



Type 1 Diabetes Resilience: Recognizing and Developing It

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Introduction

Type 1 diabetes (T1D) is a chronic condition requiring a lifetime of effective self-management for optimal outcomes, and those with T1D often face ongoing challenges related to the stress and burden of having a chronic disease.¹⁻³ Broadly, they must learn to integrate self-management practices into daily routines, deal with the financial costs of the disease, and face potential social stigma or even discrimination associated with having T1D.^{1,3-5} Additionally, they must learn to cope with difficulties in achieving and maintaining glycemic goals and other treatment targets and slowing the onset of diabetes-related complications.^{1,3} Even sleep may be negatively affected.⁶

Despite these challenges, many individuals with T1D are resilient and able to thrive and live healthy, satisfying lives.⁷ What is their secret? Researchers are now working to answer that question by studying “diabetes resilience,” with the goal of learning what people with T1D can do to successfully manage their disease, regardless of the difficulties it presents.^{8,9}

Resilience: A Goal Worth Working Toward



Although resilience has sometimes been thought of as a personality trait, it is better defined as the achievement of positive outcomes in the face of adversity or significant risk.^{8,10} Examples of resilience in T1D may include maintaining good quality of life, attaining glycemic targets, minimizing risk of complications, and avoiding hypoglycemia, diabetic ketoacidosis, and diabetes-related hospitalizations.^{8,11} It is also important for those with T1D to have good experiences in other parts of their lives, such as satisfying social relationships and successes at work.⁸

Defining resilience as the achievement of positive behavioral and health outcomes in the face of stress—rather than as a fixed trait that people have or don't have—makes room for the possibility that most individuals can become resilient in some areas of their lives and that this resilience can be developed as new challenges or situations arise.^{7,8} For example, a child with T1D may be struggling socially and in school but, with encouragement and support from parents and doctors, works hard to implement more glucose monitoring and insulin injections, thereby demonstrating resilience in management behaviors.⁸

Fostering Resilience in Individuals



Each person with diabetes has a unique set of strengths, beneficial behaviors, positive attitudes, and support systems that they use to cope with challenges and support positive behavioral and health outcomes.⁸ Clinicians can help patients cultivate resilience by identifying these strengths and finding ways to leverage them to support diabetes care.¹⁰



Individual Strengths

- ▶ What does the patient do well?
- ▶ What does the patient enjoy doing?
- ▶ How could these strengths be used to help overcome challenges in diabetes management?

Examples: Certain personal characteristics can be used to address difficulties encountered in diabetes management. An individual who is self-assured and confident, for example, may be better able to avoid getting discouraged when faced with the demands of T1D. A person with a sense of humor may be more able to cope with challenging experiences and minimize diabetes burnout. An individual who is creative may feel empowered to find new solutions to address diabetes-related barriers.



Key External Assets

- ▶ What social and environmental assets does the patient possess that could be used to combat adversity?

Examples: Perhaps the patient is a child with T1D who has supportive parents and family members. The patient may be a young adult with a roommate who wants to learn how to help in emergencies. An older individual may have a spouse or an involved adult child or caregiver who can join them for doctor visits. A person may have good health literacy that enables him to navigate healthcare systems or seek out people who can help. An individual may have excellent health insurance coverage or may live near a major diabetes center.

Diabetes Online Communities



Social media allows individuals with T1D to find peer support from others with T1D through various online platforms.¹² Despite the potential risks of misinformation and privacy concerns, the diabetes online community offers a host of benefits, including peer support, and opportunities for self-expression, humor, and information sharing.⁴ Blogging can also be a resource for diabetes caregivers and patients and provides a platform for discussing personal experiences.¹² In fact, individuals who participate substantially in the diabetes online community or in T1D-themed blogs are more likely to have lower blood glucose levels than those who participate less.^{12,13} They also report high levels of diabetes self-care and quality of life.¹³

Role of Mental Health Professionals in Promoting Resilience



Psychologist, social workers, and other mental health professionals contribute to diabetes resilience by addressing psychosocial symptoms as well as problems with adjusting to having a chronic disease. They also help people with diabetes develop strategies to manage the relentless demands of self-management.¹⁴ Studies have found that individuals with diabetes have an increased risk of developing depression, anxiety, and disordered eating, which can affect diabetes self-management and the ability to reach glycemic targets. Referral to mental health professionals to prevent or manage these and other psychological difficulties can not only optimize quality of life but can also improve involvement with treatment plans. Psychologists and other mental health professionals can also help by teaching coping strategies, facilitating supportive family relationships, teaching social skills to obtain support, and using behavioral strategies to help patients achieve self-management goals.¹⁴

