

Promoting Parent Engagement and Responding to Problematic Adherence in Type 1 Diabetes

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Agenda

- Where kids and parents get stuck
- Typical Interventions
- Strategies for:
 - Increasing social support
 - responding to increase behavior change
 - responding to decrease distress
 - building strong relationships
- Questions/Discussion

Variations in emotional distress



Distress

Burdens of daily diabetes care
Stresses and worries
Feeling overwhelmed
Twice as common as MDD



Burnout

Feeling chronically overextended by burdens of living with diabetes
At the point of giving up on diabetes care



Depressive Symptoms

Any symptoms of depression that do not reach diagnostic levels
Content may be related to diabetes or other stresses



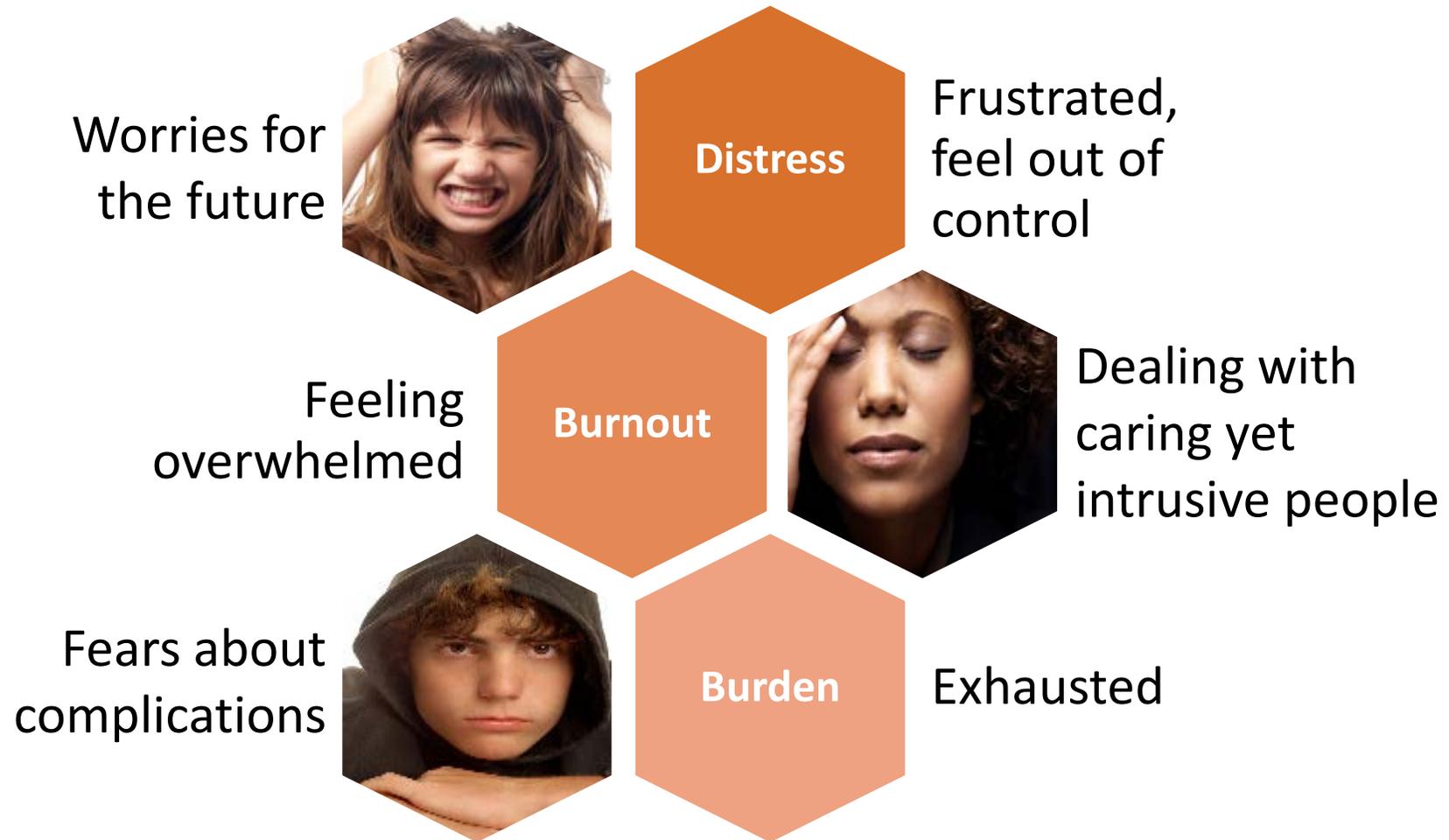
Depression

Major depressive disorder meeting DSM criteria
Content may or may not be related to diabetes

Management is demanding.

- Complex, unrelenting, expensive.
- Behavior is foundation of diabetes care, yet is *not* the only influence on BG.
- Patients/parents often feel out of control of BG, yet hold themselves 100% responsible.
- Arguments about diabetes are exhausting.
- Worries and fears can be all-consuming.

The demands take a toll.



Diabetes Distress

