

## ISPAD Clinical Practice Consensus Guidelines 2014 Compendium

# Psychological care of children and adolescents with type 1 diabetes

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**Alan M Delamater<sup>a</sup>, Maartje de Wit<sup>b</sup>, Vincent McDarby<sup>c</sup>, Jamil Malik<sup>d</sup> and Carlo L Acerini<sup>e</sup>**

<sup>a</sup>Department of Pediatrics, University of Miami Miller School of Medicine, Miami, FL, USA; <sup>b</sup>Department of Medical Psychology, EMGO Institute for Health & Care Research, VU University Medical Center, Amsterdam, Netherlands;

<sup>c</sup>Department of Psychology, National Children's Research Centre and Our Lady's Children's Hospital, Dublin, UK;

<sup>d</sup>National Institute of Psychology, Center of Excellence, Quaid-i-Azam University, Islamabad, Pakistan; and

<sup>e</sup>Department of Paediatrics, University of Cambridge, Cambridge, UK

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Corresponding author: Alan M. Delamater, Department of Pediatrics, University of Miami, Miami, FL 33136, USA.  
Tel: 305.243.6857;  
fax: 305.243.4512;  
e-mail: adelamater@med.miami.edu

Editors of the ISPAD Clinical Practice Consensus Guidelines 2014 Compendium: Carlo Acerini, Carine de Beaufort, Maria Craig, David Maahs, Ragnar Hanas.

This article is a chapter in the *ISPAD Clinical Practice Consensus Guidelines 2014 Compendium*. The complete set of guidelines can be found for free download at [www.ispad.org](http://www.ispad.org). The evidence grading system used in the ISPAD Guidelines is the same as that used by the American Diabetes Association. See page 3 (the Introduction in *Pediatric Diabetes* 2014; 15 (Suppl. 20): 1-3).

### 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](http://www.nhmrc.gov.au/publications/pdf/cp102.pdf)), Canada ([www.diabetes.ca/cpg2003](http://www.diabetes.ca/cpg2003)), and the UK ([www.nice.org.uk/pdf/type1diabetes](http://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 healthy peers (A).
- Children and young people with chronic poor metabolic control, including recurrent diabetic ketoacidosis (DKA), are more likely to have underlying psychosocial problems or psychiatric disorders than children in good metabolic control (A, B).

- 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 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).
- 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 such as phone, SMS texting, or e-mail should be made available (B, E).
- Young people with diabetes are at increased risk for information processing weaknesses and learning problems, especially if there is a background of early diabetes onset, severe hypoglycemia, or chronic hyperglycemia (B).
  - Assessment of developmental progress in all domains of quality of life (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 5yr, 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).
  - 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-care 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-care (B).
  - Identification of psychosocial adjustment problems, depression, eating disorders, 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 (e.g., high HbA1c, recurrent DKA) (B, E).
  - 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).
  - The interdisciplinary team should assess general family functioning (conflict, cohesion, adaptability, and parental psychopathology) and diabetes-related functioning (communication, parental involvement and support, and roles and responsibilities for self-care behaviors) especially when there is evidence of cultural, language, or family problems or difficulties in adjustment to diabetes (A, B, E).
  - 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).
  - Evidence-based psychosocial, behavioral, or psychiatric interventions should be made available for patients or families exhibiting conflict, disordered communication, 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).
  - In counseling young people and parents regarding advances in diabetes management, and encouraging the intensification of insulin regimens, 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 based on perceptions of limited competence, as even youth with low self-management competence have been shown to improve with intensive insulin therapy (A).
  - 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 ISPAD Clinical Practice Consensus Guidelines on 'Diabetes in Adolescence' – Assessment and management of hypoglycemia in children and adolescents with diabetes).

## Introduction

A substantial research base developed over the past 30 yr provides evidence for the significant role of psychosocial factors in the management of type

1 diabetes in children and adolescents (1–5). 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 type 1 diabetes. Based on these research findings, recommendations for optimal psychological care are offered.

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 (6):

- (i) Social workers and psychologists should be part of the interdisciplinary health care team.
- (ii) Overt psychological problems in young persons or family members should receive support from the diabetes care team and expert attention from mental health professionals.
- (iii) 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 type 1 diabetes, these general recommendations remain appropriate and are developed further with more specific recommendations for psychological care.

### **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 (7, 8). Research findings indicate that children with type 1 diabetes are at risk for adjustment problems during the initial period of adaptation after diagnosis (9, 10). When adjustment problems exist, children are at higher risk for continued adjustment difficulties (10–13). In a 10-yr prospective study from the diagnosis of type 1 diabetes, 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 (14). However, a recent longitudinal study from adolescence into emerging adulthood did not reveal group differences in psychosocial adjustment (15, 16). More recent studies suggest differences between children with and without diabetes appear to be smaller (7). Nevertheless, about 15% of youth with diabetes report elevated levels of psychological

distress, with potential negative consequences for self-care, and studies indicate that behavioral problems are associated with poor glycemic control (17, 18).

