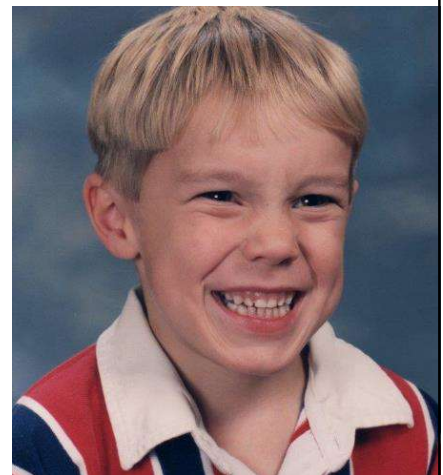





Diabetes Burnout: What is It, What Contributes to It, and How Do We Best Treat It?

Quinn Nystrom, M.S.





"When you are diagnosed, it feels like the universe has just handed you a new job with no pay and no vacations. If you are going to manage it, it takes effort and vigilance. That's why it's this balancing act."

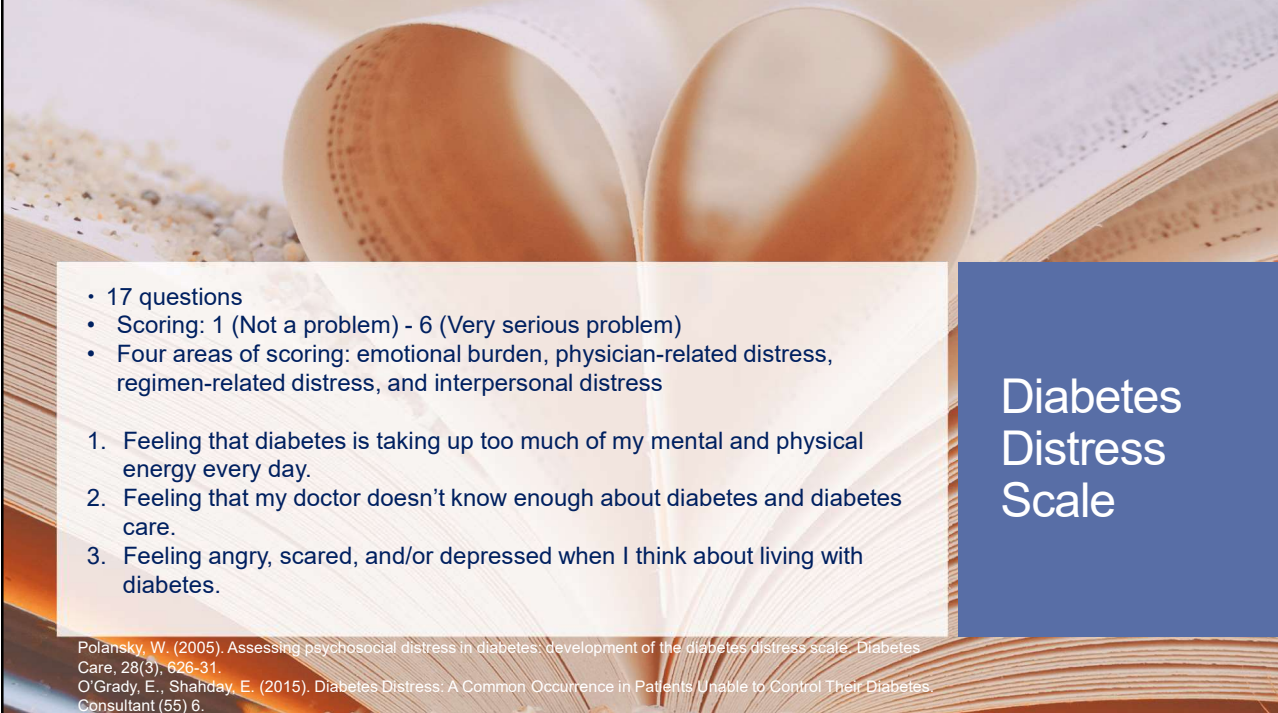
WILLIAM POLONSKY, PHD, CDE

What is it?

Diabetes Burnout

- A state of mental, emotional, and physical exhaustion following an apathetic detachment from one's illness identity, diabetes self-care behaviors, and support systems, which is commonly accompanied by a feeling of powerlessness.

