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ISPAD GUIDELINES

# ISPAD Clinical Practice Consensus Guidelines 2022: Psychological care of children, adolescents and young adults with diabetes

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## 1 | WHAT IS NEW OR DIFFERENT

- Psychological care of youth with type 1 diabetes (T1D) as well as type 2 diabetes (T2D) is covered.
- Additional sections on the psychological assessment, communication, the health care team and psychological impact of technology are added

## 2 | EXECUTIVE SUMMARY AND RECOMMENDATIONS

### 2.1 | Collaborative care

- Psychosocial care should be integrated with collaborative, person-centered medical care and provided to all youth with diabetes and their families. **A**
- Professionals with expertise in the mental health of children and adolescents are essential members of interdisciplinary diabetes health care team. **B**
- Mental health professionals should be available to interact with youth and their families, and also to support the diabetes team in the recognition and management of mental health and behavior problems. **C**
- It is preferable that mental health specialists who interact with children with diabetes have training in diabetes and its management. **E**

### 2.2 | Integrating psychosocial assessments in routine diabetes care

- Age-appropriate and validated assessment tools should be routinely implemented in clinical practice to monitor and discuss

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overall psychosocial well-being and quality of life (QoL) of all youth with diabetes. **A**
This should include the well-being of caregivers. **B**

- Screening for symptoms of depression, diabetes distress and disordered eating in children aged 12 and above using validated tools should be done at the initial visit, at periodic intervals and when there is a change in disease, treatment, or life circumstance. **B**
- Psychosocial problems should be addressed upon identification. If an 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. **B**
- Cognitive capacity and school functioning should be monitored especially in children with early onset of T1D (< age 7), as well as those who experience significant dysglycemia around the time of onset (evidenced by diabetic ketoacidosis [DKA], recurrent severe hypoglycemia, and/or severe hyperglycemia) **A**

## 2.3 | Diabetes management

- Routine assessment should be done for developmental adjustment to, and understanding of, diabetes management, including diabetes-related knowledge, insulin adjustment skills, goal setting, problem-solving abilities, and self-management autonomy and competence. This is especially important during late childhood and during adolescence. **B**
- When making treatment recommendations providers should consider the perceived treatment burden and self-efficacy, level of social and family support, and presence of significant mental health issues. **B**

## 2.4 | Diabetes in context

- The interdisciplinary team should assess general family functioning (stress, conflict, cohesion, adaptability, parental psychopathology), and diabetes-related functioning (communication, parental involvement and support, roles and responsibilities for self-management behaviors) especially during periods of transition (e.g., at diagnosis, at start of a new treatment plan, adolescence) and when there may be cultural or family based difficulties in adjustment to diabetes. **B**
  Referral to mental health professional is recommended when necessary. **E**
- Adolescents should assume increasing responsibility for diabetes management tasks with continuing, mutually agreed, parental involvement and support. **B**
- Providers need to navigate the shift in responsibilities from parents to their children by being attuned to youth's evolving competencies and readiness for independent self-care, while also taking into account the need for parental and provider support and guidance. **B**
- Authoritative, responsive, respectful, and autonomy supportive communication should be encouraged. **B**
- Communication about the demands, expectations ("who does what") and burden of diabetes management should be continuous. **B**

## 2.5 | Diabetes technology

- Technological advances in insulin delivery and glucose monitoring should be available for all youth with T1D and tailored to individual wishes and needs. **B**

## 2.6 | Psychosocial interventions

- The interdisciplinary team should aim to provide preventive interventions for youth with diabetes and families at key developmental times, particularly after diagnosis and prior to adolescence. **A**
- These interventions should emphasize appropriate family involvement and support in diabetes management, effective problem-solving, coping, and self-management skills, and realistic glycemic expectations. **A**
- Evidence-based psychosocial, behavioral, or psychiatric interventions should be available for youth with diabetes or families exhibiting conflict, disordered communication, diabetes distress, behavioral, or psychiatric difficulties in conjunction with collaborative care with the diabetes treatment team. **A**
- Consider developmental needs of children and adolescents while planning interventions incorporating social, emotional, and tangible support. **E**

## 3 | INTRODUCTION

The biopsychosocial model proposes that understanding illness requires understanding the complex interactions between biology (e.g., genes, viruses), psychology (e.g., mood, behavior) and social factors (e.g., family, society).[1] Treatments must include attention to all of these domains. Being diagnosed with diabetes in childhood or adolescence can interfere with the normative developmental changes and interact with psychological and social factors in youth and their families. Integrated, collaborative care is therefore necessary. Although routine psychosocial screening in pediatric diabetes clinics effectively identifies youth struggling with psychosocial problems and facilitates referrals to appropriate care resources, screening and referral alone are not sufficient to ensure care is actually received.[2] Integrated care models ensure that youth with diabetes access mental health care.[3–5] When screening programs are initiated, there also must be a process for appropriate referrals to address identified concerns.

Here we review the main findings from studies on stress, resilience and coping, psychological and psychiatric problems, neurocognitive functioning, and integration of psychosocial assessments. We also discuss the importance of diabetes in context, including family dynamics, social support, and the diabetes team. Given the rapid technological advances in diabetes management, we review the psychological advantages and challenges of technology. We conclude this chapter with a review of psychological and behavioral interventions in children and adolescents with diabetes. Based on these research findings, recommendations for optimal psychological care are offered and detailed in the Executive Summary (Section 2).

