

Management of Type 1 Diabetes: A Family Affair

Emily Grubbs



MISSISSIPPI STATE
UNIVERSITY™

Human Development
and Family Science

What is Type 1 Diabetes (T1D)?

- T1D is an autoimmune disease that destroys the body's ability to produce insulin, the hormone that converts food into energy.
- We cannot survive without insulin.
- T1D is incurable and irreversible.
- T1D cannot be prevented.

(Centers for Disease Control and Prevention, 2017; World Health Organization, 2016)



MISSISSIPPI STATE
UNIVERSITY™

Human Development
and Family Science

T1D Management

- Managing T1D is a lot of work, even with technological advances (Mackey et al., 2016).
- Management involves
 - careful monitoring of blood glucose levels through finger prick tests or continuous glucose monitors,
 - Self-administration of synthetic insulin through infusion pump or multiple daily injections,
 - carbohydrate counting to determine the corresponding insulin amount,
 - living a healthy, active lifestyle (World Health Organization, 2016).
- Consequences of nonadherence include hyperglycemia and hypoglycemia, both of which can quickly lead to seizures, comas, and death, and over time, can lead to organ failure and death.
- Requires constant vigilance and time-consuming adherence 24/7 (Feldman et al., 2018).



T1D & Social Support

- Managing T1D is easier with social support.
- T1D is a lifelong disease that can emerge very early in life, thus the very young and very old may depend on others for their diabetes management.
- In instances of hyper/hypoglycemia, the person with T1D will be physically and/or cognitively compromised and may need assistance from someone else to administer treatment.

(Kelly & Berg, 2018).



MISSISSIPPI STATE
UNIVERSITY™

Human Development
and Family Science

Social Support & T1D Outcomes

- Social support relates to better diabetes outcomes (de Wit, Trief, Huber, & Williang, 2020).
 - Lower reported diabetes distress
 - Higher reported diabetes empowerment
 - Better glycemic control
 - More frequent adherence behaviors such as blood glucose monitoring, exercising, and healthy eating (Joensen, Almdal, and Williang, 2013).
- Diabetes-specific social support has been found to be even more strongly correlated with positive emotional and physical diabetes-related outcomes (Joensen et al., 2016).



Social Support from Family

- Family is the most likely source and the most potent source for T1D support (Trief, Fisher, & Hopkins, 2020; de Wit, Trief, Huber, & Williang, 2020).
- However not all family interactions are healthy or helpful, meaning that not all diabetes-related “support” offered by family members is actually supportive.



Family Involvement: Helping or Hindering?

- The literature reveals that not all family involvement is helpful.
- In one study
 - 75% of respondents reported supportive family involvement in diabetes self-care
 - e.g., compassion, listening, suggesting; actions that support and encourages autonomy
 - 78% of respondents reported negative family involvement in diabetes self-care
 - e.g., criticizing, overbearing, bossing; actions that compromise and constrict autonomy
- Even when family members thought they were being helpful, they were actually hindering their loved one's T1D management.

(Rosland, Heisler, Hwa-Jun, Silveira, & Piette, 2010).



What Helps & What Hinders? Supporting & Constricting Autonomy

- Assistance and support from family members needs to be encouraging and autonomy-building, not critical and autonomy-constricting.
- Autonomy has been identified as an important factor in diabetes management and treatment adherence.
- If a person feels more autonomous, he or she is more likely to adhere to treatment behaviors and have better health outcomes.
- Constricting autonomy can cause a person to actually believe that he or she is not capable of managing life with T1D.

(Kelly & Berg, 2018; Rosland et al., 2011)



MISSISSIPPI STATE
UNIVERSITY™

Human Development
and Family Science

Self-Determination Theory (SDT)

- A theory of motivation (R. M. Ryan & E. L. Deci)
 - People who have T1D must be highly motivated to perform all the adherence behaviors required to survive and be healthy with this disease.
- Identifies autonomy as a basic psychological need.
- The literature shows that autonomy-building family involvement yields the best outcomes in terms of adherence behaviors, and psychological, emotional, and physical T1D-related results.

(Ng et al., 2012)



MISSISSIPPI STATE
UNIVERSITY™

Human Development
and Family Science

Autonomy-Building: Do's & Don't's

- **Do**

- Be empathetic to emotions and feelings about T1D
- Respect and accept the individual
- Praise individual for adherence behaviors and encourage him/her to continue
- Allow individual to have developmentally and situationally appropriate amount of choice in handling personal care
- Only take control of the situation when necessary (due to extreme hyper/hypoglycemia)
- Offer input in the form of suggestion (rather than in the form of opinion)
- Employ active problem-solving strategies (rather than passive avoidance strategies)

(Kelly & Berg, 2018; Ng et al., 2012; Rosland et al., 2010; Rosland et al., 2011; Joensen, Almdal, and Williang, 2013; Joensen et al., 2016; Mayberry & Osburn, 2014)



Autonomy-Building: Do's & Don't's

- **Don't**
 - Control
 - Criticize
 - Overprotect
 - Constrict the individual's involvement in own T1D care
 - Ignore the emotions and opinions of the person living with T1D
 - “Nag” about maintaining adherence behaviors
 - Criticize for “failing” to adhere to management behaviors
 - Argue with the person about disease management decisions (instead use problem-solving strategies)

(Kelly & Berg, 2018; Ng et al., 2012; Rosland et al., 2010; Rosland et al., 2011; Joensen, Almdal, and Williang, 2013; Joensen et al., 2016; Mayberry & Osburn, 2014)



Need for New Intervention

- An intervention is needed to aid families in supporting their loved one living with T1D.
- Intervention needs to increase family members' autonomy-supportive behaviors and decrease their autonomy-constrictive behaviors.
- SDT can guide the design of this family intervention as it identifies autonomy as a basic human need.
- This intervention should be disease-specific as diabetes-specific social support is found to be more potent than general support (Joensen, et al., 2016).
- This intervention can target the individual living with T1D at all ages and their families because support and assistance is beneficial for people of all ages, especially the very young and the very old (Kelly & Berg, 2018).
- This intervention could result in improved family support for the person living with T1D and improved T1D management and outcomes.