- Term used to define a cluster of symptoms that do not meet diagnostic criteria for a major depressive episode, but reflect negative feelings surrounding diabetes care

Sources of diabetes distress

- Demands and tolls of daily management
- Fear of hypoglycemia
- Anxiety about high BG and complications
- Family conflict
- Stigma, shame, judgement
- Unrealistic expectations for BG and behavior
- Financial strains
- Isolation

Distress vs. Major Depressive Disorder

- Diabetes distress ~2x as prevalent as MDD in adults
 - Rates are unknown in youth and parents
 - Anecdotally, we see this a lot.
- Most do not meet criteria for major depression
- Diabetes distress significantly and independently associated with adherence, A1c
- Both are “serious, treatable, and worthy of clinical concern”

Chronically high BG

- Irritability
- Mood – sadness, anxiety
- Cognitive impairments, difficulty concentrating
- Fatigue
- Weight loss
- Sleep problems
- Changes in appetite/thirst

....pretty similar to depressive symptoms.

Diabetes Burnout

- This experience is often considered to be more severe than diabetes distress and describes the frustration of living with diabetes, including:
 - Feeling overwhelmed with management
 - Feeling hopeless
 - Thinking terrible unavoidable things will happen
 - Feeling powerless
 - Feeling isolated
 - Feeling sad

