

Psychological care of children, adolescents and young adults with diabetes: ISPAD Clinical Practice Consensus Guidelines

The International Society for Pediatric and Adolescent Diabetes (ISPAD) recently published new clinical practice consensus guidelines on the psychological care of children, adolescents and young adults with diabetes (de Wit et al, 2022). Compared to the 2018 version, these 2022 guidelines now include type 1 as well as type 2 diabetes, and additional sections on psychological assessment, communication, the healthcare team and the psychological impact of technology.

Being diagnosed with diabetes in childhood or adolescence can interfere with normative developmental changes, and interact with psychological and social factors in youth and their families. Given the burden of living with a chronic illness and the greater incidence of mental health problems in youth with diabetes compared to their peers, the ISPAD guidelines recommend that psychosocial care should be an integral part of collaborative, person-centred medical care for all youth with diabetes. Professionals with expertise in the mental health of children and adolescents are essential members of the interdisciplinary diabetes healthcare team, not only to support children and families, but also to support the diabetes team in the recognition and management of mental health and behaviour problems. The Collaborative Care Model (CCM) has emerged as a promising clinical model to facilitate the integration of mental health care with physical health care to simultaneously address co-occurring physical and mental health problems (Asarnow et al, 2015; Versloot et al, 2021).

Integrating psychosocial assessments in routine diabetes care

About 1 in 7 young people with diabetes experience psychological problems related to depressive mood, anxiety and disordered eating, and youth with diabetes are twice as likely to be diagnosed

with a psychiatric disorder as their peers without diabetes (Butwicka et al, 2015; Cooper et al, 2017; Dybdal et al, 2018). Next to these more generic psychological problems, about one in three adolescents and up to 60% of young adults report diabetes-specific distress. The constant demands of diabetes management, including relentless treatment tasks and decision-making, are key contributors to diabetes distress, particularly as these constant efforts do not always lead to the expected outcomes.

The high prevalence and possible detrimental impact of these psychological symptoms and disorders on diabetes self-management and quality of life (Hood et al, 2011; Brodar et al, 2021) indicate that ongoing monitoring and screening, and integration of psychological support in the care for youth with diabetes is warranted. The guidelines, therefore, state that age-appropriate and validated assessment tools are available, and should be routinely implemented in clinical practice to monitor and discuss the overall psychosocial well-being and quality of life of all youth with diabetes. If possible, this should include the well-being of caregivers too, as parental well-being affects their children's outcomes. Levels of psychological distress among the parents of children with diabetes are greater than in parents of children without diabetes. Many parents report significant distress after their child's diabetes diagnosis, and have difficulty coping with their child's diabetes management.

Given the elevated prevalence of specific problems, screening for symptoms of depression, diabetes distress and disordered eating in children aged ≥ 12 years is recommended using validated tools. When screening programmes are initiated, there also must be a process for appropriate referrals to address identified concerns. The guidelines specifically recommend that psychosocial problems should be addressed upon identification. If an



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intervention cannot be initiated during the visit when the problem is identified, a follow-up visit or referral to a mental health specialist should be scheduled during the visit.

Cognitive functioning

Growing evidence documents that children and adolescents with type 1 diabetes are more at risk for pathophysiological brain changes and neurocognitive deficits (e.g. memory, learning and executive functioning) than peers without diabetes. Although limited, research in youth with type 2 diabetes also shows deficits in memory and processing speed compared with youth without diabetes matched by obesity status. Children with early onset of type 1 diabetes (aged <7 years), as well as those who experience significant dysglycaemia around the time of onset (evidenced by diabetic ketoacidosis, recurrent severe hypoglycaemia and/or severe hyperglycaemia), are especially at risk, and the guidelines recommend monitoring of their cognitive capacity and school functioning.

Diabetes in context

Diabetes self-management is most effective in the context of collaborative interpersonal relationships. This involves the family context, peers and diabetes team. Family functioning is strongly associated with psychological health outcomes in youth with diabetes, and the way parents are involved in a child’s management matters. Diabetes-specific family conflict negatively affects the treatment plan and glycaemic management, as well as quality of life and depressive and/or anxiety symptoms in young people. Over-involvement, or unsupportive behaviours (such as nagging), could also have adverse effects.

The guidelines, therefore, recommend that the interdisciplinary team should assess general family functioning in terms of stress, conflict, cohesion, adaptability and parental psychopathology. It should also assess diabetes-related functioning in terms of communication, parental involvement and support, roles and responsibilities for self-management behaviours (especially during periods of transition, such as at diagnosis, the start of a new treatment plan or adolescence), and when there may be cultural or family-based difficulties in adjusting to diabetes.

Continued parental involvement in diabetes care throughout adolescence and into young adulthood is beneficial, as premature transition of responsibility may be detrimental. Adolescents should, therefore, assume increasing responsibility for diabetes management tasks with continuing, mutually agreed parental involvement and support. For providers, it is important to navigate the shift in responsibilities from parents to their children by being attuned to their evolving competencies and readiness for independent self-care, whilst also taking into account the need for parental and provider support and guidance.

The guidelines state that authoritative, responsive, respectful and autonomy-supportive communication should be encouraged, as this has been shown to have positive health effects.