## 4 | STRESS, RESILIENCE, AND COPING

Childhood and adolescence are challenging developmental stages. Young children can get stressed navigating their social worlds, particularly family, school, and friendships.[6] Adolescence is characterized by major physical, hormonal, and psychological changes; hence it has been described as a period of stress and storm. Chronic illnesses such as diabetes exacerbate stress in children and adolescents,[7,8] and it is uncommon for children and adolescents with diabetes not to report stress.[7,9] The relationship between stress and diabetes is suggested to be bidirectional; stress can increase the risk of T2D, and living with diabetes can also cause stress.[10–13] Managing diabetes, family conflicts around diabetes management, and dealing with diabetes emotions are often a major source of stress.[8] Adversities and pandemics such as COVID-19 also accentuate stress levels in persons already affected by diabetes-specific stress. For example, the perceived increased risk of death due to COVID-19 and breakdowns in the supply chain affecting access to insulin and other supplies has contributed to anxiety and stress in the family related to diabetes care and management.[14] Stressors can be subjective and the interpretation and perception of stressors or the actual exposure to stress events vary depending on age, geography, and socioeconomic factors. In developing as well as in high-income countries, low income is a major stressor.[15,16] Race, ethnicity, and other sociodemographic factors are also associated with stress[17,18] and coping strategies.[19] Assessment of stressors should therefore be part of person-centered care.

### 4.1 | Diabetes distress

Diabetes distress (also referred to diabetes-related or diabetes-specific distress) is an emotional response to living with and managing diabetes. One in three adolescents with T1D,[9] one in three adolescents and young adults with T2D[20] and up to 60% of emerging adults[21] report elevated diabetes distress. Although longitudinal studies are scarce, diabetes distress also seems to persist over time.[22] Diabetes distress is best viewed as an expected emotional response to diabetes and not as a co-morbid disorder. The constant demands of diabetes management, including the 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. Diabetes distress may negatively impact engagement with treatment, and subsequent glucose outcomes.[22] Although they can co-exist, diabetes distress differs conceptually from depression and requires a different care pathway.[23]

### 4.2 | Diabetes burnout

Diabetes burnout is a relatively new and not yet well-researched concept without a widely used psychometric scale. The term diabetes burnout relates to high levels of diabetes distress and/or depression that produce significant barriers to diabetes management and glycemic management.[24] It is characterized by feelings of mental, emotional and physical exhaustion of living with diabetes, leading to a detachment from diabetes and ignoring self-management responsibilities.[25] As a consequence, burnout may lead to an experience of detachment from self, support systems (e.g., years of not attending diabetes appointments) and is associated with lack of acceptance of the condition.[24] The concept is mainly described in adults with diabetes (T1D and T2D), not in children, adolescents or parents/carers. The Diabetes Burnout Scale (DBS) measures diabetes burnout specifically and was recently validated in adults.[26] Further investigation of this concept in youth with diabetes, particularly young adults and parents, is warranted.

### 4.3 | Resilience and coping

*Diabetes Resilience* is achievement of optimal diabetes outcomes (i.e., high engagement in self-management behaviors, and close to target glycemic outcomes) despite the numerous challenges inherent in having diabetes.[27] Attention to protective skills and behaviors (i.e., strengths) that promote resilient outcomes can enhance understanding of adjustment to diabetes and have implications for clinical care. These strengths include confidence or self-efficacy to manage the demands of diabetes, seeking and receiving developmentally appropriate help and support from family and others, and adaptability to handle unpredictable diabetes-related challenges (e.g., effective problem-solving and coping).[27–31] Children and families who use adaptive coping strategies such as problem-solving have a better QoL and family functioning, and report fewer depressive and anxiety symptoms.[32–36] Maladaptive coping strategies such as avoidance are associated with more significant diabetes-specific distress and suboptimal diabetes management, including fewer glucose checks and less frequent self-care behaviors.[15,34]

Evidence-based interventions for children with diabetes such as cognitive behavioral therapy and interventions that promote parental involvement, goal setting, and problem-solving[9] and reduce family conflict[37] may be helpful in promoting resilience and addressing stress. Interventions to relieve stress and enhance social support for parents/caregivers are also needed in clinical care.[37,38]

## 5 | PSYCHOLOGICAL AND PSYCHIATRIC PROBLEMS

Based on evidence from large, population-based cohort studies youth and young adults with T1D are about twice as likely to be diagnosed with a psychiatric disorder, especially eating, mood, anxiety and behavior disorders, as peers without diabetes.[39–41] ADHD, personality disorders and substance use disorders (especially in males) are also more common.[39] Multi-morbidities are common: 1 in 5 youth has two or more psychiatric diagnoses.[39] Overall, psychiatric disorders are associated with abnormal self-management (e.g., insulin-manipulation) and lower QoL.[42,43]