TIPS FOR TEACHING PATIENTS COPING STRATEGIES

Positive coping strategies, such as problem-solving, emotional expression, acceptance, and even distraction, are associated with resilient outcomes including lower HbA1c levels and improved quality of life compared with coping strategies that involve maladaptive or avoidant behaviors, such as denial, withdrawal, or wishful thinking.¹⁵ Increased levels of stress, however, can interfere with an individual's ability to apply positive strategies and can result in a greater reliance on disengagement strategies.^{15,16} To help individuals with T1D use healthy coping strategies, clinicians can:

- ▶ **Suggest individualized coping strategies** that fit patient skills, strengths, and assets. Tailoring coping strategies to each individual can help them discover approaches that work for them.⁹ For example, if a person is a “planner” and likes to be organized, discuss using a more structured approach that incorporates goal-setting and strategic problem-solving.¹⁷ An individual who is more intuitive might prefer strategies that rely on accessing sources of social support or using relaxation techniques.¹⁶
- ▶ **Align diabetes recommendations with patient goals.** It is important for clinical recommendations to match an individual's priorities and preferences to maximize engagement and motivation.^{7,13,18} For example, clinicians may be more likely to focus on glycemic targets and other T1D-related health outcomes, whereas patients may want to lessen the daily burden of managing the condition. In this situation, you might consider ways to give priority to an individual's goal while trying to find common ground. People with T1D may have an easier time maintaining motivation if their clinician's recommendations support their own goals and concerns.⁷

Diabetes Technology: Help or Hindrance?

Diabetes management technologies, such as continuous glucose monitoring (CGM) and/or insulin pumps, aim to decrease the burden of daily diabetes management tasks and improve clinical outcomes and quality of life.¹⁷ Therefore, these technologies are potential methods of fostering resilience. However, the sheer volume of data and added device maintenance may be burdensome for some individuals. For example, CGM may promote a sense of control and competence in a person who is analytical or enjoys working with numbers or patterns, but the same technology may be stressful for an individual who is overwhelmed by data or the noises or alarms generated by the devices. Additionally, a person who is having a difficult time coping with the relentlessness of T1D may find that the addition of technologies only contributes to feeling overwhelmed.¹⁷ More research is needed to fully realize the effects of diabetes technology on coping and resilience in T1D and which patients might benefit most from its use.

Start the Conversation: Patient Engagement to Promote Resilience

When having conversations with patients about diabetes, clinicians should take care to not underestimate the power of words.¹⁸ A key element in effective patient engagement is to reinforce positive behaviors while avoiding the expression of negative or disparaging attitudes.¹⁸ Start the visit on a positive note with a strengths-based approach to support your relationship with the patient and optimize outcomes.⁹ Simply asking what is going well, taking the time to empathetically listen, and sharing in the patient's sense of accomplishment, rather than immediately delving into difficulties and deficits, can help create a positive and supportive tone to the clinic visit.^{2,18}

Examples of Conversation Starters in T1D

"What is a challenge that you've recently overcome with your diabetes?"

"I noticed that you seem calmer than the last time I saw you. What have you been doing to feel less overwhelmed by the numbers on your CGM?"

"I'm here to support you—let's celebrate your successes together, and let's also work on your diabetes goals."

"Before we talk about your A1c, what is something you have had success with in your diabetes management recently?"

"What is a positive change that you've made in your diabetes recently?"

"I see that you are really trying to do a good job at managing your diabetes."

It also matters what family members and caregivers say to their loved ones with T1D.¹⁸ Clinicians can encourage loved ones to engage in positive communications and feedback by explaining that upbeat, non-critical approaches are more beneficial than critical or negative approaches.⁹ Some examples that you can share with your patient's family members or caregivers are shown in Table 1.

TABLE 1. Examples for Family Members and Caregivers of People With T1D

CRITICAL	SUPPORTIVE
Your blood glucose is too high. You need to take better care of yourself.	I know that managing your blood glucose is hard work. How can I help you with that?
If you don't get your blood sugar under control now, you're going to have complications later on.	What can I do now to support your diabetes goals?
Cheer up, your diabetes could be a lot worse.	I am here to just listen if you need to complain or vent about your diabetes.