Studies indicate that depression and anxiety are related with less frequent glucose monitoring and poorer glycemic control (19, 20). Results from the SEARCH study in the USA found that 14% 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 (21). A recent 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 (22). Prospective studies indicate that greater depressive symptoms predict less frequent blood glucose monitoring, poorer quality of life, and poorer glycemic control over time (23, 24). Children with recurrent DKA are more likely to have psychiatric disorders than children in good glycemic control (25). Poor glycemic control has also been associated with a number of other psychosocial problems including anxiety (20), poor self-esteem, and diabetes-distress (26–28). When psychological adjustment problems persist into late adolescence, there is evidence indicating greater risk for poor diabetes management during early adulthood (29, 30). However, more research in this area is needed.

Youth who are depressed are also at an increased risk for disordered eating behavior (31). There is evidence that adolescents with diabetes, especially girls, have a higher incidence of disturbed eating behavior and eating disorders (8). It is estimated that 7% of adolescent girls with type 1 diabetes may meet diagnostic criteria for an eating disorder, a rate twice as common as in girls without diabetes (8). Disordered eating behavior is more prevalent in adolescent girls with type 1 diabetes (40%) than their peers (33%) (31). Results of a recent meta-analysis indicated that eating disorders are associated with poor glycemic control (8), although a recent longitudinal study did not show this association (31). Even at subclinical levels, glycemic control has been observed to worsen with increasing symptoms of eating disorder (32–34). Without intervention, disordered eating and insulin manipulation may worsen over time and increase the risk of serious health complications (35–37)

### **Neurocognitive and school functioning**

Studies of neurocognitive functioning indicate that young people with diabetes are at increased risk for information processing weaknesses and learning problems, especially with early diabetes onset (38–41),

history of severe hypoglycemia (40–42), and chronic hyperglycemia, even among very young children (43, 44). Research also indicates that diabetic youths are more likely to have learning problems, with such problems more frequent among boys than girls (45, 46). Academic achievement, school performance, and classroom attention are lower in children with poor metabolic control (47–49).

Prospective studies of newly diagnosed children have demonstrated mild neuropsychological deficits 2 yr after diagnosis, with reduced speed of information processing and decrements in conceptual reasoning and acquisition of new knowledge (14). Such problems were predicted by early onset of diabetes (prior to age 4 yr) and were related to poorer visuospatial functioning and both recurrent severe hypoglycemia and hyperglycemia, which was related to decreased memory and learning capacity (50). Study of neuropsychological functioning 12 yr after diagnosis found that children with diabetes performed more poorly on working memory than control children (51). Children with early onset diabetes (before age 4 yr) showed poorer sustained and divided attention and mental efficiency, while those with a history of recurrent severe hypoglycemia performed more poorly on measures of verbal ability, working memory, and non-verbal processing speed and those with chronic hyperglycemia showed poorer working memory (51). The results of meta-analytic studies indicate that children with type 1 diabetes have a variety of mild cognitive impairments and slightly reduced overall intellectual functioning (52, 53).

Parents report considerable anxiety when their children are in school, are not aware of federal laws to accommodate their children with diabetes, and believe that schools do not facilitate optimal treatment for their children while in school settings (54). 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 (55).

### Family functioning

The research literature has consistently demonstrated that family factors are integral for the management of diabetes in children (1). The findings from a number of cross-sectional and prospective studies have shown that high levels of family cohesion, authoritative parenting, agreement about diabetes management responsibilities, supportive behaviors, and collaborative problem-solving are associated with better regimen adherence and glycemic control, while conflict, diffusion of responsibilities, and regimen-related conflict have been associated with worse regimen adherence and glycemic control (56–68). Family

conflict and negative affect related to blood glucose monitoring has also been associated with depression (19). Having a collaborative relationship between youth and their parents with shared responsibilities for diabetes management is associated not only with better regimen adherence, but also with improved emotional functioning (62, 69). Significant family dysfunction for the majority of families has been observed in clinical studies of adolescents with recurrent DKA (25, 64, 70, 71). Studies have also shown sociodemographic factors such as single-parenthood (72–74) and lower income and ethnic minority status (75–81) are associated with greater risk for poor control of diabetes.

It is important to note that many parents have psychological problems after the diagnosis of type 1 diabetes in their children. One recent review indicated that on average 33.5% of parents report distress at diagnosis, with 19% of parents reporting distress 1 to 4 yr after diagnosis (82). Mothers appear to be at risk for psychological adjustment problems after their child's diagnosis, with clinically significant depression noted in approximately one third of mothers; however, most of these adjustment problems are resolved within the first year after the child's diagnosis (83). Fewer studies have addressed psychological functioning in fathers. One study found that 24% of mothers and 22% of fathers met criteria for a diagnosis of post-traumatic stress disorder 6 wk after their child had been diagnosed (84). Another study found that psychological maladjustment of fathers predicted poor glycemic control in children 5 yr after diagnosis (85). Fear of hypoglycemia has also been found to be common in parents of children with diabetes (86) and is associated with emotional distress and poorer glycemic control in children (87).

