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ISPAD Clinical Practice Consensus Guidelines 2018

Psychological Care of Children and Adolescents with Type 1 Diabetes

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1. Summary of What's New/Different

Recent literature has been reviewed and new research findings as well as systematic reviews show the important role in management of type 1 diabetes in children and adolescents of:

- 1) Depression and diabetes distress;
- 2) Disordered eating behaviors;
- 3) Cognitive functioning and school performance;
- 4) Parental distress, coping, and demographic factors;
- 5) Stress and coping;
- 6) Factors affecting quality of life, including resiliency; and
- 7) Psychosocial and behavioral intervention studies to improve glycemic control, diabetes management behaviors, and psychosocial functioning.

2. Executive Summary and Recommendations

The following summary and recommendations build upon the previous ISPAD Guidelines (1) and are consistent with the latest statements and guidelines issued by the American Diabetes Association (2), Australia (APEG - Clinical Practice Guidelines, www.nhmrc.gov.au/publications/pdf/cp102.pdf), Canada (www.diabetes.ca/cpg2003), and the UK (www.nice.org.uk/pdf/type1diabetes).

Young people with diabetes appear to have a greater incidence of depression, anxiety, psychological distress and eating disorders compared to their peers without diabetes (A). Children and young people with chronic poor metabolic control, including recurrent DKA, are more likely to have underlying psychosocial problems or psychiatric disorders than children in good metabolic control (A, B).

1. Resources should be made available to include professionals with expertise in the mental and behavioral health of children and adolescents within the interdisciplinary diabetes health care team. These mental health specialists should include psychologists, social workers, and psychiatrists (E).

Mental health professionals should be available to interact not only with patients and families at clinic visits to conduct screening and more complete assessments of psychosocial functioning, but also to support the diabetes team in the recognition and management of mental health and behavior

problems (A, E). There should also be easy access to consulting psychiatrists for cases involving severe psychopathology and the potential need for psychotropic medications (E). All mental and behavioral health specialists should have training in diabetes and its management (E).

2. The interdisciplinary diabetes health care team should maintain regular, consistent and uninterrupted contact with patients and their families. When clinic visits are missed or not frequent, other modes of contact should be made available such as by phone, SMS texting, or email (B, E).

3. Young people with diabetes are at increased risk for mild decrements in general cognitive ability, information processing skills, executive functions, and academic achievement, especially if there is a background of early diabetes onset, severe hypoglycemia or chronic hyperglycemia (B). Therefore, it is recommended that assessment of developmental progress in all domains of functioning (i.e., physical, intellectual, academic, emotional and social development) should be conducted on a routine basis (A, B, E).

- Quality of life can be reliably measured with good clinical utility (A).
- It is especially important to monitor the school performance of children who developed diabetes before age 5 years, and with a history of significant hypoglycemic episodes and/or chronic hyperglycemia at early ages (B).
- These children, as well as all children experiencing learning difficulties at school, should be referred for a psycho-educational or neuropsychological evaluation in order to determine if learning disabilities are present (B).
- Specific diabetes care plans should be formulated for the school setting and training conducted with school staff concerning diabetes management (B, E).

4. Routine assessment should be made of developmental adjustment to, and understanding of, diabetes management, including diabetes-related knowledge, insulin adjustment skills, goal setting, problem-solving abilities, regimen adherence, and self-management autonomy and competence. This is especially important during late childhood and prior to adolescence when in many families the child may take on diabetes management responsibilities without adequate maturity for effective self-management (B).

5. Identification of overall psychosocial well-being and diabetes-specific quality of life, as well as psychosocial adjustment problems, depression, eating disorders, diabetes distress, and other psychiatric disorders should be performed at planned intervals and by appropriately trained mental health professionals (B, E). These assessments are particularly important in young people not achieving treatment goals or who exhibit chronically poor metabolic control. (B, E).

