T1D Exchange

Diabetes Distress

Kelsey Howard, PhD, Jillian Merrick, PhD, Katherine Semenkovich, PhD, Ryan Tweet, PsyD, Jill Weissberg-Benchell, PhD, CDCES

November 11, 2024

Welcome

Jill Weissberg-Benchell, PhD, CDCES

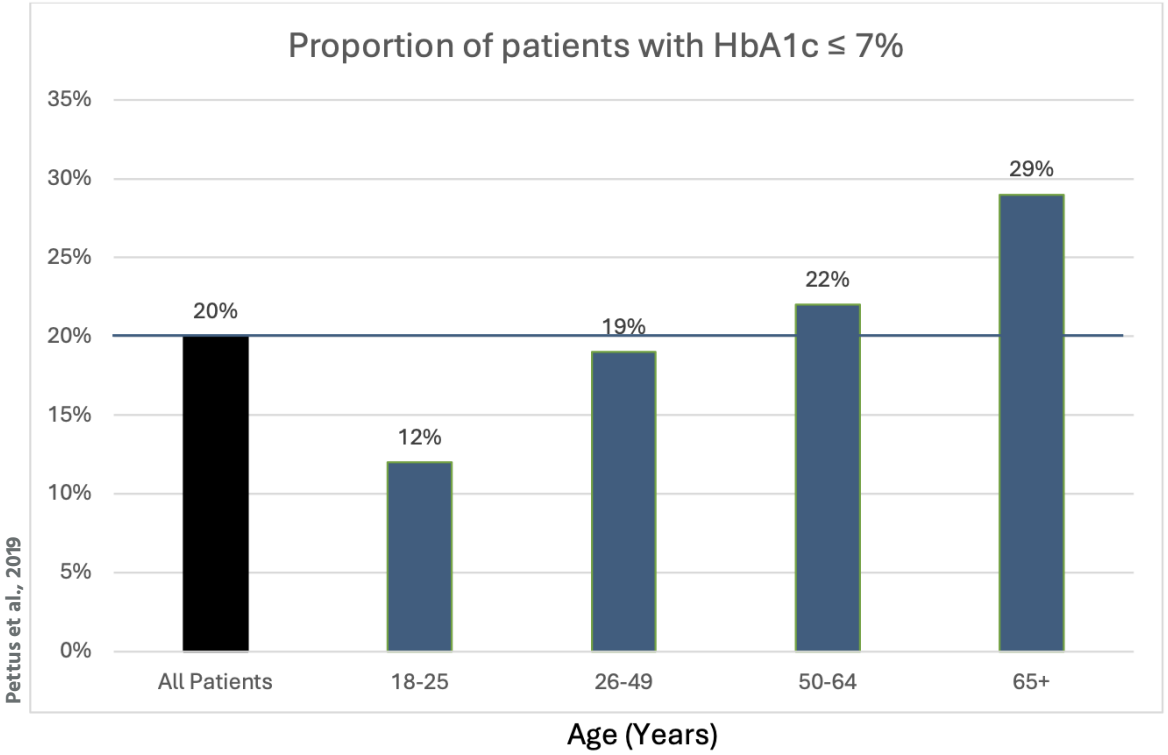
Agenda

- Welcome
- Why is addressing diabetes distress important?
- Overview of Tools and Measures; conducting a clinical interview
- Case discussions, facilitated at worktables
- Q & A and case discussion with Panel
- Wrap Up

Why is addressing diabetes distress important?

Ryan Tweet, PsyD

Considering how far we've come...



Diabetes Distress

"Refers to the worries, concerns, and fears among individuals with diabetes as they struggle to manage their disease over time" (Fisher, Gonzalez., & Polonsky, 2014)

A tough balance:

- Intersecting other life obligations
- No vacation – constant, unrelenting
- Efforts are never good enough
- Scary: hypers, hypos, complications, costs, access
- Most don't see how much work it is, and the burden involved

(BDI, 2023)

Why should we be concerned about diabetes distress?

