

Psychological challenges for children living with diabetes

Diana Naranjo and Korey Hood

Managing a chronic illness can be challenging, and developing effective coping strategies to overcome difficulties is essential for maintaining health, balance and happiness. Type 1 diabetes is one of the most common chronic illnesses of childhood and requires a complex and demanding treatment regimen. While the large majority of childhood diabetes is type 1, there are increasing numbers of adolescents with type 2 diabetes who, requiring a similar treatment regimen, are subject to comparable risk factors for stress. Frequent administration of insulin, checking blood glucose levels, and treating high and low blood sugars are all a part of daily life with diabetes. Children with diabetes and their families must also coordinate these tasks with dietary intake and physical activity. Other aspects of diabetes management include attendance at regularly scheduled diabetes care appointments in clinics and hospitals, monitoring risk and treatment for medical complications and actively supporting a healthy immune system in order to prevent infections. These tasks are demanding and can be disruptive and stressful, illustrating how children living

with diabetes and their families have a number of stresses that children living without diabetes do not experience.

Living with diabetes can feel overwhelming for parents and children because constant vigilance is required for proper care. Childhood diabetes means that no food is supposed to be consumed without understanding: the carbohydrate level, how much insulin to take, waiting for an effect, and problem solving if numbers are too high or low. Additionally, as children age, there may be social functions that they may miss altogether or participate in a limited fashion because of their condition. For example, some children are excluded from friends' sleepovers, birthday parties, and summer camps because of fears from other parents and adults. Parents of children with diabetes may feel obligated to educate their child's school at the beginning of the year, and advocate throughout the year by speaking with teachers, principals, and school nurses. Many children report feeling singled out and different from their peers. There is a range of reported experiences: some children have a network of very supportive

friends and classmates, while others are bullied and teased.

Living with diabetes can feel overwhelming for parents and children because constant vigilance is required for proper care.

In addition to these obvious stresses, there are also more subtle difficulties that often include family stress. Often in young children, it is the parents who are managing the child's diabetes and, therefore, parental roles often include reminders about and supervision of all diabetes related tasks.¹ Parents work very hard to promote development as with any other child while maintaining safety and health now and in the future. Even so, children can report feeling that parents 'nag them' or chastise them more than siblings. This can lead to increased arguments and tension between parents and youth. There can also be tensions with siblings, and the feeling that parental concerns are all centred on the child with diabetes. In

studies of quality of life, family members report limitations and anxiety related to living with someone with diabetes.² For all of these reasons, it is no surprise that children with diabetes have a higher risk of developing depression, anxiety, and psychological challenges than children without diabetes.³

Children with diabetes experience higher rates of depression and other emotional problems than the general population.¹ Specifically, about 15-25% of adolescents with type 1 diabetes experience depression^{3,4} compared to 14.3% in children without a chronic illness,⁵ which translates into a rate 2-3 times that found in the general adolescent population.⁶ Recent reports also suggest that youth with type 2 diabetes are at equal risk if not higher risk than youth with type 1 diabetes for these psychological challenges. Depressive symptoms are particularly worrisome in youth with type 1 diabetes, given that on the lower end of risk these symptoms are related to poor self-care and on the higher end of risk are related to suboptimal glycaemic care and even recurrent diabetes hospitalizations.^{7,8}

One possible link that explains why depressive symptoms are related to poorer diabetes health outcomes is through self-efficacy. Those with higher depressive symptoms have lower self-efficacy, or the belief that they cannot control their diabetes. If you feel a lack of control it can lead to making unhealthy decisions because you feel that whatever you do, it will not change the outcome. Finally, depression and depressive symptoms not only relate to negative disease outcomes, but are also related to poor overall functioning and low perceived quality of life. Signs of depression can include sadness, apathy, distractibility, lethargy, sleep disturbances, appetite changes, low motivation, not participating in previously en-

joyed activities, and thoughts about suicide. For young children, other common symptoms of depression are irritability, anger, tantrums, and aches and pains such as stomach ache or headache. When these occur it is important to talk with a health care team about them. In some cases, families may need to seek out mental health services to talk more thoroughly with a professional who can help develop positive coping strategies.

For people with diabetes, there is also the risk of developing diabetes distress, which includes negative feelings that are directly related to diabetes. For example, feeling extreme frustration with blood sugars, feeling bogged down by all the daily management tasks, or feeling isolated in the diabetes experience. Prolonged diabetes distress can lead to 'diabetes burnout,' a term used to encompass the feeling of being unable to cope with diabetes.⁹ There may be other general depressive symptoms, or the feeling may be solely related to diabetes. With diabetes distress, patients are at increased risk of poor coping skills, poor problem-solving skills and poor self-care.^{10,11} These are the fundamental building blocks toward successfully navigating both diabetes management and other stresses that arise; therefore successful coping skills need to be fostered. Diabetes burnout is less likely to occur when a person feels supported by those around them, talks regularly to his

or her medical team about these feelings, and is connected with other children and families with diabetes.