6. Several family factors including levels of family cohesion, agreement about diabetes management responsibilities, and levels of supportive and collaborative problem-solving behaviors influence treatment regimen adherence and glycemic control (B, C). Family conflict is associated with lower regimen adherence and poor glycemic control (B, C). Therefore, the interdisciplinary team should assess general family functioning (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, early adolescence) and when there is evidence of cultural, language or family problems or difficulties in adjustment to diabetes (A, B, E).

7. The interdisciplinary team should aim to provide preventive interventions for patients and families (including training parents in effective behavior management skills) at key developmental times, particularly after diagnosis and prior to adolescence (A, E). These interventions should emphasize appropriate family involvement and support (i.e., teamwork) in diabetes management, effective problem-solving and self-management skills, and realistic expectations about glycemic control (A, E).

8. Evidence-based psychosocial, behavioral, or psychiatric interventions should be made available for patients or families exhibiting conflict, disordered communication, diabetes distress, behavioral or psychiatric difficulties or adherence problems affecting glycemic control (A, B, E). Developmental needs of children and adolescents should be considered while planning interventions incorporating social, emotional and tangible support (C, E).

9. In counseling young people and parents regarding advances in diabetes management, and encouraging the intensification of insulin regimens and use of advanced technologies, motivational interviewing may be useful (A). This may help in clarifying patient and parental goals and resolve ambivalence about regimen intensification. Patients should not be denied access to regimen intensification and advanced technologies based on perceptions of limited competence, as even youth with low self-management competence have been shown to improve with intensive insulin therapy (A).

10. Adolescents should assume increasing responsibility for diabetes management tasks but with continuing, mutually agreed, parental involvement and support (A, E). The transition to adult diabetes care should be discussed, negotiated and carefully planned with adolescents, their parents and the adult diabetes team well in advance of the actual transfer to adult care (E) (see guidelines on Adolescent Care).

3. Introduction

A substantial research base developed over the past thirty years provides evidence for the significant role of psychosocial factors in the management of type 1 diabetes (T1D) in children and adolescents (3-7). We review the main findings from studies of psychological adjustment, psychiatric disorders, neurocognitive and educational functioning, family dynamics, social support, stress and coping, quality of life, and behavioral interventions in children and adolescents with T1D. Based on these research findings, recommendations for optimal psychological care are offered, as detailed in the Executive Summary.

The ISPAD Consensus Guidelines 2000 stated that *“Psychosocial factors are the most important influences affecting the care and management of diabetes,”* and went on to make the following three general recommendations (8):

1. Social workers and psychologists should be part of the interdisciplinary health care team.
2. Overt psychological problems in young persons or family members should receive support from the diabetes care team and expert attention from mental health professionals.
3. The diabetes care team should receive training in the recognition, identification, and provision of information and counseling on psychosocial problems related to diabetes.

After reviewing the evidence base on psychological issues and interventions for children and adolescents with T1D, these general recommendations remain appropriate and are developed further with more specific recommendations for psychological care.

4. Psychological Adjustment and Psychiatric Disorders

Young people with diabetes appear to have a greater incidence of depression, anxiety, psychological distress and eating disorders compared to their healthy peers (9, 10). Research findings indicate children with T1D are at risk for adjustment problems during the initial period of adaptation after diagnosis (11, 12). When adjustment problems exist, children are at higher risk for continued adjustment difficulties (12-15). In a ten-year prospective study from diagnosis of T1D, adolescents were at high risk for various psychiatric diagnoses; females were more likely than males to receive a diagnosis, and half of those with a history of poor glycemic control had a psychiatric diagnosis (16). However, a recent longitudinal study from adolescence into emerging adulthood did not reveal group differences in psychosocial adjustment (17, 18). More recent studies suggest differences between children with and without diabetes appear to be smaller (9). Nevertheless, about 15% of youth with diabetes report elevated levels of psychological distress, with potential negative consequences for self-management, and studies indicate behavioral problems are associated with poor glycemic control (19, 20).