### 5.1 | Disordered eating and eating disorders

Children and adolescents with diabetes have increased rates of eating disorders (ED) and disordered eating behaviors (DEB) rates compared to peers without diabetes.[44–47] These issues are especially magnified in older adolescents and young adults. Consequences of eating disorders and disordered eating include increased risk and frequency of DKA, accelerated development of vascular complications and mortality.[48,49] Even mild symptoms are relevant, as they impact self-management.[50] Population cohort studies show 1%–10% of adolescents and young adults with T1D have an ED.[39–41] Bulimia and “other specified feeding and eating disorders” are more common, but not anorexia nervosa.[51] Longitudinal studies of youth with T1D reveal that ED behaviors and symptoms are likely to persist and become more severe in young adulthood.[50,52]

ED in youth with diabetes are often associated with comorbid psychiatric disorders and sub-optimal glycemic management. Relationships between disordered eating and depression symptoms, anxiety symptoms and lower QoL in populations with T1D and T2D[53] are bi-directional. Risk factors for eating disorders and disordered eating include female gender (related to societal pressure to be thin, pubertal changes), DKA, and hyperglycemia.[54]

DEBs such as dietary restriction and intentional insulin omission[55] are more prevalent than eating disorders. In children with T1D, DEBs affect about 30%–50% of females and 10%–20% of males.[51] In youth with T2D the prevalence of DEB has been found to be about 50%.[53] Youth with T2D and DEB had a significantly higher BMI, lower insulin sensitivity, more depressive symptoms, and poorer QoL than those without DEB, with no differences between males and females.[53] A maladaptive family environment (e.g., lack of family mealtime structure, parent–child relationship quality) together with parents' personal eating attitudes (e.g., weight/shape concerns) and habits (e.g., attempts at weight loss) and negative comments about their child's weight are important when it comes to DEB in their children.[56]

DEBs often go unnoticed as adolescents and young adults refrain from being open and providers do not always feel equipped to identify and talk about them.[57,58] What usually is symptomatic and raises the attention of HCPs is frequent hospital admissions associated with DKA. Given the high prevalence and serious consequences, this calls for routine monitoring and screening of eating behaviors. A stepped approach, starting with screening with more detailed assessment following positive screens could be considered to facilitate discussion in clinical practice.[57]

### 5.2 | Depressive and anxiety symptoms and disorders

Initial elevation of depressive symptoms and anxiety at diagnosis is often a transitional normal adaptive response.[59] Thereafter, symptoms of depression and anxiety increase once again with longer disease duration, corresponding with the children's experience of diabetes management and implications as being more difficult and upsetting. For a smaller group of children, psychological problems persist.[59]

#### 5.2.1 | Depressive symptoms and disorders

Youth with T1D are at an increased risk of elevated self-reported depressive symptoms compared to peers with prevalence rates ranging from 17% to 63%, depending on population, study design and diagnostic tool.[60–62] Core symptoms include low mood, no enjoyment and negative cognitions, although coexistent irritability or oppositional behavior may lead to missed diagnosis. Somatic symptoms such as fatigue and brain fog may overlap with T1D symptoms from hypo- or hyperglycemia. European population-based studies also show an increased risk of diagnosed mood disorders in youth with T1D, both in boys and girls.[39–41] Females and youth with a history of depressive episodes are especially at an increased risk. Despite the increased risk of depression, population-based studies do not find an increased risk of suicide attempts in youth with T1D compared to peers.[39,40]

Fewer studies have been conducted in youth with T2D. In the TODAY study the prevalence of elevated depressive symptoms in youth with T2D was 15%, comparable to the US population without diabetes.[63] The SEARCH study did not report prevalence rates for T2D specifically, however males with T2D were reported to have an increased risk of elevated depressive symptoms compared to males with T1D.[64] Recent studies in Canada and the US showed an increased risk of depressive disorders as well as attempted and completed suicides in youth with T2D compared to peers without diabetes.[20,65] Longitudinal studies show mixed results regarding fluctuations in depressive symptoms and glycemic changes. Within-person increases in depressive symptoms over 6 months were associated with concurrent declines in glycemic management.[66] However, 3- to 5-year longitudinal studies in adolescents and young adults with T1D did not show significant within-person associations between fluctuations in depressive symptoms and glycemic management changes.[67–69]

#### 5.2.2 | Anxiety symptoms and disorders

Anxiety is characterized by a predominance of exaggerated fear or worry, dysfunctional coping behaviors (e.g., preoccupation or avoidance of feared situations or experiences, the use of safety behaviors to mitigate perceived threats) and adrenergic symptoms. Generalized anxiety is described as “free floating” with continual symptoms and no specific focus. There is substantial comorbidity between anxiety and depression. As a counter to chronic uncomfortable feelings of anxiety, a person will compensate by avoiding as many stressful experiences as possible. In the context of diabetes, behaviors could include not attending appointments, checking blood glucose levels or taking insulin. Studies of anxiety symptoms in children and adolescents with T1D are mixed. Although up to 32% may have elevated anxiety symptoms, this may not be higher compared to peers without diabetes.[62,70] However, children and young adults with T1D and youth with T2D are at an increased risk for diagnosed anxiety disorders compared to controls varying from 11% to 32%.[40–43,65,71–73] The highest risk is for those with onset of diabetes between age 10 and 14 years and increasing risk with diabetes duration.[39] Children with diabetes and anxiety disorders are at risk for suboptimal glycemic outcomes, more hospitalizations, suboptimal self-management, lower QoL, more depressive symptoms and higher family conflict than peers with diabetes without anxiety disorders.[74,75]