Diabetes distress is significantly linked cross-sectionally and over time with:

- High A1c (TIR; impactful throughout range; Schmitt et al., 2021; Hessler et al., 2024)
- Low heart rate variability, a CVD risk factor (Ehrmann et al., 2023)
- Reduce medication/insulin taking (Hessler et al., 2017; Schmitt et al., 2021)
- Lower frequency of set changes, greater number of scheduled and missed appointments (Khan et al., 2018)
- Diabetes distress is a better predictor of glycemic outcomes than depression in the pediatric and adult literature (Sturt et al., 2015; Hessler et al., 2014; Berlin et al., 2012)
- Lower QOL, increased risk of hospitalization, missed healthcare visits, increased costs (Ehrmann, et al., 2023; Fisher et al., 2015, 2016, 2018; Hessler et al., 2017)

Elevated levels of diabetes distress are common

- Between 20-77.4% of individuals experience elevated diabetes distress (Skinner et al., 2020; Patra et al., 2021; Fisher et al., 2012, 2016)*

Diabetes distress is very responsive to intervention

- Diabetes distress and HbA1c can be reduced through education and time-limited, emotion-focused intervention; reduced DD improves outcomes (e.g., Fisher et al., 2018; Hessler et al., 2017, 2021; Hessler et al., 2024 [EMBARK]; Schinckus et al., 2018)

Addressing diabetes distress can improve patients' day-to-day functioning, diabetes outcomes, and overall wellbeing

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Overview of Tools & Measures

+

Conducting a Clinical Interview

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Tools & Measures for Assessing Diabetes Distress

Clin Diabetes. 2021 Jan; 39(1): 14–43. doi: 10.2337/cd21-as01

PMCID: PMC7839613 | PMID: 33551551

Standards of Medical Care in Diabetes—2021 Abridged for Primary Care Providers

American Diabetes Association

Diabetes Distress

Recommendation

5.39 Routinely monitor people with diabetes for diabetes distress, particularly when treatment targets are not met and/or at the onset of diabetes complications. **B**

- **Assess DD Regularly & Systematically With Standardized Measures:**
- **Makes no sense providing education/intervention when DD will limit responsiveness.**
- **Regular assessment makes it part of your clinical routine.**
- **Harder to forget or skip.**
- **Assessment is comprehensive – leaves no important gaps.**
- **The results can be used to start an intervention through a clinical conversation.**
- **Change can be assessed over time (individuals & panels).**

Fisher, et al., 2019; Masharani, et al., 2022

Tools & Measures for Assessing Diabetes Distress

Standards of care recommend screening for diabetes distress *at least annually* for both youth and adults (American Diabetes Association, 2024)

There are a number of validated screening instruments available to incorporate into your clinical practice. Resources to find screening instruments:

- ADA's Behavioral Health Toolkit
- Behavioral Diabetes Institute
- Society of Pediatric Psychology Diabetes Special Interest Group Website

Tools & Measures for Assessing Diabetes Distress

- The original, 17-Item Diabetes Distress Scale (DDS)
  - Teen and parent versions available
- The original, 28-item Type 1 Diabetes Distress Scale (T1-DDAS)
- Current, T1-Diabetes Distress Assessment System (T1DDAS)
  - Core scale (8 items)
  - Source scale (22 items)
  - Combined
- Problem Areas in diabetes Scale (PAID; 20 items)
  - Child, Teen, and Parent Versions available