Studies indicate that depression and anxiety are related with less frequent glucose monitoring and poorer glycemic control (21, 22). Results from the SEARCH study in the USA found that 14% percent of youth with diabetes reported mild depression and 8.6% reported moderate to severe depression; girls reported more depressive symptoms than boys, and depression was associated with poorer glycemic control and increased diabetes-related hospitalizations (23). A meta-analysis showed that depression is associated with poorer treatment adherence, and this association is even stronger in more recent studies; the association between depression and glycemic control is small to moderate, and smaller in more recent studies (24). Prospective studies indicate that greater depressive symptoms predict less frequent blood glucose monitoring, poorer quality of life, and poorer glycemic control over time (25, 26). Children with recurrent DKA are more likely to have psychiatric disorders than children in good glycemic control (27). Poor glycemic control has also been associated with a number of other

psychosocial problems including anxiety (22), poor self-esteem, and diabetes distress (28, 29). Diabetes distress is common in adolescents with T1D and associated with decreased regimen adherence and poor health outcomes (30). When psychological adjustment problems persist into late adolescence, there is evidence indicating greater risk for poor diabetes management during early adulthood (31, 32). However, more research in this area is needed.

Youth that are depressed are also at an increased risk for disordered eating behaviors (e.g., restricting food intake and insulin omission) (33, 34). There is evidence that adolescents with diabetes, especially girls, have a higher incidence of disturbed eating behavior and eating disorders (10). It is estimated that 7 % of adolescent girls with T1D may meet diagnostic criteria for an eating disorder, a rate twice as common as in girls without diabetes (10). Disordered eating behavior is more prevalent in adolescent girls with T1D (40%) than their peers (33%)(33). Results of a recent meta-analysis indicated that eating disorders are associated with poor glycemic control (10), although a recent longitudinal study did not show this association (33). Even at subclinical levels, glycemic control has been observed to worsen with increasing symptoms of eating disorder (35-37). Without intervention, disordered eating and insulin manipulation may worsen over time and increase the risk of serious health complications (38-40).

5. Neurocognitive and School Functioning

Subtle neurocognitive deficits (41-44) and pathological brain changes (45) have been documented in children and adolescents with T1D. IQ scores are typically well within the average range but significantly lower than those of healthy controls. In a robust test of the impact of childhood onset diabetes on IQ, Lin et al. (46) calculated IQ change scores using measures obtained at diagnosis, and at follow up 12 years later, and showed a greater decline in Verbal and Full Scale IQ in participants with T1D than was evident in the healthy controls. In addition to this difference in intellectual functioning, specific neurocognitive deficits have been documented in youth with T1D. The specific skills most affected include information processing (attention, memory, processing speed) and executive skills (planning, organization problem solving, mental flexibility) (41-43, 47-50). It is important to note that intact information processing and executive skills are often required for disease management (51), thus possible weaknesses in these skills should be considered when children present with sub-optimal metabolic control.

Attempts to identify specific diabetes-related risk factors for neurocognitive sequelae in children with T1D have been a focus of much recent research. Meta-analytic and systematic reviews reveal a significant relationship between early disease onset and neurocognitive deficits (42, 43, 52, 53) with attention, memory/new learning and executive skills particularly affected in children who develop diabetes prior to 5-6 years of age (42, 43, 47, 50). A positive history of hypoglycemia (41, 47, 54) episodes of DKA (55) and chronic hyperglycemia (43, 47-50, 56) have all been associated with neurocognitive deficits, albeit with some inconsistency in findings. The U-shaped relationship between blood glucose levels and neurocognitive performance demonstrated in field studies (57), difficulty in obtaining comprehensive, accurate, often retrospective accounts of metabolic control history, our inability to pinpoint the exact timing of putative neural insults as well as the fact that many children experience a combination of risk factors for neurocognitive sequelae have probably contributed to

inconsistent findings. Current evidence is robust enough, though, to argue that optimal neuroprotection of the developing brain in children with T1D is achieved by meticulous avoidance of glycemic extremes.

Neurocognitive deficits in children with T1D are usually mild, but even subtle decrements can have an impact in children engaged in ongoing learning and skill development. There is evidence from both longitudinal cohort and population studies of poorer academic achievement (55-58) and lower rates employment post school (58, 59) in youth with T1D. Children who develop diabetes prior to 6-7 years of age (60) and those with a history of chronic hyperglycemia (61, 62) appear at particular risk of academic underachievement. Neurocognitive assessment, together with appropriate educational interventions, should be offered to all children with T1D who present with unexplained academic underachievement or difficulties managing the problem solving demands inherent in optimal disease management.