Abdoli, S. (2019). Experiences of Diabetes Burnout: A Qualitative Study Among People with Type 1 Diabetes. *American Journal of Nursing, (119)* 22-31.



• 17 questions
• Scoring: 1 (Not a problem) - 6 (Very serious problem)
• Four areas of scoring: emotional burden, physician-related distress, regimen-related distress, and interpersonal distress

1. Feeling that diabetes is taking up too much of my mental and physical energy every day.
2. Feeling that my doctor doesn't know enough about diabetes and diabetes care.
3. Feeling angry, scared, and/or depressed when I think about living with diabetes.

Diabetes Distress Scale

Polansky, W. (2005). Assessing psychosocial distress in diabetes: development of the diabetes distress scale. *Diabetes Care*, 28(3), 626-31.
O'Grady, E., Shahday, E. (2015). Diabetes Distress: A Common Occurrence in Patients Unable to Control Their Diabetes. *Consultant* (55) 6.

What contributes to it?

- Blood glucose meter
- Blood glucose test strips
- Ketone strips
- Lancing device
- Lancets
- Continuous Glucose Monitor & Sensor
- Alcohol swabs
- Syringes
- Insulin pump supplies
- Batteries
- Glucose tablets
- Glucagon kit
- Waterproof tape
- Adhesive remover
- Frio cooling wallet