- www.Diabetesdistress.org

T1D: T1-Diabetes Distress Scale

Tools & Measures for Assessing Diabetes Distress

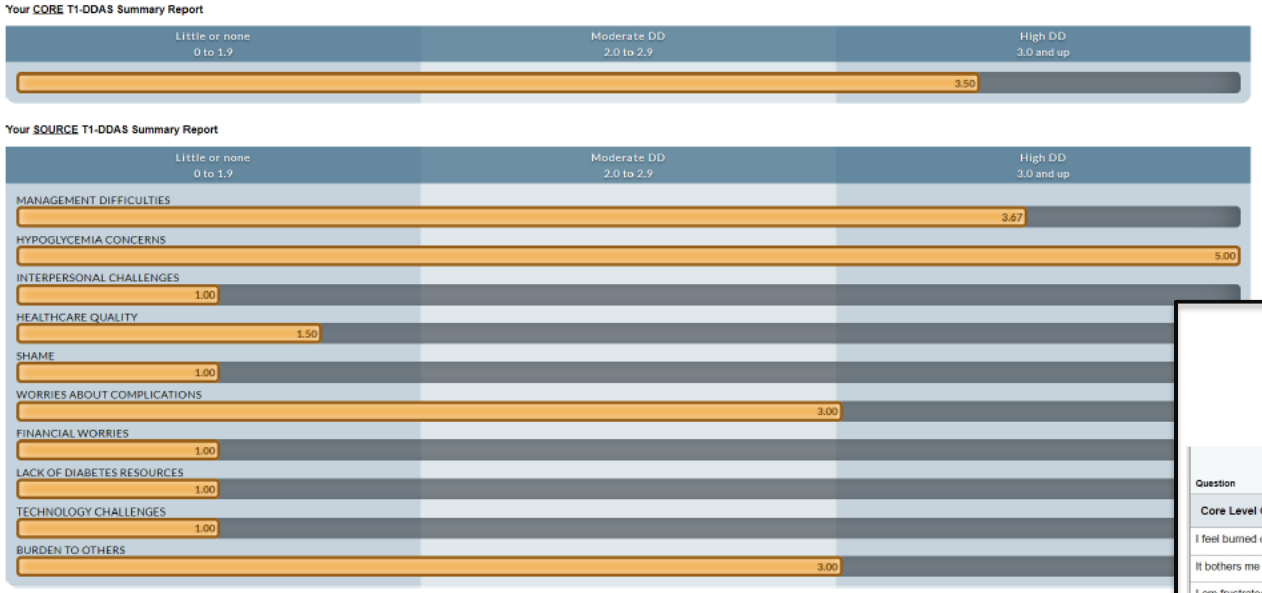
The T1-Diabetes Distress Assessment System (T1-DDAS)

- 8-item Core Scale: intensity/extent of DD
- Ten, 2- or 3-item Source Scale: where DD comes from:
  - Financial worries
  - Interpersonal challenges
  - Healthcare provider (trust, relationship)
  - Hypo concerns
  - Healthcare quality
  - Shame, stigma
  - Lack of diabetes-related resources
  - Technology challenges
  - Burden to others
  - Worries about complications

Each has a cut-point (≥2.0) that defines elevated DD.

Tools & Measures for Assessing Diabetes Distress

T1-DDAS Core and Source Scales



T1-DDAS Item Report

Question	Not a Problem (1)	A Slight Problem (2)	A Little Problem (3)	A Serious Problem (4)	A Very Serious Problem (5)
Core Level Of Distress					
I feel burned out by all of the attention and effort that diabetes demands of me.			✓		
It bothers me that diabetes seems to control my life.				✓	
I am frustrated that even when I do what I am supposed to for my diabetes, it doesn't seem to make a difference.				✓	
No matter how hard I try with my diabetes, it feels like it will never be good enough.				✓	
I am so tired of having to worry about diabetes all the time.				✓	
When it comes to my diabetes, I often feel like a failure.					✓
It depresses me when I realize that my diabetes will likely never go away.	✓				
Living with diabetes is overwhelming for me.			✓		
Management Difficulties					
I feel discouraged when I see high blood glucose numbers I can't explain.				✓	
I feel that thoughts about food and eating control my life.			✓		
I get angry at myself for not managing diabetes better.				✓	
Hypoglycemia Concerns					
I worry a lot that I could have a serious low glucose event.					✓
I feel so scared of going low that I avoid things in my life.					✓

What can I do in a short clinic visit to address diabetes distress?

Acknowledge and Validate the distress

- "It sounds like there's a lot about diabetes that's been really challenging lately. I can imagine that's been so hard with everything else on your plate."
- "I bet these high numbers have been frustrating."
- "It’s normal to feel stressed or burned out by diabetes because diabetes is hard. I want to know what this has been like for you so that we can find some solutions together."

Focus in on what's most important to the patient

- "There's a lot that feels stressful with diabetes right now. Are there one or two things that are bothering you the most that we could focus on in our time together today?”
- "What would you say is the worst part about diabetes right now?”

What can I do in a short clinic visit to address diabetes distress?

Two simple questions that can give you great information:

- **What do you feel has been going well with diabetes care? What are you proud of right now?**
  - Let's celebrate and build on these successes
    - "Even though things have felt really hard, you've still managed to accomplish _____. It's clear to me that working on your diabetes goals is really important to you."
  - If the answer is NOTHING, then we know that we have some work to do

- **What has been the worst part about diabetes recently?**
  - If we accomplish nothing else, can we find a way to make this a little less challenging or frustrating?