The school setting also presents challenges for parents of a child with diabetes and they report considerable anxiety when their child is at school. Parents report feeling that schools are often not well informed about federal laws to accommodate their child with diabetes and believe that schools do not facilitate optimal treatment for their child (63). In describing school experiences of students with diabetes, better glycemic control and quality of life occurs when school personnel and friends receive some training in diabetes and its management (64).

6. Family Functioning and Social Support

The research literature has consistently demonstrated that family factors are integral to the management of diabetes in children (7, 65). Cross-sectional and prospective studies have shown that high levels of family cohesion, authoritative parenting, agreement about diabetes management responsibilities, supportive behaviors, parental monitoring of diabetes management, and collaborative problem-solving are associated with better regimen adherence and glycemic control, while family conflict, diffusion of responsibilities, and over- or under-involvement in diabetes management relative to the child's developmental level and abilities have been associated with worse regimen adherence and glycemic control (66-77). Family conflict and negative affect related to blood glucose monitoring have also been associated with depression (21). A collaborative parent-child relationship with shared responsibilities for diabetes management is associated not only with better regimen adherence but also with improved emotional functioning (69, 78, 79). Socio-demographic family factors such as single-parent households or higher family density (more youth per adults in the household) (79-83), lower family income, and racial/ethnic minority status (79, 82-88) are associated with less optimal parental involvement in diabetes management and greater risk for poor control of diabetes.

It is important to note that many parents have psychological distress after the diagnosis of T1D in their children. One recent review indicated that on average 33.5% of parents report distress at diagnosis, with 19% of parents reporting distress one to four years after diagnosis (89); estimates of clinically elevated symptoms of depression and anxiety have been reported to be as high as 74% and 59%, respectively, in the month following diagnosis (90). One study found that 24% of mothers and 22% of fathers met criteria for a diagnosis of post-traumatic stress disorder six weeks after their child had been diagnosed (91). Providing support to parents after the diagnosis of diabetes of their child is an important

need and can promote better diabetes management (92, 93). Parental adjustment difficulties and stress have been related to lower parental self-efficacy for diabetes management and greater child behavior problems (94, 95). Another study found that psychological maladjustment of fathers predicted poor glycemic control in children five years after diagnosis (96). Fear of hypoglycemia has also been found to be common in parents of children with diabetes (97) and is associated with emotional distress and poorer glycemic control in children (98).

Social support from parents and other family members is especially important for children and adolescents with T1D. Research has shown that supportive cohesive families are more likely to have adolescents with improved adherence and metabolic control than families without such cohesion. Furthermore, adolescents with good adherence have interactions with their parents that are characterized as open and empathetic, whereas adolescents with poor adherence have interactions characterized as emotionally charged and confrontational (99, 100). It was also noted that levels of diabetes-specific family support were inversely related to youngsters' age, with older children and adolescents reporting significantly less family support for diabetes (100). Although the level of support provided by parents decreases as adolescents get older and take a greater degree of responsibility for their diabetes management, premature withdrawal of parental involvement is associated with poor diabetes outcomes, whereas continued parental support and monitoring is associated with better outcomes (101). It must be noted that while continued parental support in adolescent diabetes management may lead to better outcomes for adolescents, over-involvement by parents is associated with poorer metabolic control, and is a stronger predictor of metabolic control than age, gender, or insulin treatment regimen (76).

Social support from friends can be a unique source of support that complements parents' involvement and improves adolescents' diabetes management (101), with youths receiving instrumental support from their families and also considerable emotional support from their friends (102-106). When youth attribute negative peer reactions to their self-management, they are more likely to have adherence difficulties and increased diabetes stress, which in turn worsens glycemic control (107). Fear of stigmatization appears to be a barrier in acquiring support from peers (103). Poor peer relations has been associated with decreased regimen adherence and worse glycemic control over time, while more family support predicted better glycemic control (108). 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 (109).

