Emotional, Psychological, and Social Issues of People with Diabetes

Gary K. Levenston, Ph.D.
Licensed Psychologist

DIABETES COALITION OF PALM BEACH COUNTY
DIABETES EDUCATIONAL SYMPOSIUM
APRIL 22, 2016
Financial Disclosure

I do not have any financial relationships relative to the content of this program.
Contact Information

Gary K. Levenston, Ph.D.
LevenstonPsychologicalServices@gmail.com
(571) 236-3688
Overall Goals

Promote a greater awareness of the psychosocial issues that can impact patients and families affected by diabetes.

Promote a greater understanding of actions that health care providers can take to help their diabetes patients connect with needed psychosocial support, resources, and services.
Program Objectives

Participants will:

(1) Develop an understanding of common mental and behavioral health conditions in diabetes populations.

(2) Describe at least three distressing emotional, psychological, and/or social issues commonly experienced by individuals and/or families living with diabetes.

(3) Demonstrate an understanding of current standards of care that pertain to psychosocial issues and identify practical approaches to address these issues in clinical practice.
What’s So Tough About Having Diabetes?

“What’s So Tough About Having Diabetes?

“As the outside, diabetes looks like it should be fairly simple. After all, all you have to do is take your insulin or oral medications every day at the right time and in the right amount, eat perfectly without ever “cheating,” check your blood glucose regularly, and exercise frequently. Balance these tasks with each other so that your blood glucose levels never get too low or too high. And don’t gain – or lose – too much weight. Stay vigilant at all times just in case something goes wrong. Finally, remember that you must continue to do all of this every day for the rest of your life, with no vacations from diabetes, ever!” – Diabetes Burnout (1999)
How should we think about those who seem to be ______?

- “unmotivated”
- “unwilling to change”
- “in denial”
- “non-compliant”
- “BAD DIABETICS”
- ___________

For starters, seriously contemplate the following premise:

*Very few people with diabetes are unmotivated . . . to live a long, healthy life.*
As a chronic health condition, diabetes is primarily self-managed, and there are countless potential obstacles to effective self management.

As clinicians, it is our challenge to identify those barriers and help our patients remove them (or at least minimize their influence).
“Advance understanding and awareness of the unmet needs of people with diabetes and their families”

Sources in Diabetic Medicine (2013), 30
- Nicolucci, A., et al., p. 767-77
- Kovacs Burns, K., et al, p. 778-88
- Holt, RIG, et al., p. 789-98
DAWN2 – Key Worldwide Findings

PEOPLE WITH DIABETES
- 14% had low enough wellbeing score consistent with depression
- 45% had elevated level of diabetes specific emotional distress
- Diabetes negatively impacts
  - interpersonal relationships (21%)
  - leisure activities (38%)
  - work/studies (35%)
  - financial situation (44%)
- 56% worried about hypoglycemia
- 39% taking meds interferes with ability to lead a normal life

FAMILY MEMBERS
- Diabetes negatively impacts their emotional wellbeing (45%)
- They themselves
  - had a high level of distress (40%)
  - worried about hypoglycemia (61%)
  - were frustrated not knowing how to help (37%)
- wanted more involvement in care (39%)
- wanted to help the PWD cope with feelings about diabetes (46%)
PSYCHOSOCIAL CARE

- 52% of healthcare professionals reported asking patients on a regular basis how diabetes affects their lives, but
  - Only 24% of PWD reported being asked
- 32% of PWD reported that in the prior 12 months they were asked by a member of their healthcare team about being anxious or depressed
- Among healthcare professionals
  - 59% -- would like to receive training in addressing patient psychosocial needs
  - Only 20% -- had received training in management of psychosocial aspects

See NDEP Webinar: “The DAWN2 Study: Putting the Results into Your Practice”
Mental & Behavioral Health Conditions

**Depression**
- Major Depressive Disorder (6.7% in gen. pop. 2x higher in diabetes populations)
- When depressive symptoms assessed via self-report, the rate is higher (12-27%). Rates even higher in adolescents than adults.
  - **Implications:** non-adherence, poor glycemic control, more long-term complications, decreased quality of life, and increased mortality