Conducting a Clinical Interview

CONVERSATIONAL TOOLS

OPEN-ENDED QUESTIONS: Talk less, listen more (50%) (how, what, why)

- Please tell me more.
- What might be going on?
- Why do you think that might be happening? (non-judgmental)

ACTIVE LISTENING: Face directly, slow speech, eye contact, empathy

CLINICAL ENGAGEMENT TOOLS:

Label feelings and beliefs: ***sprinkle feeling words frequently***

- Sounds like you were feeling...
- That might have left you feeling...

Summarize and reflect:

- So, you are saying that...Is this correct?
- Let me see if I understand...Do I have that right?

Normalize and accept without judgment:

- So many of the people I work with feel the same way.
- It makes sense that you would feel that way under the circumstances
- If I were in your shoes, I'd probably feel the same way.

DD-ASSIST INTERVENTION STEPS:

Use the conversational tools throughout

REVIEW T1-DDAS REPORT: Focus on high source scores and high items

HAVE THEM SELECT ONE HIGHLY RATED ISSUE THAT IS IMPORTANT TO THEM: A diabetes story

- Get one recent example. what happened?
- How did they feel/believe when it happened?
- What did they do when it happened?
- What would they have wanted to have done but didn't?
- Summarize without judgment!

SEPARATE FEELINGS/BELIEFS FROM ACTIONS/BEHAVIORS:

- It sounds like you really wanted to..., but your feelings/beliefs directed you to...
- would you be willing to tolerate some of these tough feelings and try something different, something that you would really want to do (that would meet your goals?)
- If so, what are some things that you might want to do differently - something not driven by your feelings, but, instead, something that might best meet your goals?
- Pick one to start with?
- Let's make a plan.
- What might get in your way? what might you do then?

FOLLOW-UP WITHIN TWO WEEKS: In person, video, text, email, etc.

When in doubt, remember that reflective listening, validation, and empathy are powerful interventions!

- Increases patient satisfaction and trust
- Enhances treatment adherence
- Reduces anxiety and improves mental health
- Improves health outcomes
- Enhances patient self-efficacy

(e.g., Abughosh et al., 2019; Bakker et al., 2016; Licciardone et al., 2024; Menendez et al., 2015; Pollak et al., 2011)

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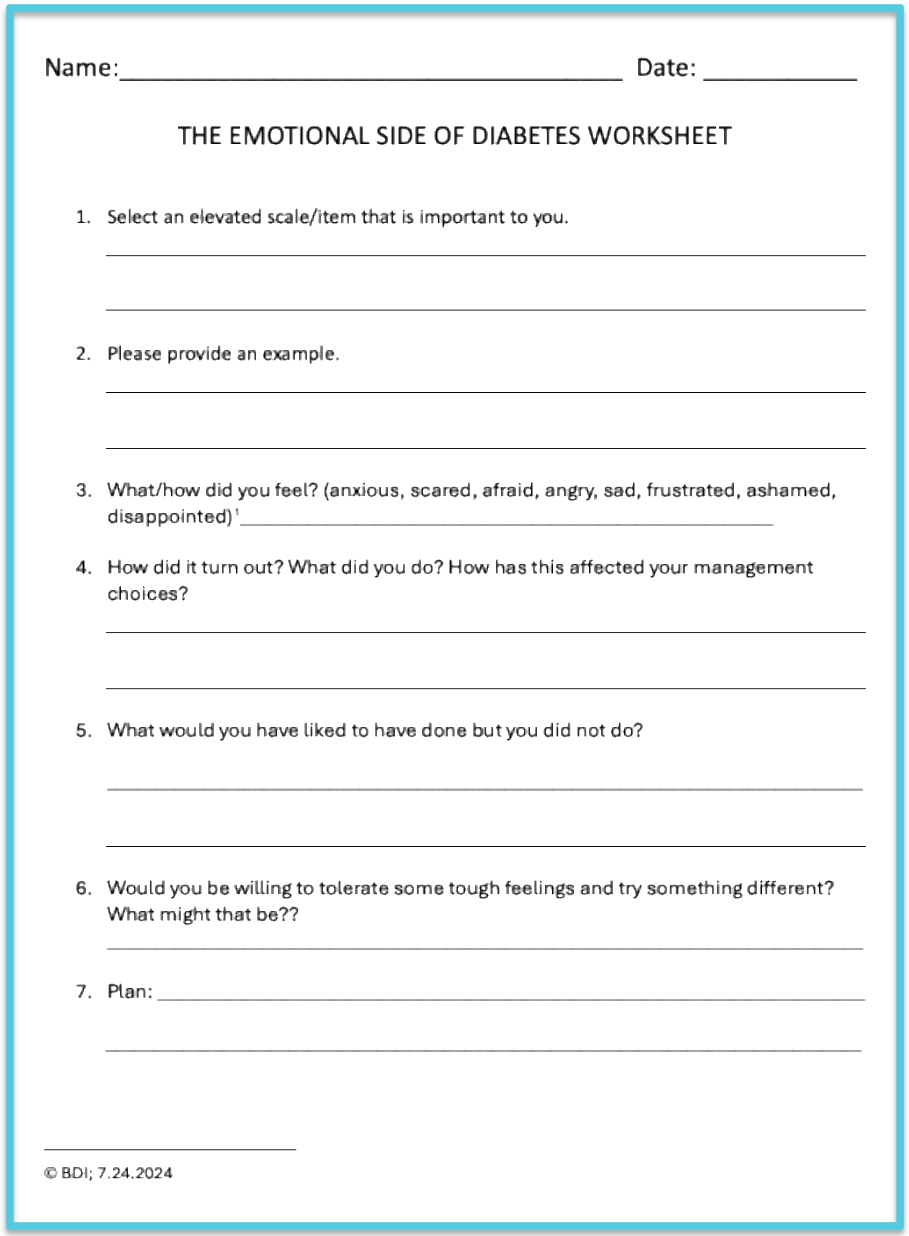
Conducting a Clinical Interview