Current Interventions

- Mostly pilot studies with mixed results
(de Wit, Trief, Huber, & Williang, 2020)
- No current frontrunner
- Few are disease-specific or family-centered
- Most are pilot studies targeting adolescents



Looking Towards the Future...

- Implications for Practice:
 - It is important that Family Life Educators equip families to best assist and support their loved ones.
- Implications for Research:
 - An exciting avenue for future research includes designing and piloting a disease-specific family intervention program that is built on SDT and focused on promoting autonomy.
- Implications for Policy
 - Until further research has been conducted, we cannot officiate policies and protocol.



Conclusion

- Managing T1D requires a lot of motivation to comply with numerous adherence behaviors.
- Disease-specific social support can lead to better health outcomes, especially when the support comes from family members.
- However, not all family involvement is helpful.
- There is a need for a family-centered, disease-specific intervention that is built upon Self-Determination Theory and promotes autonomy-building rather than autonomy-compromising family interactions.



References

- Centers for Disease Control and Prevention. (2017). *National Diabetes Statistics Report, 2017: Estimates of Diabetes and Its Burden in the United States*. Retrieved from <http://www.diabetes.org/assets/pdfs/basics/cdc-statistics-report-2017.pdf>
- de Wit, M., Trief, P. M., Huber, J. W., & Willaig, I. (2020). State of the art: Understanding and integration of the social context in diabetes care. *Diabetic Medicine*, 37, 473-482. doi: 10.1111/dme.14226
- Feldman, M. A., Anderson, L. M., Shapiro, J. B., Jedraszko, A. M., Evans, M., Weil, L. E. G., Garza, K. P., & Weissberg-Benchell, J. (2018). Family-based interventions targeting improvements in health and family outcomes of children and adolescents with type 1 diabetes: A systematic review. *Current Diabetes Reports*, 18, 1-12. doi: 10.1007/s11892-018-0981-9
- Kelly, C. S., & Berg, C. A. (2018). Close relationships and diabetes management across the lifespan: The good, the bad, and autonomy. *Journal of Health Psychology*. Advance online publication. doi: 10.1177/1359105318805815
- Joensen, L. E., Almdal, T. P., & Willaig, I. (2013). Type 1 diabetes and living without a partner: Psychological and social aspects, self-management behavior, and glycaemic control. *Diabetes Research and Clinical Practice*, 3, 278-285. doi: 10.1016/j.diabres.2013.07.001
- Joensen, L. E., Almdal, T. P., & Willaig, I. (2016). Associations between patient characteristics, social relations, diabetes management, quality of life, glycaemic control and emotional burden in type 1 diabetes. *Primary Care Diabetes*, 10, 41-50. doi: 10.1016/j.pcd.2015.06.007
- Mackey, E. R., Herbert, L., Monaghan, M., Cogen, F., Wang, J., & Streisand, R. (2016). The feasibility of a pilot intervention for parents of young children recently diagnosed with type 1 diabetes. *Clinical Practice in Pediatric Psychology*, 4, 35-50. doi: 10.1037/cppp0000123
- Mayberry, L. S., & Osborn, C. Y. (2014). Family involvement is helpful and harmful to patients' self-care and glycemic control. *Patient Education and Counseling*, 97, 418-425. doi: 10.1016/j.pec.2014.09.11
- Ng, J. Y. Y., Ntoumanis, N., Thøgersen-Ntoumani, C., Deci, E. L., Ryan, R. M., Duda, J. L., & Williams, G. C. (2012). Self-determination theory applied to health contexts: A meta-analysis. *Perspectives on Psychological Science*, 7(4) 325-340. doi: 10.1177/1745691612447309
- Rosland, A., Heisler, M., Hwa-Jung, C., Silveira, M. J., & Piette, J. D. (2010). Family influences on self-management among functionally independent adults with diabetes or heart failure: Do family members hinder as much as they help? *Chronic Illness*, 6, 22-33. doi: 10.1177/1742395309354608
- Rosland, A., Heisler, M., & Piette, J. D. (2011). The impact of family behaviors and communication patterns on chronic illness outcomes: A systematic review. *Journal of Behavioral Medicine*, 35, 221-239. doi: 10.1007/s10865-011-9354-4
- Ryan, R. M., & Deci, E. L. (2000). Intrinsic and extrinsic motivations: Classic definitions and new directions. *Contemporary Educational Psychology*, 25, 54-67. doi: 10.1006/ceps.1999.1020
- Trief, P. M., Fisher, L., & Hopkins, R. (2020). Family therapies for adults with diabetes. In A. M. Delamater & D. G. Marrero (Eds.), *Behavioral Diabetes* (pp. 403-416). Basel, Switzerland: Springer Nature.
- World Health Organization (2016). *Global Report on Diabetes*. Retrieved from http://apps.who.int/iris/bitstream/handle/10665/204871/9789241565257_eng.pdf?sequence=1