**Eating Disorders/Disordered Eating**
- T1D females 2x more at risk for eating disorder (ED) and about 2x more at risk for sub-clinical eating disorders than women without diabetes. (e.g., binge eating, caloric purging through insulin restriction)
  - **Implications:** poorer glycemic control, with higher rates of hospitalizations and retinopathy, neuropathy and premature death versus non-ED T1D women

Mental & Behavioral Health Conditions

While no more prevalent, these conditions warrant clinical attention:

Anxiety disorders/Issues
- Complicate treatment and are associated with poorer glycemic control (particularly with co-occurring depression)
  - Fear of needles/blood draws, generalized anxiety disorder
  - Anxiety after diagnosis and at onset of complications
  - Fear of hypoglycemia or hyperglycemia

Cognitive disorders
- Learning/attentional problems in youth - impacts self-management
- Cognitive dysfunction in aging patients – heightened risks

General Emotional Stress

- Stressful events often involve a “fight or flight” response, including release of stress hormones, which can result in elevated blood glucose.

- Highly stress-reactive individuals, particularly those with hostility/anger issues and/or depression, are at increased risk of cardiac problems.

- Stressors can be:
  - Acute (e.g., reprimand at work, road rage, pump failure, blood draw)
    - Note: in PWD, physiological anxiety symptoms can mimic hypoglycemia
  - Chronic (e.g., marital strife, work-life imbalance, worrisome rumination)
    - Note: in PWD, we see elevations in BG, which can, in turn exacerbate or contribute to irritability, labile mood, fatigue
Acute Stress of Venipuncture

- T1D pre-adolescent male, with prior history of aversive experiences
- Anticipatory worry and arousal
- Increased BG (on CGM)
- Post-draw, vasovagal response + anxiety, mis-attributed to low BG, and mistakenly treated with fast-acting glucose
Chronic stress and impact of hyperglycemia on mood

Facebook post – “Type Casted Diabetes”
Diabetes Distress

- Worries, fears, and concerns related to struggling with this progressive and demanding health condition

- Distinct from and much more prevalent than depression in PWD

- Associated with poor treatment adherence, glycemic control, and quality of life; even more worrisome when coupled with clinical or subclinical depression

- Even at moderate levels, should be a focus of clinical attention

Fisher et al. (2014) Diabetic Medicine, 31, 764-772
Diabetes Distress Scale (DDS)

- 17-item, patient rating scale
- Items scored “Not a problem” to “A very serious problem”
- Sensitive to change over time
- Starts a patient-centered, constructive dialog
- Available at BehavioralDiabetes.ORG (new versions under development)

Diabetes Distress Scale (DDS)

Yields total and subscale scores, with recommended interpretive score cutoffs.

- **Emotional Burden** (e.g., feeling overwhelmed by demands of living with diabetes, feeling helpless about averting serious long-term complications)

- **Regimen Distress** (e.g., feeling like failing with self-care, feeling unmotivated to keep up with diabetes management)

- **Interpersonal Distress** (e.g., feel like not getting enough emotional support from others)

- **Physician Distress** (e.g., not getting enough clear directions on how to manage diabetes, feeling like concerns are not taken seriously enough)
Adverse Outcome of Diabetes Distress: Burnout

Some possible indicators (Polonsky, 1999)

- Having strong, persisting negative feelings about diabetes
- Worrying about poor self-care but feeling unmotivated or unwilling to change
- Denying the importance of self-care and the likelihood of complications, but still feeling doomed
- Partially or totally quitting self-care
- Avoiding care tasks that could inform you of the consequences of your actions
Stress of a New Diagnosis

Shock, grief, denial

Lack of clear plans/expectations

Overwhelm with new/possibly conflicting information

Feeling afraid and vulnerable

“Happy Easter - don't expect too much!”
Social & Societal Stressors

Blame/Shame

Misinformation

“Diabetes Police”

Peer rejection/ridicule

“I’m Diabetes, and these are my constant companions: Stereotype, Ignorance and Rudeness.”
Jimmy Kimmel Live! (April 2015)

Hotel Transylvania
Columbia Pictures (2015)

"The scariest monster of all is diabetes!"
"Make sure you pour some out for your dead homies." — Greg Glassman #CrossFit #Sugarkills @CrossFitCEO
Standards relating to “Psychosocial” issues
“It is preferable to incorporate psychological assessment and treatment into routine care rather than waiting for a specific problem or deterioration in metabolic or psychological status.”