More recent studies seem to show similar prevalence rates of depressive and anxiety symptoms and disorders as the general pediatric population, possibly reflecting the advances in diabetes treatment and awareness of mental health problems.[73,76] Nevertheless, about 1 in 7 young people with diabetes experience psychological problems, which tend to increase with diabetes duration and remain elevated in young adults with type 1 and T2D.[68,76,77] The high prevalence and the possible detrimental impact of these psychological symptoms and disorders on diabetes self-management and QoL[4,66] indicates that ongoing monitoring and screening and integration of psychological support in the care for youth with diabetes is warranted. An approach is outlined below. There should also be easy access to consulting psychiatrists for cases involving severe psychopathology and the potential need for psychotropic medications.

## 6 | NEUROCOGNITIVE FUNCTIONING

Growing evidence documents that children and adolescents with T1D are more at risk for pathophysiological brain changes[78–84] and neurocognitive deficits (e.g., memory, learning, and executive functioning)[82,83,85–90] than healthy peers. Although limited, research in youth T2D also shows deficits in memory and processing speed compared with youth without diabetes matched by obesity status.[91–93] Intelligence quotient (IQ) scores of youth with diabetes are statistically significantly lower than those of their peers without T1D.[82] However, IQ scores in youth with diabetes are typically well within the average range and the clinical impact might be minimal. In addition to lower IQ, youth with diabetes are at risk for specific neurocognitive deficits such as information processing difficulties (attention, memory, processing speed), learning disabilities and problems with executive functions.[82,90–93] Executive functions involve goal-oriented behavior and other key skills for self-management such as planning, problem-solving and organization. While executive function deficits can make diabetes self-management more difficult, in turn, these difficulties in self-management could lead to worsening glycemic outcomes,[94–97] which may lead to a dysfunctional cycle of further brain injury and even greater neurocognitive function deficits.[83] Additionally, worse executive functions are linked to lower QoL and mental health problems.[98–100]

Hypoglycemia, hyperglycemia and DKA, especially if recurrent, can impact school functioning and educational attainment via a combination of mechanisms including altered cognitive function and non-attendance for acute treatment.[101] However, findings regarding the impact of T1D on academic performance in young people are mixed. Older studies reported young people with T1D have lower academic performance compared to their peers or siblings without T1D[102,103] while more recent studies have not found differences in academic performance compared to peers.[104–107] There is some evidence that young people with optimal glycemic management perform better academically.[104,105,107]

Several illness-related risk factors contribute to the greater risk for these brain changes and neurocognitive deficits in youth with T1D. Early age of diabetes onset is a specific risk factor for decline in IQ over time and neurocognitive deficits.[88,108] Recent research suggests that high-time outside range (TIR), the percentage of time blood glucose levels are in the target range of 3.9–10 mmol/L (70–180 mg/dl), negatively impacts brain development in youth with T1D,[84] as does DKA, particularly at the time of diagnosis, with a decline in IQ over time and/or neurocognitive deficits.[109–111] Protective strategies have also been identified, such as improving child sleep, continued family support, reducing caregiver distress and use of diabetes technology.[82,95] Collectively, studies identified early disease onset, and factors experienced around onset (higher HbA1c, severe hypoglycemic events and DKA) as major contributors to initial cognitive decrements, and with no or limited decline in cognitive abilities if these are experienced later after diagnosis. It is hypothesized that these early disease factors provide an ‘initial strike’, after which the brain adapts to the new situation of fluctuating glucose levels.[112]

The SEARCH for Diabetes in Youth study found that acquired knowledge, obesity, and depression contribute to executive functioning in youth with T1D and T2D and that differences in executive functioning observed in youth with T2D compared with those with T1D are in part attributable to differences in these factors.[93] Interdisciplinary diabetes teams should be aware of risk and protective factors for neurocognitive deficits in youth with all types of diabetes. Ideally, questionnaire- or performance-based measures of neurocognitive function should be available for assessment by a mental health specialist when youth with diabetes are at risk and when they show signs of neurocognitive deficits in dealing with their diabetes self-management tasks (e.g., planning, prioritizing).

## 7 | PSYCHOLOGICAL ASSESSMENT: ROUTINE MONITORING AND SCREENING

Given the critical role of self-management and psychosocial factors impacting diabetes outcomes and QoL, it is imperative that psychological assessment be integrated routinely into clinical diabetes care. Validated psychological questionnaires are instrumental for screening and assessment. Such measures can facilitate addressing relevant psychosocial needs in a dialog with the person with diabetes and their family as part of routine diabetes team consultations.[113,114] The use of these assessments is feasible and accepted by children and youth with diabetes, families and HCPs and helps focus the clinical encounter more on psychosocial factors, facilitate shared-decision making and drive care decisions instead of mainly focusing on outcomes such as HbA1c and TIR.[4,114,115] Routine assessments have been shown to positively impact well-being and satisfaction with care in young people with diabetes,[114,116,117] without direct impact on self-management and glycemic outcomes.[113,115]

Choice of assessment tool depends on the purpose, age and literacy of the person with diabetes. Children from the age of 8 years onwards are generally able to complete self-report questionnaires. In younger children, often parent-proxy measures are used, although instruments enabling the assessment of how the child is doing are available.[118–120] Generic questionnaires can be used across different populations and capture more common aspects of the person's life, allowing for comparison to normative populations. Diabetes-specific questionnaires tap into and are more sensitive to symptoms and problem areas experienced by young people with diabetes. Diabetes-specific measures should be considered for DEB assessment because generic measures might capture behaviors that are part of treatment (e.g., carbohydrate counting and calorie restriction), and adverse effects of treatment such as excessive hunger secondary to hypoglycemia. In addition, generic measures are not able to capture insulin restriction or omission to lose weight.