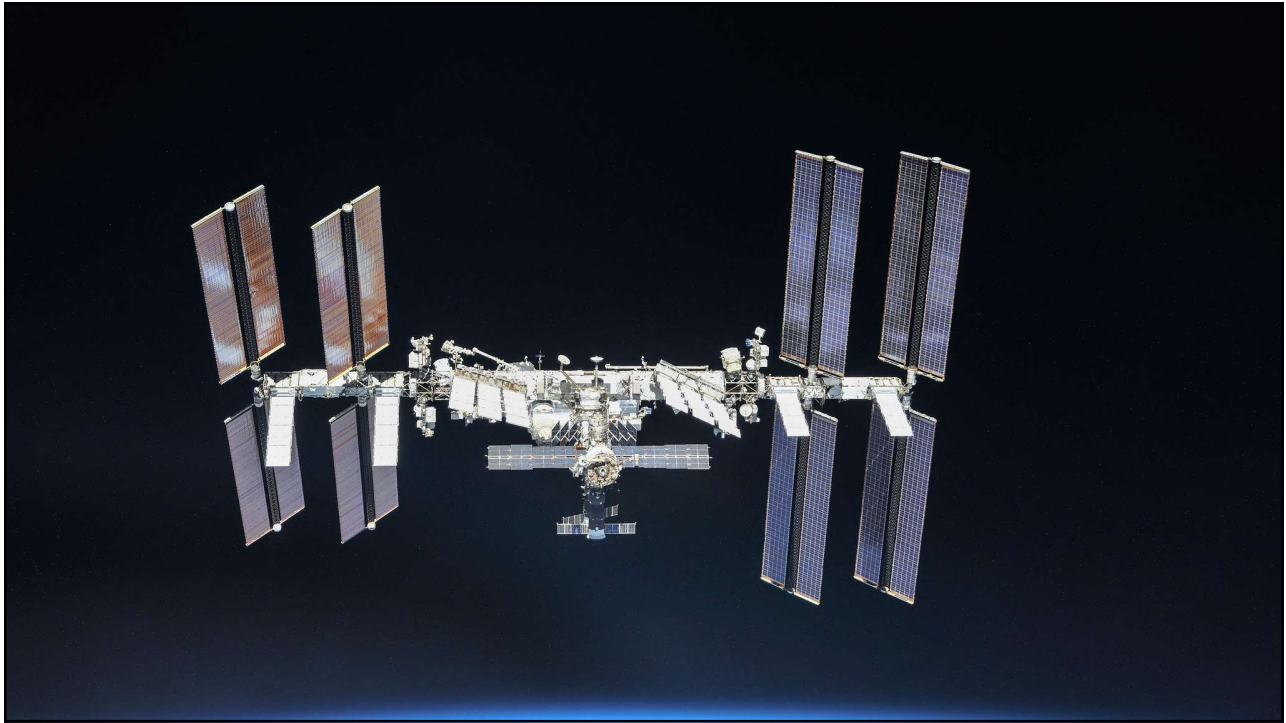


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Factors That Affect BG

Food	Biological
<ul style="list-style-type: none"> ↑↑ 1. Carbohydrate quantity →↑ 2. Carbohydrate type →↑ 3. Fat →↑ 4. Protein →↑ 5. Caffeine ↓ 6. Alcohol ↓↑ 7. Meal timing ↑ 8. Dehydration ? 9. Personal microbiome 	<ul style="list-style-type: none"> ↑ 20. Insufficient sleep ↑ 21. Stress and illness ↓ 22. Recent hypoglycemia →↑ 23. During-sleep blood sugars ↑ 24. Dawn phenomenon ↑ 25. Infusion set issues ↑ 26. Scar tissue and lipodystrophy ↓↓ 27. Intramuscular insulin delivery ↑ 28. Allergies ↑ 29. A higher glucose level ↓ 30. Periods (menstruation) ↑↑ 31. Puberty ↓ 32. Celiac disease ↑ 33. Smoking
Medication	
<ul style="list-style-type: none"> →↓ 10. Medication dose ↓↑ 11. Medication timing ↓↑ 12. Medication interactions ↑↑ 13. Steroid administration ↑ 14. Niacin (Vitamin B3) 	
Activity	Environmental
<ul style="list-style-type: none"> →↓ 15. Light exercise ↓↑ 16. High-intensity and moderate exercise →↓ 17. Level of fitness/training ↓↑ 18. Time of day ↓↑ 19. Food and insulin timing 	<ul style="list-style-type: none"> ↑ 34. Expired insulin ↑ 35. Inaccurate BG reading ↓ 36. Outside temperature ↑ 37. Sunburn ? 38. Altitude
	Behavioral & Decision Making
	<ul style="list-style-type: none"> ↓ 39. Frequency of glucose checks ↓↑ 40. Default options and choices ↓↑ 41. Decision-making biases ↓↑ 42. Family relationships and social pressures





Graduate School
Research

Social Learning Theory

- Albert Bandura
- Perceived self-efficacy is conceptualized as perceived operative capability.
- “Human behavior has often been explained in terms of unidirectional causation, in which behavior is shaped and controlled either by environmental influences or by internal dispositions”.
- Scare tactics are ineffective.

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Q12: How helpful is your diabetes medical team in helping you with the management of your diabetes?

- 15 - very helpful
- 10 - pretty good or fair
- 7 – responded with criticism

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Conclusions

- 75% told of a person having misinformation.
- 40.6 % reported that they had a negative experience where they were called overweight.
- 71% say a motivating factor in improving self-management is curability/controllability.

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“
People with diabetes do what anyone else does: very few of us can follow every single healthy habit or change, so we choose the ones we can.”

- Bill Polonsky

Mental Health

- 33-50% of people with diabetes will experience diabetes distress at some point
- Up to 45% of mental health conditions and cases of severe psychological distress go undetected among patients being treated for diabetes.

Fisher, L., Polonsky, W. H., Hessler, D. M., Masharani, U., Blumer, I., Peters, A. L., Bowyer, V. (2015). Understanding the sources of diabetes distress in adults with type 1 diabetes. *Journal of Diabetes and Its Complications*, 29(4), 572-577.
 Li, C., Ford, E. S., Zhao, G., Balluz, L. S., Berry, J. T., & Mokdad, A. H. (2010). Undertreatment of mental health problems in adults with diagnosed diabetes and serious psychological distress: the behavioral risk factor surveillance system, 2007. *Diabetes care*, 33(5), 1061-1064.

Other Autoimmune Diseases

- Celiac Disease
- Thyroid
- MS
- Lupus
- Gastritis
- Addison's Disease
- Vitiligo
- Autoimmune arthritis

Witek, P., Witek, J., Pankowska, E. (2012) Type 1 diabetes-associated autoimmune diseases: screening, diagnostic principles and management. *Med Wieku Rozwoj.* 16(1):23-34.