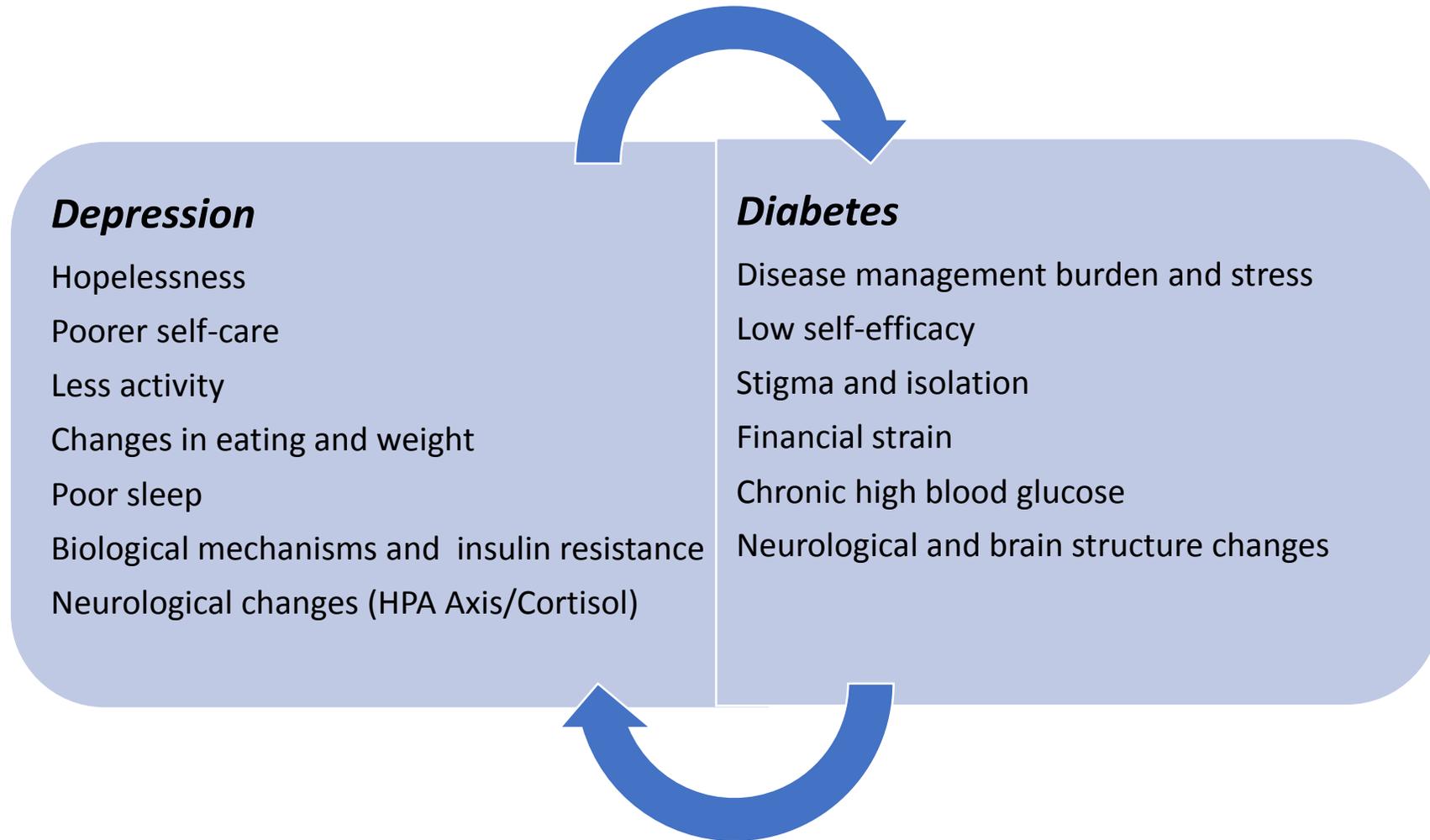
Depression and Diabetes

- 15 – 25% of teens with diabetes have elevated depressive symptoms¹
 - Slightly lower rates in younger children
 - Similar to rates in adults (25%)²
- Equally large percentage of adolescents with *subclinical levels* (23%)

1. Kovacs et al, 1997; Grey et al, 2002; Hood et al, 2006; McGrady et al, 2009

2. Anderson et al, 2000

The cycle.



Family members

- At risk for depressive symptoms, distress, burnout
 - Esp. mothers of youth with T1D
 - Significant worry about diabetes, relationship stress
 - Feel burdened by diabetes (~1/3)
- Distress and coping in parents related to symptoms and diabetes management in youth

Summary

Type 1 diabetes carries significant psychosocial burden that creates fertile ground for difficulties managing diabetes, and sets the stage for potential biologic effects and increased risk for complications

Intervention Strategies & Considerations

Treatment Targets – Influences on Distress & Diabetes Outcomes



Goals for mental health support in T1D

1. Promoting good quality of life balance with glycemic goals/T1D care (QOL = mood, academic/work functioning, social relationships, etc.)
2. Supporting medical care (Attending medical visits, Adherence to treatment regimen)
3. Distress reduction

What do we work on?