Name:_____ Date: _____

THE EMOTIONAL SIDE OF DIABETES WORKSHEET

1. Select an elevated scale/item that is important to you.

   _____

   _____

2. Please provide an example.

   _____

   _____

3. What/how did you feel? (anxious, scared, afraid, angry, sad, frustrated, ashamed, disappointed)[1] _____

4. How did it turn out? What did you do? How has this affected your management choices?

   _____

   _____

5. What would you have liked to have done but you did not do?

   _____

   _____

6. Would you be willing to tolerate some tough feelings and try something different? What might that be??

   _____

7. Plan: _____

   _____

_____

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Key Considerations:

- *PWD have their reasons for the management choices they do or do not make.*
- *Management change has to be based on PWD choice, requiring us to become the helper, not the fixer.*
- *Not enough time? Stay open-minded, learn the material, then find a way to make it work for you.*

Conducting a Clinical Interview

Step 1: Assess DD

"We know that tough thoughts and feelings are common for people with diabetes and can make diabetes even harder to live with and manage. This questionnaire tells us how distressed you are about diabetes and what you might be distressed about. Let's look at your results together."

Step 2: Identify a "DD Story"

- Help them tell you a brief, recent story about their highly scored item(s) using the conversational tools:
  - "Which if these highly scored items is of most concern to you?"
  - "Given our limited time, can you briefly describe a recent example?"
  - "Ideally, what would you have really wanted to do?"

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Conducting a Clinical Interview

Step 3: Foster a New Perspective

"You really want____,rather than what your____(feelings, beliefs, expectations) direct you to do. To make this happen, would you be willing to tolerate some tough feelings and thoughts and do something different?"

Step 4: Consider a Different Choice: Make a Plan

"If you are able to tolerate some tough feelings/expectations/beliefs, what are some things that you might do differently?"

Step 5: Plan for Follow-Up

- Review and revise goals
- Remind them that it's an experiment and not a test of their character
- Reinforce their strengths/ why they picked the goal
- Determine next steps

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Considerations for Pediatric Populations

- Clinical Interview Tools
  - Many skills will still apply
  - Some things will be different
    - Some aspects of tools may not apply to youth (e.g. tolerating distress)
    - Goals may be different for youth
      - Developmentally salient goals (e.g. getting a driver's license, spending more time with friends) vs. glycemic outcomes
- Parents/Caregivers
  - Caregivers may have their own diabetes distress
  - Important to align with youth AND their caregivers
    - It is normal for youth and caregivers to see things differently
    - Can we develop some shared goals/rules of engagement for conversations about diabetes?