Mental Health

- People living with type 1 or type 2 diabetes are at increased risk for depression, anxiety and eating disorders.
- Rates of depression across the lifespan are 2 times greater for people with diabetes than in the general population.
- People with type 1 diabetes are twice as likely to live with disordered eating.
- In women with type 1 diabetes, bulimia is most common eating disorder while women with type 2 diabetes are more likely to deal with binge eating.
- It is estimated that only around 1/3 of people with diabetes and mental health conditions receive a diagnosis and proper treatment.

Ducat, L., Philipson, L. H., & Anderson, B. J. (2014). The mental health comorbidities of diabetes. *JAMA*, 312(7), 691–692.
 2 Eating Disorders. (n.d.). Retrieved from <http://www.diabetes.org/living-with-diabetes/treatment-and-care/women/eating-disorders.html>

Financial Distress

- Diabetes is the most expensive health condition in U.S.
 - 57.6% of the \$ paying for pharmaceuticals
- 2.3x greater health care costs for Americans with diabetes
- \$327B annual cost of diagnosed diabetes in America
- \$1 in \$7 health care dollars is spent treating diabetes and its complications
- Price of insulin has skyrocketed 1200% in the past 20 years

American Diabetes Association. (2017). The Cost of Diabetes. Retrieved from <https://www.diabetes.org/resources/statistics/cost-diabetes>.

Appold, K. (2020). What Will Be the Most Costly Medical Conditions in 10 Years?. *MHE Publication*. 30(3).

Financial Distress

- 40% of American patients with diabetes report financial hardship
 - Including patients with health insurance
- 46% of people with diabetes have reported difficulty in affording food, cost-related medication underuse, housing instability and energy instability, and poor diabetes control.
- The report concluded that “the efforts of patients and clinicians are insufficient in situations where patients could not afford basic needs.”
- 1 in 2 people with diabetes can’t afford or get access to insulin worldwide
- Only 3% of people globally can afford a Continuous Glucose Monitor (CGM)

Patel, M. (2016). Financial stress: a barrier to diabetes care. *Practical Patient Care*. Retrieved from <https://www.practical-patient-care.com/features/featurefinancial-stress-a-barrier-to-diabetes-care-5683743>.

Suthar, M. (2020). 40% of American Patients with Diabetes Report Financial Hardship. *Diabetes in Control*. Retrieved from www.diabetescontrol.com/40-of-American-patients-with-diabetes-report-financial-hardship/.

How do we best treat it?

Language

- The biggest problem with terms like “non-compliant” — is its impact on the person with diabetes and their motivation and empowerment to improve their health.
- “Words have the power to ‘elevate or destroy.’ This is also true of language referring to persons with diabetes, which can express negative and disparaging attitudes and thereby contribute to an already stressful experience of living with this disease. On the other hand, encouraging and collaborative messages can enhance health outcomes.”

Dickinson, J. (2017). The Use of Language in Diabetes Care and Education. *Diabetes Care*, 40, 1790-1791.

What if...

- Their health insurance won't cover adequate diabetes education.
- They can't get affordable health insurance and are paying out-of-pocket for every visit.
- They have a severe phobia of needles or swallowing pills but no one asked that when prescribing insulin injections or oral medications.
- They're struggling with depression, anxiety, or diabetes burnout.
- Another major life event (like a death, a divorce, childcare, changes in employment) is significantly affecting their ability to make diabetes management a priority.
- The side effects of their medications are unbearable and they've stopped taking them.
- They were never educated on the purpose and value of taking that medication.
- They live in an unsafe home, facing daily abuse.
- They don't have the financial resources for the costs of test strips and medications.

Vieira, G. (2020). "I Struggle with Diabetes. Don't Call Me 'Non-Compliant'". *Nativeweb*. Retrieved from <http://www.healthline.com/diabetesmine/i-struggle-with-diabetes-dont-call-me-non-compliant>

Barriers to Adherence

- Ineffective coping skills
- Lack of support from family and friends
- Misconceptions about the disease and its treatment
- Inability to understand, purchase, and use medications
- Poor nutritional choices
- Lack of availability of better food options
- An environment that is not conducive to physical activity
- Poor self-efficacy (i.e., the confidence that they can achieve long-term behavioral change)

O'Grady, E., Shahday, E. (2015). Diabetes Distress: A Common Occurrence in Patients Unable to Control Their Diabetes. *Consultant* (55) 6.