Several standardized and validated measures are available for providers to monitor well-being and screen for psychological difficulties of young people with diabetes.[113,121,122] Monitoring tools can track changes over time across a broad range of domains and become part of person-centered care when feedback is provided to the person with diabetes during a clinical consultation.[123] An example is routine monitoring of HRQOL which facilitates discussion between youth with diabetes and clinicians regarding psychosocial concerns as well as the different domains of HRQOL and the impact on diabetes self-management and well-being.[113,115,117] Screening tools can help identify problems that may have gone otherwise unnoticed. Often, the score is weighted based on norm scores. An example is screening for depressive symptoms, where a cut-off is used to screen for young people at risk for clinical depression.[4,124] Screening is especially of importance in adolescence and young adulthood as this is are critical developmental periods where most psychological problems first arise.[125] Routine screening for psychological difficulties from 12 years onwards, at least once a year, is recommended. Comprehensive psychosocial screening is feasible and can efficiently detect potential mental health problems and other issues impacting diabetes management.[4] Many instruments have been developed to monitor QoL and screen for psychological problems in adolescents.[113,121,126,127] Only a few instruments capture the specific developmental domains of young adults.[128]

Standardized and validated questionnaires for psychosocial monitoring, screening, and diagnosis can be used in a stepped approach with positive findings leading to further evaluation.[4,5] Starting with informal verbal inquiries for monitoring well-being and/or QoL, including mood and distress where positive responses can be probed with additional questions and/or use of standardized measures and finally by structured interviews for diagnosis. These formal diagnostic assessments and interviews should be conducted by a qualified mental health professional, familiar with the care of young people with diabetes and help guide the selection of most appropriate intervention.

Mental health specialists should train members of the health care team in screening instrument use. Further, if formal assessments are used, there must be a process for appropriate referrals to mental health specialists to address identified concerns. Screening and referral alone are not sufficient to impact clinical and psychological outcomes, nor can they ensure referrals are done so that mental health care is actually received.[2] Integrated care models are critical.[3–5]

## 8 | DIABETES IN CONTEXT

Diabetes self-management is most effective in the context of collaborative interpersonal relationships.[129,130] This involves the family context, peers, and diabetes team. The Social Ecological Theory and the biopsychosocial model consider the social environment or “interpersonal context of illness” as key to understanding the development and behavior of youth with diabetes to improve their health outcomes.[131,132] The interactions between youth with diabetes and their environments are reciprocal, and an individual's characteristics interact uniquely with their environment, creating a developmental context that is specific to that individual. This view helps to explain the differing developmental trajectories and outcomes of individuals with the same diagnosis of diabetes.[131]

### 8.1 | Impact of parental mental health

Parental well-being affects their children's outcomes. Levels of psychological distress among parents of children with diabetes are greater than parents of children without diabetes.[133] Many parents report significant distress after their child's diabetes diagnosis and have difficulty coping with their child's diabetes management.[32] Parental depression and anxiety symptoms are common in the months following diagnosis, as are symptoms of post-traumatic stress due to the new responsibilities[134–137] with nearly one in five parents reporting distress up to 4 years after diagnosis.[138] Parents of younger children report an all-encompassing impact due to constant worry and the perceived need for vigilance.[139] Fear of hypoglycaemia in parents of younger children, and distress about caring for a child with diabetes, affect parental well-being and relationships. This could, in turn, affect parenting behavior and the child's glycemic management.[17,139–142] Greater social support is associated with less stress in parents of children with recent diagnosis of diabetes.[143] Connecting with other parents caring for a child with T1D can provide valued emotional and practical support and diabetes technology use could also lessen some burdens.[139] Literature on the specific impact of T2D in youth on parental well-being is scarce.

Parental well-being and coping also impacts their child's physical and mental health. When parents have adjustment difficulties and are greatly stressed, studies indicate they also have less diabetes management self-efficacy and their children have more behavioral and psychological problems.[144–148] Although most studies have been conducted in mothers, it is important to consider fathers as well since paternal psychological maladjustment predicted suboptimal glycemic management in children 5 years after diagnosis.[149] Further, avoidant coping in fathers was related to increased parenting stress when they were more involved in diabetes management.[150] Providing psychological support to parents is an important clinical need and helping parents can lead to more effective management of diabetes.[151,152] Parenting and family interventions can be instrumental here and will be discussed below in Section 10.