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Case Discussions, facilitated at worktables

Kelsey Howard, PhD, Jillian Merrick, PhD, Katherine Semenkovich, PhD, Ryan Tweet, PsyD, Jill Weissberg-Benchell, PhD, CDCES

Guidelines for the case discussions, pediatrics

Review the cases provided and discuss which tools, measures, and clinical interview strategies you would use. Use the following questions to guide your discussion:

- What feels like the most important piece to address?
- What questions would you have for this patient?
- What questions would you have for their parent?
- Are there any resources or referrals you would consider?

Guidelines for the case discussions, adults

At your table you will find the vignette, DD-ASSIST worksheet, and conversational tools to aid in the following exercise:

1. Find a partner; one will be the healthcare provider (HCP) and the other will play the patient (PWD).
2. Briefly, both HCP and PWD individually review the case and the T1-DDS results. Then, the HCP works through the DD-ASSIST worksheet with the PWD. Feel free to make it your own and don't get caught up in trying to be perfect!
3. Switch roles and repeat. (Feel free to mix up partners as well.)

Case #1, Pediatric Vignette, by Katherine Semenkovich, Ph.D., Pediatric Psychologist, Nationwide Children's Hospital

Please review the information and consider how you would support Ana in balancing optimal diabetes management and quality of life:

- Ana is a 15-year-old female and has had type 1 diabetes for 7 years.
- Her HbA1c today is >14%.
- She reported being a high achiever in school and gets straight As and is involved in several extracurricular activities.
- She has many friends at school.
- Parents are not very involved in diabetes management and think Ana should be managing diabetes herself.

Parents have been frustrated at Ana because her HbA1c has increased significantly over the past year.

Ana communicates that she doesn't miss insulin doses and reports regularly checking blood sugars. She didn't bring her meter or blood glucose logs today.

Case #2, Pediatric Vignette, led by Kelsey Howard, PhD and Jillian Merrick, PhD

Please review the information and consider how you would support Sophie in balancing optimal diabetes management and quality of life:

- Sophie is a 16-year-old female with type 1 diabetes.
- She presents to her diabetes clinic appointment with her mother.
- She has followed with your team since her diagnosis 5 years ago.
- She was wearing a CGM; she is not wearing a CGM today and did not bring a meter.
- Per family, she stopped wearing CGM six weeks ago because they felt that readings were not accurate.
- A1c has increased since her last visit.
- Sophie shares with the CDCES that she is feeling annoyed by diabetes and that she just can't seem to do anything right no matter how hard she tries.

She prefers that others do not know about diabetes or see her manage diabetes because she's sick of answering questions. Her mother feels frustrated; she does her best to provide support and supervision when they are together, but Mom works long hours and Sophie is home for a few hours after school before Mom comes home from work. Mom doesn't want Sophie to do diabetes alone; however, she wants Sophie to be able to be able to spend time out of the home and with friends. Both Sophie and her mother express that they are upset and surprised to see that her A1c has increased. Mom thought that Sophie was becoming more independent in her care, but now she wonders if there is missed insulin after school.

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Case #3, Adult Vignette, led by Ryan Tweet, PsyD (He/Him), Clinical Psychologist, Oregon Health & Science University

Please review the information and consider how you would use the questionnaire to support Sally in balancing optimal diabetes management and quality of life:

- Sally is a 45-year-old woman who has lived with T1D for 30 years.
- She resides with her husband and two teenage children.
- Sally currently uses an insulin pump, but does not use a CGM, expressing disappointment after trying one many years ago.
- Her recent A1C has increased to 8.8%, up from 7.4% at her last visit six months ago, and she has experienced an 8-pound weight gain during this period.
- Sally is facing challenges with her diabetes management and may benefit from revisiting her care plan.

Q & A and Case Discussion with Panel

Kelsey Howard, PhD, Jillian Merrick, PhD, Katherine Semenkovich, PhD, Ryan Tweet, PsyD, Jill Weissberg-Benchell, PhD, CDCES

Wrap Up

Jill Weissberg-Benchell, PhD, CDCES

Resources

- ADA Behavioral Health Toolkit
  - https://professional.diabetes.org/professional-development/behavioral-mental-health/behavioral-health-toolkit
- SPP Diabetes SIG
  - https://sppdiabetes.weebly.com/assessment-resources.html
- Behavioral Diabetes Institute
  - https://behavioraldiabetes.org/
  - https://diabetesdistress.org/access-dds/ (For access to screeners)