Additional Resources



We hope that you found this to be a helpful summary on identifying and fostering resilience in your patients with T1D. The following are a selection of trusted online resources that provide education and support for persons with T1D, their family members, and caregivers that you and your patients may find helpful:

- Beyond Type 1 (<https://beyondtype1.org>)
- TypeOneNation, JDRF (<https://typeonenation.org>)
- PEP Squad, Diabetes Research Institute Foundation (www.diabetesresearch.org/PEP-Squad)

References

1. Fisher L, Polonsky WH, Hessler DM, et al. Understanding the sources of diabetes distress in adults with type 1 diabetes. *J Diab Complications*. 2015;29(4):572-577.
2. Davidson M, Penney ED, Muller B, Grey M. Stressors and self-care challenges faced by adolescents living with type 1 diabetes. *Appl Nurs Res*. 2004;17(2):72-80.
3. Monaghan M, Helgeson V, Wiebe D. Type 1 diabetes in young adulthood. *Curr Diabetes Rev*. 2015;11(4):239-250.
4. Hilliard ME, Sparling KM, Hitchcock J, Oser TK, Hood KK. The emerging diabetes online community. *Curr Diabetes Rev*. 2015;11(4):261-272.
5. Powell PW, Corathers SD, Raymond J, Streisand R. New approaches to providing individualized diabetes care in the 21st century. *Curr Diabetes Rev*. 2015;11(4):222-230.
6. Jauch-Chara K, Schmid SM, Hallschmid M, Born J, Schultes B. Altered neuroendocrine sleep architecture in patients with type 1 diabetes. *Diabetes Care*. 2008;31(6):1183-1188.
7. Lord JH, Rumburg TM, Jaser SS. Staying positive: positive affect as a predictor of resilience in adolescents with type 1 diabetes. *J Pediatr Psych*. 2015;40(9):968-977.
8. Hilliard ME, Harris MA, Weissberg-Benchell J. Diabetes resilience: a model of risk and protection in type 1 diabetes. *Curr Diab Rep*. 2012;12(6):739-748.
9. Hilliard ME, Eshtehardi SS, Minard CG, et al. Strengths-based, clinic-integrated nonrandomized pilot intervention to promote type 1 diabetes adherence and well-being. *J Pediatr Psychol*. 2019;44(1):5-15.
10. Hilliard ME, McQuaid EL, Nabors L, Hood KK. Resilience in youth and families living with pediatric health and developmental conditions: introduction to the special issue on resilience. *J Pediatr Psychol*. 2015;40(9):835-839.
11. Yi-Frazier JP, Hilliard M, Cochrane K, Hood KK. The impact of positive psychology on diabetes outcomes: a review. *Psychology*. 2012;3:1116-1124.
12. Oser TK, Oser SM, McGinley E, Stuckey HL. A novel approach to identifying barriers and facilitators in raising a child with type 1 diabetes: qualitative analysis of caregiver blogs. *JMIR Diabetes*. 2017;2(2):e27.
13. Litchman ML, Edelman LS, Donaldson GW. Effect of diabetes online community engagement on health indicators: cross-sectional study. *JMIR Diabetes*. 2018;3(2):e8.
14. Kichler JC, Harris MA, Weissberg-Benchell J. Contemporary roles of the pediatric psychologist in diabetes care. *Curr Diabetes Rev*. 2015;11(4):210-221.
15. Jaser SS, White LE. Coping and resilience in adolescents with type 1 diabetes. *Child Care Health Dev*. 2011;37(3):335-342.
16. Jaser SS, Faulkner MS, Whittemore R, et al. Coping, self-management, and adaptation in adolescents with type 1 diabetes. *Ann Behav Med*. 2012;43(3):311-319.
17. Prahalad P, Tanenbaum M, Hood K, Maahs DM. Diabetes technology: improving care, improving patient-reported outcomes and preventing complications in young people with type 1 diabetes. *Diabet Med*. 2018;35(4):419-429.
18. Dickinson JK, Guzman SJ, Maryniuk MD, et al. The use of language in diabetes care and education. *Diabetes Care*. 2017;40(12):1790-1799.