“Although the clinician may not feel qualified to treat psychological problems, optimizing the patient-provider relationship as a foundation may increase the likelihood of the patient accepting referral for other services.”
2016 ADA Standards of Medical Care in Diabetes

- **Initial Evaluation**
  - Assess for “psychosocial problems” and screen for depression (PHQ/EPDS), diabetes distress (DDS/PAID) and history substance use, and make referrals for “emotional health concerns”

- **Ongoing Care Management**
  - Additional screening opportunities: office visits, hospitalization, onset of complications, problems with diabetes management or quality of life
    - depression, diabetes distress, eating disorder, anxiety, cognitive impairment (age 65+), attitudes and expectations about diabetes and treatment, affect/mood, quality of life, resources (financial, social, and emotional), and psychiatric history
  - Address psychological and social factors that could impair the individual or family’s ability to carry out care tasks, and make referrals for:
    - possibility of self-harm, gross disregard for the medical regimen (by self or others), depression, stress related to work-life balance, debilitating anxiety, suspected eating disorder, or cognitive functioning that significantly impairs judgement
Many of the same recommendations, but providers are required to

- be capable of evaluating the educational, behavioral, emotional, and psychosocial factors that impact implementation of treatment plan

- work with patient and family to overcome barriers or redefine goals.

- negotiate a plan to resolve diabetes-specific family conflict, or make a referral.

Encourage developmentally appropriate family involvement in diabetes management tasks for children and adolescents....
Your Challenge (If you chose to accept it ....)

Make a goal and plan of action for incorporating something NEW into the way you practice that addresses the psychosocial challenges of diabetes (e.g., screening, patient education plan, independent study, professional training, etc.).

Make it S.M.A.R.T. (Specific, Measureable, Achievable, Realistic, Time-defined)

GOAL: ____________________________________________________________

PLAN OF ACTION:

• WHAT: __________________________________________________________

• BY WHOM: ____________________________________________________

• BY WHEN: _____________________________________________________
Some Other Practical Ideas for Clinical Practice
(SEEN HANDOUTS)

- **Anticipatory guidance** that normalizes diabetes distress and prepares patients and families for potential future challenges (e.g., “diaversaries”, starting school, adolescence, transition to adult care, complications, insulin initiation).

- Provide patients with **high-quality literature** on the emotional side of diabetes.

- Provide a **patient resource list** and keep it prominently displayed.

- Encourage **family members to attend appointments** and engage with them.

- **Make continuing education a priority** – e.g., lunch-and-learn video series; webinars; training in behavior change techniques (UPCOMING EVENTS).

- Use the DAWN Study person-centered dialogue tools to facilitate better collaboration and communication with patients (www.dawnstudy.com).

- **Host support groups** for your patients at your practice.
Patient Social Support Resources

Online Internet Communities

I can not thank you all enough! I appreciate having a place where I can learn and have support without judgement! You guys are life savers! Thank you!

Like · 3 · Reply · More · 11 hours ago

Diabetes Support Conferences

Diabetes Camping
More practical ideas for clinicians...
High-quality Patient Handouts

BehavioralDiabetes.org

THE EMOTIONAL SIDE OF DIABETES

10 THINGS YOU NEED TO KNOW

2ND EDITION

DON'T FREAK OUT!

10 important things to know when you've been diagnosed with type 2 diabetes

BREAKING FREE FROM DEPRESSION AND DIABETES

10 THINGS YOU NEED TO KNOW AND DO
High-quality Patient Handouts
BehavioralDiabetes.org
Laughter can be good medicine, too!
Contact Information

Gary K. Levenston, Ph.D.
LevenstonPsychologicalServices@gmail.com
(571) 236-3688