Although less prevalent than depressive and distress symptoms, there is evidence that children with diabetes are also at elevated risk of anxiety symptoms and have rates estimated between 13-17%.¹² Anxiety can negatively impact children and their families in various ways. Fears of specific diabetes events like future hypoglycaemic episodes can contribute to heightened levels of stress and general anxiety overall. Parents also lose a great deal of sleep checking overnight blood sugars and worrying about trends toward lows. For the person living with diabetes, any level of increased anxiety is negatively related to the quality of glycaemic control, making diabetes self-management more difficult.¹² Constantly worrying can weigh on children, and at worse, can lead to feeling helpless and being unable to manage diabetes. When children or



parents voice worries about diabetes, whether they seem reasonable or not, they should be heard. Sometimes a worry can be addressed through more education and sometimes a concern needs the help of a trained mental health professional. However, listening to parents and children and validating their concerns and worries is an excellent first step to reassuring them that diabetes can be managed and people with diabetes can thrive in life.

The presence of diabetes in a child's life can increase risks for stress and distress.

Although these risks do exist, it is important to note that by and large, children with diabetes are resilient. Studies have found that after an initial spike in psychological problems following diagnosis, by 12 months post diagnosis, many of the symptoms have alleviated.¹³ Another group followed children six years post diagnosis and found that on average negative symptoms increased directly after diagnosis, but these symptoms largely dissipated after a year. Following this, some symptoms did increase again with greater duration of disease shown with a moderate elevation of depressive symptoms for both boys and girls and an increase in anxiety for girls. However, during this six year period, the average levels of symptoms were lower than the means reported for normative samples, and lower than cut offs for clinically significant diagnosis. There are specific things that can improve resilience in children with diabetes: increasing communication in the family can lead to more perceived emotional support and empathy from parents, leading to more positive interactions. Social support is also another important factor. When people

in their social circle like teachers, friends, and extended family understand and support diabetes management, this can buffer potential barriers like discomfort associated with administering insulin.

In summary, the presence of diabetes in a child's life can increase risks for stress and distress in the child and family. These stresses should be assessed and

programmes should be in place for their prevention and treatment if they arise. Working alongside a psychologist or social worker with advanced training in diabetes can be a major help to children and families. However, listening to families and validating and addressing their concerns will always remain the first step in helping families achieve a balance with diabetes and thriving.

Diana Naranjo and Korey Hood

Diana Naranjo is Assistant Adjunct Professor, University of California San Francisco, Madison Clinic for Paediatric Diabetes, San Francisco, USA.

Korey Hood is Associate Professor, University of California San Francisco, Madison Clinic for Paediatric Diabetes, San Francisco, USA.

Suggested Reading

Screening for Depression and other Psychological Problems in Diabetes: a Practical Guide by Cathy E Lloyd (Editor), Frans Pouwer (Editor), Norbert Hermanns (Editor). Illustrated, 220 pages, Springer Press (2012 Edition).

References

- Hood KK, Naranjo D, Barnard K. Measuring depression in children and young people. In: Lloyd CE, Pouwer F, Hermanns N, editors. *Screening for Depression and Other Psychological Problems in Diabetes: A Practical Guide*. New York: Springer Press; 2012: 119-38.
- Barnard KD, Lloyd CE, Skinner TC. Systematic literature review: quality of life associated with insulin pump use in type 1 diabetes. *Diabet Med* 2007; 24: 607-17.
- Hood KK, Huestis S, Maher A, et al. Depressive symptoms in children and adolescents with type 1 diabetes: association with diabetes-specific characteristics. *Diabetes Care* 2006; 29: 1389-91.
- Grey M, Whittemore R, Tamborlane W. Depression in type 1 diabetes in children: natural history and correlates. *J Psychosom Res* 2002; 53: 907-11.
- Merikangas KR, He JP, Burstein M, et al. Lifetime prevalence of mental disorders in U.S. adolescents: results from the National Comorbidity Survey Replication--Adolescent Supplement (NCS-A). *J Am Acad Child Adolesc Psychiatry* 2010; 49: 980-9.
- Lewinsohn PM, Clarke GN, Seeley JR, et al. Major depression in community adolescents: age at onset, episode duration, and time to recurrence. *J Am Acad Child Adolesc Psychiatry* 1994; 33: 809-18.
- Kokkonen J, Lautala P, Salmela P. The state of young adults with juvenile onset diabetes. *Int J Circumpolar Health* 1997; 56: 76-85.
- McGrady ME, Laffel L, Drotar D, et al. Depressive symptoms and glycemic control in adolescents with type 1 diabetes: mediational role of blood glucose monitoring. *Diabetes Care* 2009; 32: 804-6.
- Polonsky WH. *Diabetes Burnout: what to do when you can't take it anymore*. American Diabetes Association, New York 2000.
- Wysocki T, Iannotti R, Weissberg-Benchell J, et al. Diabetes problem solving by youths with type 1 diabetes and their caregivers: measurement, validation, and longitudinal associations with glycemic control. *J Pediatr Psychol* 2008; 33: 875-84.
- Hood KK, Peterson CM, Rohan JM, et al. Association between adherence and glycemic control in pediatric type 1 diabetes: a meta-analysis. *Pediatrics* 2009; 124: e1171-9.
- Herzer M, Hood KK. Anxiety symptoms in adolescents with type 1 diabetes: association with blood glucose monitoring and glycemic control. *J Pediatr Psychol* 2010; 35: 415-25.
- Northam E, Anderson P, Adler R, et al. Psychosocial and family functioning in children with insulin-dependent diabetes at diagnosis and one year later. *J Pediatr Psychol* 1996; 21: 699-717.