7. Stress and Coping

Considerable research has demonstrated the important role of stress and coping in predicting psychosocial adjustment and glycemic control among youth with T1D (110). Diabetes-related stress may have effects on the life of children and adolescents directly or indirectly. Using a direct approach, studies have shown that children with high life stress tend to have worse glycemic control (28, 107, 111-115). Other research, using an indirect approach, found an adverse effect of diabetes stress on diabetes self-management (110, 116, 117). There is support from intervention studies targeting diabetes stress for improved glycemic control (113, 118). Daily stressors faced by younger children are usually related to

friends/peers and siblings, and their coping behaviors include choosing an alternate activity and taking personal responsibility (119). Research examining coping styles has indicated that youths in poor metabolic control are more likely to use the learned helplessness style (120) and engage in avoidance coping and wishful thinking in response to stress (121, 122), while youths in good glycemic control have high levels of self-efficacy (123) and engage in active coping (110, 124-128). Longitudinal studies suggest a reciprocal relationship between active coping and better glycemic control (125, 129), while avoidance coping was linked with worse glycemic control and increased psychological stress (130, 131). Additionally, maladaptive coping in youth has also been associated with poor regimen adherence (132, 133). It has also been shown that resilience to stress is associated with better glycemic control (134, 135) and other diabetes outcomes including depressive symptoms, diabetes management, and quality of life (126, 136).

Research addressing the Health Belief Model in adolescents indicate that beliefs related to the seriousness of diabetes, personal vulnerability to complications, costs of regimen adherence, and beliefs in the efficacy of treatment/mediation beliefs, have been associated with both regimen adherence and glycemic control (137-140). Studies have also shown that individuals' personal models of illness belief for diabetes were associated with psychological adjustment and regimen adherence: greater impact of diabetes was related to increased anxiety, while beliefs about the effectiveness of treatment predicted better dietary self-management (141, 142). Personal model beliefs about diabetes were also shown to mediate the relationship between personality variables (emotional stability and conscientiousness) and self-management behaviors (143, 144). Studies of health risks associated with diabetes indicate that youth underestimate their own risks while acknowledging greater risks of diabetes attributed to other youths (145).

Identification and improvements in primary caregivers' (mostly mothers) coping may have the potential to improve both maternal and adolescent outcomes (146-151). Children with parents exhibiting the negotiator coping pattern had better glycemic control than children with parents classified as avoiders or doers (152). Research suggests that parental support groups may help parents cope more effectively in managing their children with T1D (153).

8. Quality of Life

Quality of life is recognized as a central outcome in diabetes care. In general, children with diabetes rate their own quality of life as similar to their healthy peers (154). However, parents tend to rate their child's quality of life somewhat lower, except for those 5-7 years of age (155-158). Boys tend to report better quality of life (159) as well as youth with longer diabetes duration and those from a better socio-economic background (154, 158, 160, 161). Lower quality of life seems associated with psychiatric disorders, especially depression and anxiety (162, 163) and a negative family environment, especially diabetes conflicts (164). Less favorable quality of life also appears to be related with youths' perceptions that diabetes is upsetting, difficult to manage, and stressful, as well as fear of hypoglycemia (164, 165). There is some evidence that better quality of life is associated with better glycemic control, but the relationship between glycemic control and quality of life appears modest (157, 166-168). In a prospective study, poorer quality of life predicted subsequent poor glycemic control via less frequent

blood glucose monitoring (169). Use of the insulin pump does not appear to adversely affect quality of life (170-172) and may be associated with improved quality of life. In addition, use of continuous glucose monitoring does not seem to adversely affect quality of life (173). A revised and updated measure of diabetes-specific quality of life has recently been shown to be reliable and valid for use in pediatric and adolescent patients with T1D, providing scores for diabetes symptoms and diabetes management (174). Research has shown that diabetes symptoms are associated with general health-related quality of life, which is partially mediated by diabetes management (175).