Can diabetes cause mental illness?

Changes in blood sugar can cause rapid changes in mood and other mental symptoms such as fatigue, trouble thinking clearly, and anxiety. Having diabetes can cause a condition called diabetes distress which shares some traits of stress, depression and anxiety.

Diabetes and Mental Health. (2020). Retrieved from <https://www.mhanational.org/diabetes-and-mental-health#1>.

Recommendations

1. Use Language That is neutral, nonjudgmental, and based on facts, actions, or physiology/biology.
2. Use language that is free from stigma.
3. Use language that is strengths based, respectful, inclusive, and imparts hope.
4. Use language that fosters collaboration between patients and providers.
5. Use language that is person centered.

Dickinson, J. (2017). The Use of Language in Diabetes Care and Education. *Diabetes Care*, 40, 1791-1797.

Helpful communication

- Upfront communication
- Work with the person with diabetes on perceptions of their illness and diagnosis.
- Involve the patient in self-management decisions, regardless of age.
- Take time to build resiliency with the patient.
- Involved all members of a person's family.
- Continue with educating yourself on diabetes and current research.
- Speak about the elephant in the room.

✘ Instead of...	✔ Try saying...	💬 Explanation
A diabetic	Person (living) with diabetes	There is much more to a person than their diabetes, so it is preferable to avoid labeling someone as a disease.
Control (as a verb or adjective)	Manage	Control is virtually impossible to achieve in a disease where the body no longer does what it is supposed to do, so it is preferable to focus on what the person is doing well and intent.
Control (as a noun): glucose control, good control, bad control, etc.	A1c, blood glucose levels, targets, goal, stability, variability	Focusing on neutral words and the biology removes judgment, shame, or blame.
Lifestyle disease	Diabetes	Saying "diabetes" instead of "lifestyle disease" removes any implied judgment.
Cheating, sneaking Good/bad/poor	Making decisions Choices Numbers Food	Moving away from value judgments to neutral language removes any implied judgment.
Nondiabetic, normal	Person without diabetes	The opposite of "normal" is "abnormal," and people with diabetes are not abnormal.
Test (blood sugars)	Check blood sugars	A test implies good/bad or pass/fail. Checking blood glucose is simply a way to gather information to make decisions.
Prevent, prevention	Reduce risk	There is no guarantee of prevention (disease or complication); therefore, focusing on what the person can do limits blame if the person does develop diabetes or complications.
Compliant/compliance Adherent/adherence	Engagement Participation Involvement	Compliance and adherence imply doing what someone else wants. In diabetes care, people make choices and perform self-management.
Victim, suffer, etc.	Lives with diabetes Has diabetes Diagnosed with diabetes	Assuming that someone is suffering puts them in victim mode rather than empowering them.

Anticipate the Patient's Feelings

- "I am guessing you must be overwhelmed and frustrated to have to do all of these things day after day. Is that accurate?"
- "My intuition tells me you feel defeated. Does that seem true?"
- "You seem to feel you like can't get this diabetes under control. Is that right?"

O'Grady, E., Shahday, E. (2015). Diabetes Distress: A Common Occurrence in Patients Unable to Control Their Diabetes. Consultant (55) 6.



Getting Help

- Cognitive-behavioral therapy (CBT)
- Family therapy
- Dialectical-behavioral therapy (DBT)
- Medication

A, J., Lustman, J. P., Scherrer, F. J., Salas. (2016). Antidepressant medication use and glycemic control in co-morbid type 2 diabetes and depression. Retrieved from <https://academic.oup.com/fampra/article/33/1/30/2450739>
 Mental Health America. "Diabetes and Mental Health". Retrieved from <https://www.mhanational.org/diabetes-and-mental-health#4>

Conclusion

- “The paradigm of diabetes care and education is moving past an approach that views the health care provider as the expert who tells people with diabetes what to do. It is moving toward an approach where people with diabetes are the central members of their care teams, experts on their experiences, and integral to the management of their disease.”

Dickinson, J. (2017). The Use of Language in Diabetes Care and Education. *Diabetes Care*, 40, 1797.

www.QuinnNystrom.com