## 8.2 | Familial and social support

Parent support, levels of parent involvement, family conflict, parenting style, and family/parent–child relationship quality are all associated with psychological health outcomes in youth with diabetes, with some associations varying by parent gender, child age and demographic factors.[153] Continued parental involvement in diabetes care throughout adolescence and into young adulthood is beneficial[154,155] as premature transition of responsibility may be detrimental.[156] This involves parental monitoring of child behavior, which has favorable effects on youth internalizing and externalizing symptoms.[153] Especially close parental monitoring of self-management tasks requiring executive functioning skills like problem-solving and impulse control is warranted to prevent glycemic outcome declines.[95] The way parents are involved in their child's management matters. Diabetes-specific family conflict negatively affects treatment plan, glycemic management as well as QoL and depressive and/or anxiety symptoms in young people.[157] Over-involvement, or unsupportive behaviors (such as nagging), could have adverse effects.[140,158] Parenting styles are important in these family interactions. An authoritative and responsive style (i.e., clear levels of expectations for self-management and warmth and sensitivity) is associated with better self-management (e.g., checking blood glucose levels more frequently, making healthy food choices) and glycemic management, and less overweight (therefore perhaps preventive for T2D); conversely, more psychological control is associated with suboptimal outcomes.[155,159] The benefits of an authoritative parenting style transcend ethnicity, socioeconomic status, and household composition.[159] Studies that explored relationship quality and child psychological health generally found that more cohesive family relationships were associated with lower youth externalizing symptoms. There may be a relationship between higher quality family relationships and lower internalizing in youth with T1D, especially for youth of color.[153] In addition, a warm and accepting environment is associated with better physiologic and psychosocial outcomes.[154,158]

Although most research on the social context of youth with diabetes has focused on the family environment, as children get older (particularly during adolescence) peer relationships become more important. Supportive friends can complement parents' involvement in psychological outcomes[160,161] with youth receiving instrumental support from their families and also considerable emotional support from their friends. On the other hand, social conflict and greater orientation toward peers negatively affects diabetes outcomes.[161,162] When youth attribute negative peer reactions to their self-management (e.g., joking about being a "junkie" when administering insulin), they are more likely to have difficulties being consistent with their treatment plan and have increased diabetes stress, which in turn worsens glycemic management. Overall, the research linking peer relations to diabetes outcomes is mixed. Although qualitative studies reveal that adolescents believe peers have an impact on their diabetes, the quantitative findings are inconclusive.[162]

## 8.3 | Communication

Pediatric diabetes care is characterized by a triadic relationship.[163] Youth, parents and pediatric care providers must sustain effective communication about the demands, expectations ("who does what") and burden of diabetes management[164] as youth face many physical and psychosocial developmental changes from childhood to adolescence, as responsibility for diabetes management gradually shifts from parents to youth. Providers need to navigate this shift by being attuned to youth's evolving competencies and readiness for independent self-care,[165,166] while also considering the need for parental and provider support and guidance. Research has shown that responsive and supportive communication between youth with diabetes and their family, caregivers and the broader social environment (e.g., peers, school system, other relatives, sport coaches) is essential for youth well-being, including better glycemic outcomes, self-management, QoL, and satisfaction with care.[117,129,130,167] Person-centered communication by providers, which is closely linked to autonomy-supportive communication (i.e., explaining the personal relevance of treatment guidelines and offering choices),[130,163,168] puts the young person with diabetes and their family at the forefront by eliciting their perspectives on the proposed treatment recommendations, and by engaging in a shared-decision making process. This communication style promotes openness and trust, and fosters dialog about the best way to optimize diabetes management and outcomes for each young person with diabetes and their family.[168] Clinically, person-centered communication includes elements of motivational interviewing. At the core of motivational interviewing are reflective listening, being empathic, not engaging in arguments or persuasion and focusing on changing behavior and enhancing self-efficacy.[168,169] In clinical practice, communication is an effective, modifiable tool to enhance diabetes self-management and to establish a constructive relationship between providers, youth with diabetes, and their families.

## 8.4 | Diabetes team

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, psychosocial care should be an integral part of the collaborative, person-centered medical care for youth with diabetes. 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.[5,170] The shared goal of care should be to optimize health outcomes and QOL. Easy access to mental health professionals such as psychologists, social workers and psychiatrists must be available.[121] These mental health professionals should have training in diabetes and its management, have expertise in the mental and behavioral health of youth, and be available to interact with youth with diabetes and families at clinic visits to conduct screening and more complete assessments of psychosocial functioning on a regular basis. In addition, the mental health professionals should support the diabetes team in the recognition and management of mental health and behavior problems. In case of severe psychopathology and the potential need for psychotropic medications, referral to a psychiatrist is indicated.[171]

# 9 | DIABETES TECHNOLOGY

Technological advances in diabetes care have changed the way many persons manage diabetes in the last two decades, and in some countries more than half of children and adolescents use insulin pumps and continuous glucose monitoring (CGM).[172,173] Developments such as insulin pumps, real time and intermittent scanned CGM and automated insulin delivery systems improve diabetes management, health outcomes and reduce frequency of hypoglycaemia in the majority of those using them.[174] Technology uptake is increasing most especially in the pediatric population.[172,173] CGM use is also now considered to be “standard of care” for people with T1D and is recommended by the EASD/ADA Clinical Consensus Report 2021 to manage T1D.[175]