9. Psychosocial and Behavioral Interventions

Previous systematic reviews of the literature and meta-analysis (176-178) indicate that a number of controlled studies have shown the efficacy of psychosocial and behavioral interventions for children and adolescents with diabetes, although this literature is not without some methodological limitations (4, 5, 176, 179-182). Most of these interventions have included the family as an integral part of treatment (183).

The results of these studies indicate that family-based, behavioral procedures such as goal-setting, problem solving, self-monitoring, positive reinforcement, behavioral contracts, supportive parental communications, family restructuring, and appropriately shared responsibility for diabetes management have improved regimen adherence and glycemic control (180, 183, 184). In addition, these interventions have improved the parent-adolescent relationship (180, 185-187), and improved regimen adherence (177, 187). Studies of behavioral family systems therapy with diabetes-specific tailoring targeting diabetes-specific behavioral problems, and training in behavioral contracting techniques have shown improvements in family conflict and regimen adherence (188) as well as improved glycemic control over 18 months (189). Controlled research has demonstrated this approach to improve parent-adolescent communication and problem solving which in turn was associated with improvements in glycemic control (190).

Given the crisis that diagnosis presents for children and families, the period just after diagnosis presents opportunities for intervention. Interdisciplinary intervention programs have been described and reported to improve outcomes (191-193). Psycho-educational interventions with children and their families that promote problem-solving skills and increase parental support early in the disease course have been shown to improve long-term glycemic control of children (194). Other trials involving psychosocial intervention after diagnosis showed improved family functioning without improved glycemic control (195, 196).

Research has shown that when parents allow older children and adolescents to have self-management autonomy without sufficient cognitive and social maturity, youths are more likely to have problems with diabetes management (197). Thus, a critical aspect of behavioral family management of diabetes is finding ways for parents and family members to remain involved and supportive, but not intrusive, in their children's daily care (198). A randomized controlled trial for positive parenting provides some support for improving parent and family outcomes, and reducing child internalizing and externalizing behavior problems (199).

An intervention delivered during regular outpatient clinic visits and based on family-focused teamwork was shown to increase family involvement without causing family conflict or adversely affecting youth quality of life, and helped prevent worsening of glycemic control (200). A psycho-educational intervention addressing eight diabetes care issues (i.e., understanding HbA1c, factors affecting blood sugars, the “blame and shame” cycle, a team approach to diabetes care, blood glucose monitoring, carbohydrate counting, research trends) delivered by a “care ambassador” at regular outpatient visits was shown to improve the frequency of outpatient visits, and reduced acute adverse outcomes such as hypoglycemia and emergency department visits (201).

Additional studies have been conducted on behavioral interventions integrated with outpatient medical clinic appointments. For example, monitoring and discussing quality of life issues with adolescent patients was found to improve psychosocial functioning over time (202). A recent randomized controlled trial showed little improvement in glycemic control yet significant improvement in psychosocial well-being as a result of a cognitive behavioral intervention program (203). A family-centered program integrated with routine clinic appointments led to improvements in glycemic control and parental involvement when families participated in two or more such sessions over the course of a 12 month follow-up. The program was designed to improve diabetes management by teaching problem-solving skills, communication skills, and appropriate responsibility sharing (204). In a large multi-site randomized trial, a family teamwork intervention delivered at the time of quarterly outpatient clinic visits led to improved glycemic control for young adolescents, but effects were not as strong for older children (205, 206).

Another approach utilized intensive home-based multi-systemic therapy with inner city adolescents in chronically poor metabolic control, a patient population that has not received much attention in the intervention literature. This approach incorporated interventions that encompasses the individual adolescent, the family system, and the broader community systems (i.e., school and health care system). Initial studies of this approach suggested it had potential to improve outcomes (207). The results of a larger randomized trial indicated this approach improved frequency of blood glucose monitoring, reduced inpatient admissions, improved glycemic control, and reduced medical costs (208, 209). Another study demonstrated reduced hospitalizations and costs for this high-risk group of adolescent patients using multi-systemic therapy (210).