Diabetes technology

Technological advances in diabetes care in the last two decades have changed the way that many people manage their type 1 diabetes. Developments, such as insulin pumps, real-time and intermittently scanned continuous glucose monitoring (CGM) and automated insulin delivery systems, improve diabetes management and health outcomes, and reduce the frequency of hypoglycaemia in the majority of those using them (Dovc and Battelino, 2020). Technology uptake is increasing, most especially in the paediatric population. CGM use is now considered to be “standard of care” for people with type 1 diabetes, and its use is recommended in the 2021 ADA/EASD clinical consensus report for the management of type 1 diabetes (Holt et al, 2021).

Psychological benefits associated with the use of diabetes technology, especially CGM, include improved quality of life, reduced diabetes distress and reduced fear of hypoglycaemia, as well as “better sleep, safety and flexibility”, improved family functioning and lower stress in both youth and their caregivers. Some psychological disadvantages of diabetes technology adoption have been reported, including issues with body image, disruptive alarms and painful insertions. The large amount of data and real-time remote glucose monitoring can be a source of conflict between children with type 1 diabetes and their

parents, as deviations from recommended diabetes management are more readily and immediately noticeable to caregivers. The research literature, however, does not demonstrate any evidence of increased family conflict following CGM introduction. The ISPAD guidelines state that the advantages of diabetes technology in insulin delivery and glucose monitoring lead to the recommendation that it should be available for all youth with type 1 diabetes, and be tailored to individual wishes and needs, to address the possible disadvantages.

Psychosocial interventions

It can generally be concluded that there is a solid evidence base for psychosocial and behavioural interventions on psychosocial well-being (Hilliard et al, 2016), although the effects on glycaemic outcomes are inconsistent. The ISPAD guidelines recommend that the interdisciplinary team should aim to provide preventive interventions for youth with diabetes and their families at key developmental times, particularly after diagnosis and prior to adolescence. These interventions should emphasise appropriate family involvement and support in diabetes management, effective problem-solving, coping and self-management skills, and realistic glycaemic expectations. Once psychological problems are present, evidence-based psychosocial, behavioural or psychiatric interventions should be available for youth with diabetes or families exhibiting conflict, disordered communication, diabetes distress, or behavioural or psychiatric difficulties, in conjunction with collaborative care with the diabetes treatment team.

Nevertheless, there is work to be done when it comes to interventions. There is growing evidence supporting the use of the internet and other digital approaches to deliver behavioural interventions, and a need for higher quality studies. In general, psychosocial and behavioural intervention research is limited by not including enough high-risk youth (i.e. low-income, ethnic minority or single-parent youth) in their study samples. In addition, there is a need for more studies specifically targeting youth with type 2 diabetes and young adults. There are also opportunities for more research using clinic-based brief interventions during routine care that

focus on improved self-management and reduction of diabetes distress, which could have the potential to maximize reach and impact through scalability.

Conclusion

The *ISPAD Clinical Practice Consensus Guidelines 2022* on the [psychological care of children, adolescents and young adults with diabetes](#) highlight the importance of collaborative care for youth with type 1 and type 2 diabetes. This includes integrating psychosocial assessments in routine diabetes care, and the availability of psychological and behavioural interventions to maintain or achieve optimal mental health in youth with diabetes. ■

Asarnow JR, Rozenman M, Wiblin J, Zeltzer L (2015) Integrated medical-behavioral care compared with usual primary care for child and adolescent behavioral health: A meta-analysis. *JAMA Pediatr* **169**: 929–37

Brodar KE, Davis EM, Lynn C et al (2021) Comprehensive psychosocial screening in a pediatric diabetes clinic. *Pediatr Diabetes* **22**: 656–66

Butwicka A, Frisén L, Almqvist C et al (2015) Risks of psychiatric disorders and suicide attempts in children and adolescents with type 1 diabetes: a population-based cohort study. *Diabetes Care* **38**: 453–9

Cooper MN, Lin A, Alvares GA et al (2017) Psychiatric disorders during early adulthood in those with childhood onset type 1 diabetes: Rates and clinical risk factors from population-based follow-up. *Pediatr Diabetes* **18**: 599–606

de Wit M, Gajewska KA, Goethals ER et al (2022) ISPAD Clinical Practice Consensus Guidelines 2022: Psychological care of children, adolescents and young adults with diabetes. *Pediatr Diabetes* **23**: 1373–89; <https://doi.org/10.1111/peidi.13428>

Dovc K, Battelino T (2020) Evolution of diabetes technology. *Endocrinol Metab Clin North Am* **49**: 1–18

Dybdal D, Tolstrup JS, Sildorf SM et al (2018) Increasing risk of psychiatric morbidity after childhood onset type 1 diabetes: a population-based cohort study. *Diabetologia* **61**: 831–8

Hilliard ME, Powell PW, Anderson BJ (2016) Evidence-based behavioral interventions to promote diabetes management in children, adolescents, and families. *Am Psychol* **71**: 590–601

Holt RIG, DeVries JH, Hess-Fischl A et al (2021) The management of type 1 diabetes in adults. A consensus report by the American Diabetes Association (ADA) and the European Association for the Study of Diabetes (EASD). *Diabetes Care* **44**: 2589–625

Hood KK, Rausch JR, Dolan LM (2011) Depressive symptoms predict change in glycemic control in adolescents with type 1 diabetes: rates, magnitude, and moderators of change. *Pediatr Diabetes* **12**: 718–23

Versloot J, Ali A, Minotti SC et al (2021) All together: Integrated care for youth with type 1 diabetes. *Pediatr Diabetes* **22**: 889–99

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