Psychological benefits associated with use of diabetes technology, especially CGM use, usually include improved QOL, reduced diabetes distress, reduced fear of hypoglycaemia, as well as “better sleep, safety and flexibility,” QOL, family functioning and stress in both youth and their caregivers.[176–178] The widespread migration from self-monitoring of blood glucose (SMBG) to CGM has greatly increased the amount of real time blood glucose information available to parents and youth. For insulin pump therapy, the evidence regarding QOL benefits are not that clear.[179,180] These studies are, however, limited by small sample sizes as outlined in systematic reviews. The consensus statement on insulin pump use in children and adolescents states that QOL with insulin pump therapy is similar to, or higher than of children and adolescents using MDI.[179,181] The benefits are more obvious from the emerging evidence on automated insulin delivery systems: these improve clinical outcomes (TIR, HbA1c, reduction in the number of hypoglycemic events),[182,183] and also enhance QOL, reduce diabetes distress, and improve sleep quality in children and caregivers.[184,185]

Some psychological disadvantages of diabetes technology adoption have been reported, including issues with body image,[186] disruptive alarms and painful insertions.[176] The large amount of data and real-time remote glucose monitoring can be a source of conflict between children with T1D 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.[187–189] There even might be a reduction in family conflict after the commencement of CGM.[178,190] Anecdotal evidence from diabetes clinics often lists “body image” as an obstacle to technology adoption, as some people with diabetes (adolescents, young adults), “do not want to have anything attached to their bodies.”[191] However, according to a systematic review on this topic, there were no differences in body image between those with T1D using and not using technology (insulin pumps, CGM).[192] Frequent exposure to device alarms (in particular false or unnecessary ones) for a device user or a caregiver can result in poor or interrupted sleep and/or unwelcome distractions, as well as “alarm fatigue,” when, over time, the user becomes less likely to respond to true alarms.[192–194] These disadvantages of technology used in diabetes management are usually listed as barriers to its adoption, and rarely, these might be the reasons to discontinue pump or CGM. Evidence from the T1D Exchange, US-based diabetes registry, highlights that the overall insulin pump discontinuation was 3%. Those who discontinued insulin pump therapy were more likely to have higher HbA1c levels at baseline, and the most frequently listed reasons for discontinuation were problems with wearability (57%), disliking the pump or feeling anxious (44%).[195] Therefore, the fears and obstacles should be acknowledged and discussed with adolescents with T1D and their parents/carers, and advantages should be carefully explained, so the family can make an informed decision about whether to use a device.

Little information is available regarding the use of diabetes technology in youth with underlying mental health issues. Registry-based data from the German and Austrian DPV diabetes registry showed that the use of CSII was more common in youth with depression, anxiety disorders, or needle phobia compared with people without any mental health issues. On the other hand, those with psychotic disorders least frequently used insulin pumps, and those with eating disorders and ADHD had similar levels of uptake.[196] There is some indication that the use of pumps is associated with fewer disordered eating behaviors because of the flexibility a pump provides[197]; however youth with ED or depression are more likely to discontinue pump use than children without co-morbid mental health conditions.[196]

# 10 | PSYCHOSOCIAL AND BEHAVIORAL INTERVENTIONS

There is a substantial literature addressing psychosocial and behavioral interventions for the treatment of children and adolescents with

T1D. Systematic reviews including meta-analyses have shown the efficacy of various approaches[198–200] including family based interventions.[38,201] While methodological limitations have been noted,[198,202–205] it can generally be concluded that there is a solid evidence base for psychosocial and behavioral interventions[206] although the effects on glycemic outcomes are inconsistent.[202] Many children and adolescents receive psychosocial interventions, as demonstrated by a nationwide study in Germany that revealed approximately 30% receive psychosocial support. These youth had suboptimal glycemic management but with continued psychosocial support, this remained stable over time.[207] A recent study documented that having pediatric psychologists integrated with the interdisciplinary health care team has benefits for youth as well as insurers: youth who met with psychologists during their clinic visit had better subsequent glycemic management and reduced health care costs.[208] It should be noted that almost all research has been conducted in children and adolescents with T1D and the evidence-base in young adults and youth with T2D is scarce.[209,210]

## 10.1 | Family based interventions

Family based interventions show improved psychosocial outcomes for youth and families such as reducing family conflict and improved parent–child relationships, but mixed results for glycemic outcomes.[211,212] Family based, behavioral interventions include goal-setting, problem-solving, self-monitoring, parental praise for regimen-related behaviors, use of behavioral contracts, clear and consistent parental communications, and appropriately shared responsibility for diabetes management tasks. Behavioral family systems therapy with diabetes-specific tailoring reduced family conflict and improved ability to be consistent with treatment plans, with improved glycemic management over 18 months, by means of improved parent-adolescent communication and problem-solving.[213] It is important to provide psychosocial interventions during the period after diagnosis as this is a stressful time for the child and the family. Several interdisciplinary programs for newly diagnosed children have been reported to improve child and parental outcomes.[214–218]