- Work with patient/parent to define developmentally appropriate goals
- Discuss expectations and strategies for assuming increased responsibility
- Continued parent monitoring
- Identify key sources of support
- Increase accountability for behavior

Interventions in T1D

Behavioral Family Systems Therapy-Diabetes

- Effective communication skills

Coping Skills Training

- Adaptive coping strategies

Family Teamwork

- Cooperative problem-solving

Quality of Life Monitoring

- Patient-provider communication about QOL

Strategies for Behavior Change,
Decreasing Distress, and
Building Strong Relationships

Need for support (“Diabetes is not DIY” – Anderson/Laffel)

Family

Friends

Disease “Self-Management” is not DIY



- Youth has limited involvement in management
- Parents do most management



- Youth does some management
- Parents actively involved



- Youth does more management independently
- Parents shift to monitoring, active involvement PRN



- Youth has primary management responsibility
- Parents as supports



- Adult has primary management responsibility
- Spouse/partner, family, friends as supports

Social Support

- **In-person supports**

- Community groups (NDA); clinic-sponsored events; JDRF; NDA, DYF and other camping options
- Diabetes care team for a referral
- Seek therapy or social support groups

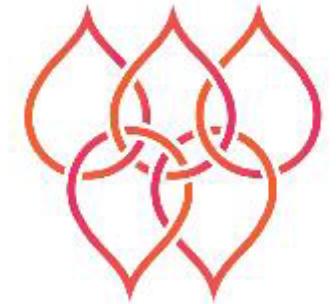
Social Support

- **Online supports**

- tuDiabetes
 - childrenwithdiabetes.com
 - Diatribe.org
- Feel supported by others who understand the experience; share stories and strategies

Strengths-based communication

- Review what is going well in diabetes management:
 - Patient and family diabetes strengths
 - Ratings from resilience and self-management surveys
- Goal is to shift focus and tone of clinical encounters toward reinforcing strengths.



diabetes
STRENGTHS
— s t u d y —

Hilliard et al., 2018

Praise behavior, not numbers.

- ❑ So many influences on BG
 - ❑ Most control over diabetes management behaviors.
 - ❑ **Punishing** numbers → “Blame and shame” → not an effective strategy to change behavior or improve mood!

- ❑ Catch youth **doing well** with diabetes management:
 - ❑ More likely to happen again
 - ❑ Create positive atmosphere
 - ❑ Develop confidence & ownership



Set realistic goals.

- Major changes can be daunting
- Small changes, one step at a time
- Focus on **behavior** goals
- Each step achieved will reinforce management behaviors
- Celebrate each success!



Ways to Improve Well being

- Healthy coping
- Parents and Providers Stay involved in diabetes
- Decrease family conflict over diabetes

Healthy Coping

- Coping with and accepting diabetes is associated with better outcomes
 - “I have diabetes, but it does not define me.”
 - “It is hard work, but diabetes can be managed.”
 - “I will find ways to make diabetes work for me.”
- Some need to learn problem-solving and communication skills

Parents and Providers Stay Involved

Strategies:

1. Adapt involvement over time
2. Stay involved in different ways – words and actions
3. Don't transfer responsibility until ready
4. Create system for accountability

Supported by studies from Harris, Wysocki, Anderson, Laffel, and Weissberg-Benchell

Reduce Family Conflict

Strategies:

1. Calm, Care, and Consistency
 - Avoid displays of anger
 - Show empathy for struggles and praise often
 - Set clear rules and limits; set clear rewards and consequences
2. Refrain from “blame and shame”
3. Use general parenting strategies

Supported by studies from Rubin, Wysocki, Hood, Laffel, Grey, Berg, and Jacobson

Build Strong Relationships

- Empathy and respect for quality of life challenges
- Encourage social support building
- Repairing relationships when trust is lost
 - Identify common ground or goal
 - Return to it frequently
 - Make small plans towards that goal that fit expectations of both groups
 - Appreciate their frustrations while staying firm on non-negotiables

Thank you!

- Questions?
 - Case examples to discuss?
 - Specific challenges you are facing now?
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- Consultation?
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