Peer group interventions have also been evaluated. Results indicate that peer group support and problem-solving can improve short-term glycemic control (211). Group-based training in using effective coping skills improved glycemic control and quality of life for adolescents involved in intensive insulin regimens (212-214). Stress management, problem-solving and coping skills training delivered in small groups of youths has reduced diabetes-related stress (215, 216), improved social interaction (217), and increased glucose monitoring and improved glycemic control (218).

Several studies have examined coping skills training with younger, school-age children. Results indicate this approach had some favorable effects on life satisfaction and family functioning (219). Although coping skills training for younger children was not shown to be more effective than an educational intervention, results from controlled studies do support the use of group interventions for children in

this age range (220). Furthermore, coping skills training with parents of young children has also been shown to be helpful, although outcomes were not significantly different from the control group that received educational support (147).

It is important to maintain regular ongoing contact with families, as research findings indicate that children who have infrequent and irregular visits with the health care team are more likely to have glycemic control problems (221, 222). Research indicates that early adolescence represents a high risk time for diabetes management, with worsening of adherence observed over time (223), which may be due to decreased parental involvement.

Intrinsic motivation for diabetes management can be measured reliably and validly and has been shown to predict better diabetes management, glycemic control, and psychosocial functioning (224). Thus, increasing intrinsic motivation may be an effective way to improve regimen adherence and glycemic control in youth. Motivational interviewing appears to be a promising approach for adolescents, with initial studies showing improved glycemic control (225-227). A larger multi-center randomized trial demonstrated that motivational interviewing with adolescents improved long-term glycemic control and quality of life (228). Another study targeting motivation with an individualized personal trainer showed improved glycemic outcomes in older but not younger adolescents (229). It was demonstrated that this approach had long-term positive effects on glycemic control in older adolescents (230). However, in a recent multicenter study in which non-psychologist health care providers were trained in motivational interviewing, favorable effects on glycemic control were not observed (231), a finding which could be attributed to inadequate training and counseling skills of the health care staff (232). Meta-analytic reviews, however, support the use of motivational interviewing with various pediatric populations in terms of health outcomes (232, 233).

A recently reported large randomized controlled trial evaluated the effects of an 8-session, individually-delivered distress and depression prevention program for adolescents with T1D. In this trial, a resilience program tailored to T1D was compared to an advanced diabetes education program. Results one year post-treatment demonstrated significant reductions in diabetes distress for adolescents in the resilience program, indicating that diabetes distress can be prevented in youth prior to symptoms of psychological distress (234).

Studies have also examined the use of the Internet to deliver behavioral interventions. For example, it was demonstrated that using an Internet program for diabetes problem-solving led to significant improvements in diabetes management and problem-solving, with stable glycemic control (235). This approach was particularly sensitive to diabetes management barriers with regard to social issues, time pressures, and dealing with emotions (236). Another study examined the effects of coping skills training for adolescents delivered over the Internet, compared with an Internet-delivered educational intervention. The results of this randomized controlled multi-site trial indicated clinical improvements for youth in both groups, supporting the concept that behavioral interventions can be effectively applied to youth with T1D using the Internet (237).

A meta-analysis of intervention studies to promote regimen adherence in youth with T1D was conducted and found 15 studies that met criteria for analysis (238). While the results indicated small effect sizes for improvements in glycemic control, multi-component interventions addressing psychosocial and emotional processes had stronger effects. In a review of family-centered interventions, nine studies were examined and found that such interventions improve glycemic control and family functioning while reducing family conflict (239).

In summary, the results of controlled intervention research have shown that family-based interventions utilizing positive reinforcement and behavioral contracts, communication and problem-solving skills training, negotiation of diabetes management goals, and collaborative parental involvement have led not only to improved regimen behaviors and glycemic control, but also to improved family relationships. Group interventions for young people with diabetes targeting coping and stress management skills have also shown positive effects on regimen adherence, glycemic control, and quality of life. Individual interventions with adolescents have shown motivational interviewing approaches to improve glycemic control and psychosocial outcomes, although more evidence is needed. There is growing evidence supporting the use of the Internet to deliver behavioral interventions.

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