## 10.2 | Psychosocial interventions during clinic visits

One approach is to deliver brief psychosocial interventions during routine clinic visits. Family teamwork could help to increase positive parental involvement, reduce family conflict and help prevent worsening of glycemic management in younger youth.[219–222] Improving problem-solving and communication skills, and appropriate sharing of responsibility for diabetes management showed improvements in glycemic management and parental involvement. Similarly, a psycho-educational intervention addressing various diabetes management issues delivered by a "care ambassador" at regular outpatient clinic visits, resulted in reduced hypoglycemia and emergency department visits.[223]

## 10.3 | High-risk individuals

Other studies have targeted psychological interventions to youth at high risk for worse health outcomes, such as low income, ethnic and/or racial minority adolescents with chronically sub-optimal glycemic management. Intensive home-based multi-systemic therapy that addressed the individual adolescent, the family system, and the broader community systems (i.e., school and health care system) seem most successful here in improving blood glucose monitoring and glycemic management, and reducing health care utilization and medical costs.[224,225] The subgroup of youth with chronically suboptimal glycemic management is a high-risk population that requires novel approaches to intervention.[226] High-intensity frequent contact with these youth through various means of communication may be necessary to improve diabetes management outcomes.[227,228]

## 10.4 | Peer group interventions

Another approach to psychosocial intervention involves peer groups.[229,230] In adolescents as well in younger, school-age children, coping skills training have a positive effect on glycemic management and QOL,[231–234] reduced diabetes-related stress,[235,236] improved social relationships.[237] A recent Chinese study showed that coping skills training was more effective for younger than older youth.[238]

## 10.5 | Interventions with individual participants

Other psychosocial interventions have addressed individual youths. Cognitive behavior therapy for youth with diabetes is one of the most well researched therapies, and feasible and acceptable, with improvements noted in psychosocial functioning.[202,239] As research has shown that higher levels of intrinsic motivation for management tasks improves diabetes management, glycemic management, and psychosocial functioning,[240] motivational interviewing is designed to increase this intrinsic motivation. Indeed, motivational interviewing delivered by a psychologist is shown to improve long-term glycemic management and QoL,[241] especially in older adolescents.[242] It should be noted that these types of interventions are generally delivered by a mental or behavioral health professional trained in this approach. Motivational interviewing delivered by trained non-psychologist HCPs who did not show improved glycemic management,[243] likely due to inadequate training and counseling skills.[244] Motivational intervention combined with problem-solving training resulted in significant improvements in motivation, problem-solving, diabetes management, QOL, and reduced family conflict, but not glycemic outcomes.[245] A motivational intervention delivered by a nurse during home visits for adolescents with suboptimal glycemic management showed a positive effect on glycemic management over 6 months.[246] Another approach, to increase external motivation for diabetes management, is to use monetary reinforcement to improve youth performance using a hybrid closed loop system,[247] suggesting behavioral economics may be a feasible way to improve self-management behavior. Another approach to psychosocial interventions with individual youth targets distress and depression prevention by promoting resilience. A large RCT examined the impact of an eight-session diabetes distress and depression prevention program for adolescents (STePS). Adolescents reported significant reductions in diabetes distress and depressive symptoms after 1 and 3 years.[248] Recent intervention research has employed several innovative approaches, such as mindfulness-based stress reduction or gratitude.[249,250]

## 10.6 | Internet-based and digital interventions

Problem-solving skills training and coping skills training can both successfully be delivered via the Internet, showing positive outcomes.[251,252] Further, adolescents respond well to behavioral intervention using Skype,[228] tele-health,[253] text messaging,[227,254] and can receive social support via chat rooms.[255] Also more complex interventions, such as an multicomponent motivational and cognitive intervention targeting youth with suboptimal glycemic management and emotional regulation difficulties, can be delivered via the Internet as it resulted in increased frequency of blood glucose monitoring, improved working memory, and improved glycemic management[256]; youth with more emotional control problems benefited the most from this approach.[257]

Digital health interventions (i.e., programs or tools which use digital technology to encourage or foster behavior change, such as websites, mobile applications [apps], text messaging, or online games) for youth with diabetes have some impact on their mental health such as self-efficacy, but few consistent effects for other psychological, behavioral, or health outcomes; results also indicated studies showed high risk of bias and more research was needed using theory-based approaches with stronger methodologies.[258]

## 10.7 | Interventions for parents

Parents often need additional coping supports. Parenting interventions in parents of children and adolescents with T1D could significantly reduce parents' depression and distress, and help them ask for positive social support.[38] Coping skills training for parents of young children may be helpful.[259] Interventions to reduce distress and fear of hypoglycemia in parents are under development.[260–262]

In summary, the results of controlled intervention research for individual and family based interventions show promising effects with respect to psychosocial outcomes and inconsistent results for glycemic outcomes. Future work should investigate which key intervention components may be attributed to positive diabetes outcomes. It should consider the competency of the interventionists delivering the therapy and match psychological approaches to a person and their life course. There is growing evidence supporting the use of the Internet and other digital approaches to deliver behavioral interventions, and a need for higher quality studies. In general, psychosocial and behavioral intervention research is limited by not including enough high-risk youth (i.e., low income, ethnic minority, single parent youth) in their study samples.[263,264] In addition, there is a need for more studies specifically targeting youth with T2D 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.[265]

## PEER REVIEW

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## DATA AVAILABILITY STATEMENT

Data sharing not applicable to this article as no datasets were generated or analysed during the current study.

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