

We can provide explanations to patients. And so the more explanations we can provide to patients about how diabetes really works can help to change the framework for patients and how they think about their diabetes. We can create judgment-free zones. So thinking about our signage, thinking about the posters we have up on the walls in our exam rooms, are any of those contributing to negative or harsh judgments about diabetes? And we can make use of our patients as important sources of information. So we can ask our patients for feedback to help inform our practice. "Is there any interaction that you've had in your visit today that has made it more difficult for you to share or feel comfortable here?" Likewise is "What have we done in our practice today that has made it easier for you to come here and make good use of your health care?" And we can also ask our patients with diabetes if they have mindshare and time to be able to contribute to our practice to be champions for organizational change. So if you are a caring provider that sees a need for some change to signage or to the checkout process or to the way height and weight are gathered or blood pressure or other vitals, and you'd like to make that change more organizational-wide, do you have patients who would be willing to speak to their experience? The more we can empower people with diabetes, the more we are able to create a safe zone for them.

Dr. Buse:

For those just tuning in, you're listening to *Diabetes Discourse* on ReachMD. I'm Dr. John Buse, and today I'm speaking with Dr. Mary de Groot about her study on diabetes stigma and discrimination.

So if we come back to your article, Mary, I particularly love the section that referred to family, friends, and the general public, and it said, "Some people with diabetes report feeling that their family and friends become the diabetes police, but that the blaming, shaming or judging could be founded in good intentions." Apparently, this is known in the field as miscarried helping. What should we do about that?

Dr. de Groot:

Yes, this is such a rich and important topic. And, John, I want to really give credit where it's due here for this paper that came out in *Lancet Diabetes & Endocrinology* and give credit to Dr. Elizabeth Truscott-Holmes and Dr. Jane Speight both from Australia, who were the organizers and leaders of this 51-member panel that created this international consensus statement.

So you're right that we have many sources of stigma that occur and many sources of miscarried helping. I love the term "diabetes police," and I think many of our patients can relate to that term. This was a term coined, as you know, by Dr. Bill Polonsky, and it really captures this dynamic that happens all too frequently where we have people who care for us, loved ones who are very well-intentioned and who go about helping in all the wrong ways. And help is a lot like art. It's in the eye of the beholder. And so what one person might consider to be a helping statement, comment, or action may be exactly the opposite for the person it was intended for.

And so the way out of that dance is about good communication, and we start first with the person with diabetes. So for them, what kind of help do they actually need? What kind of help would be truly helpful? As patients, if we can identify that for ourselves, then that's half the battle right there. Then we can communicate that to the people that care for us. But if we don't communicate that, what happens is that people come to their own conclusions about what can be helpful, and then that might be exactly the wrong thing or just not the right thing.

The second piece is that we want to acknowledge the good intentions that the people who care for us have, that most of the time, miscarried helping comes from a really well-intentioned place. It's just not the right way to go about doing it. And so we want to acknowledge those good intentions.

Dr. Buse:

There are so many areas in stigma and discrimination that are touched on in the article. Unfortunately, we just don't have enough time

to review it all, but do you have any final thoughts before we close?

Dr. de Groot:

There is a wonderful website that I would love to refer everyone to. It is enddiabetesstigma.org, and on that website, there is key information from the paper that's news you can use to inform your own thoughts and practices around diabetes-related stigma to help end it. And there's also a pledge and the pledge I think is just a really empowering experience.

The pledge has been endorsed by more than 250 organizations worldwide and more than 2,000 people across more than 95 countries around the world. So when you take the pledge, you're part of this international movement and community that is making the world a better place for all of us and especially for people with diabetes. So, come join us.

Dr. Buse:

This has been a really interesting conversation. I'd like to thank my guest, Dr. Mary de Groot, for sharing her findings on diabetes stigma and discrimination. Dr. de Groot, it was a pleasure speaking with you today.

Dr. de Groot:

Thanks so much, John.

Dr. Buse:

For ReachMD, I'm Dr. John Buse. To access this and other episodes from our series, visit *Diabetes Discourse* on ReachMD.com where you can Be Part of the Knowledge. Thanks for listening.