### Social support

Social support from parents and other family members is especially important for children and adolescents with type 1 diabetes. Research has shown that family members who provide high levels of support for diabetes care have youngsters who adhere better to their diabetes regimen (58). 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. Youths may receive instrumental support from their families and also considerable emotional support from their friends (58, 88–91). When youth attribute negative peer reactions to their self-care, they are more likely to have adherence difficulties and increased diabetes stress, which in turn worsens glycemic control (92). Fear of stigmatization and sense of autonomy appeared to be major barriers withholding adolescents to solicit required support from peers (88). Poor peer

relations has been associated with decreased regimen adherence and worse glycemic control over time, while more family support predicted better glycemic control (93). Providing support to parents after the diagnosis of diabetes of their child is an important need and can promote better diabetes management (94, 95).

### Stress and coping

Studies have shown that children with high life stress tend to have worse glycemic control (92, 96, 97). 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 (98). Diabetes-specific stress has also been linked to poor glycemic control (28, 27). Research examining attributional and coping styles has indicated that youths in poor metabolic control are more likely to use the learned helplessness style (99) and engage in avoidance and wishful thinking in response to stress (100), while youths in good glycemic control have high levels of self-efficacy (101) and engage in active coping (102–106). A longitudinal study suggested a reciprocal relationship between active coping and better glycemic control, while avoidance coping was linked with worse glycemic control and increased psychological stress (103). Maladaptive coping has also been associated with poor regimen adherence (107). Resilience is associated with better diabetes management, quality of life, and glycemic control (104, 108).

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 have been associated with both regimen adherence and glycemic control (109–111). Studies have also shown that their 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-care (112). Personal model beliefs about diabetes were also shown to mediate the relationship between personality variables (emotional stability and conscientiousness) and self-care behaviors (113). Studies of health risks associated with diabetes indicate that youth underestimate their own risks while acknowledging greater risks of diabetes attributed to other youths (114).

Identification and improvements in primary caregivers (mothers') coping may have the potential to improve both maternal and adolescent outcomes (115–119). Children with parental dyads exhibiting the negotiator coping pattern had better glycemic control than children with parents classified as avoiders or doers (120).

### Quality of life

In general, children with diabetes rate their own quality of life as similar to their healthy peers (121). However, parents tend to rate their child's quality of life somewhat lower (122–124). Boys report better quality of life as well as youth with longer diabetes duration and those from a better socioeconomic background (121, 125–129). Lower quality of life seems associated with depression (130) and a negative family environment, especially diabetes conflicts (131). 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 (131, 132). 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 (124, 133–135). In a prospective study, poorer quality of life predicted subsequent poor glycemic control via less frequent blood glucose monitoring (136). Quality of life does not appear to be adversely affected by use of the insulin pump (127, 137, 138), and may be associated with improved quality of life (130). In addition, use of continuous glucose monitoring does not seem to adversely affect quality of life (139).

### Psychosocial and behavioral interventions

Previous systematic reviews of the literature 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 (3, 4, 140–142). Most of these interventions have included the family as an integral part of treatment.

The results of these studies indicate that family-based, behavioral procedures such as goal-setting, self-monitoring, positive reinforcement, behavioral contracts, supportive parental communications, and appropriately shared responsibility for diabetes management have improved regimen adherence and glycemic control (141, 143). In addition, these interventions have improved the parent–adolescent relationship (141, 144–146), and improved regimen adherence (146). Studies of behavioral family systems therapy with diabetes-specific tailoring have shown improvements in family conflict and regimen adherence (147) as well as improved glycemic control over 18 months (148). Controlled research has demonstrated this approach to improve parent–adolescent communication and problem-solving which in turn was associated with improvements in glycemic control (149).

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 (150, 151). 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 in children (152). Other trials involving psychosocial intervention after diagnosis showed improved family functioning without improved glycemic control (153, 154).

Research has shown that when parents allow older children and adolescents to have self-care autonomy without sufficient cognitive and social maturity, youths are more likely to have problems with diabetes management (155). 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.

An intervention based on family-focused teamwork increased family involvement without causing family conflict or adversely affecting youth quality of life, and helped prevent worsening of glycemic control (156). A psycho-educational intervention 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 (157).

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. Initial studies of this approach suggested that it had potential to improve outcomes (158). 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 (159, 160). A more recent study demonstrated reduced hospitalizations and costs for this high-risk group of adolescent patients using multi-systemic therapy (161).

Peer group interventions have also been evaluated. Results indicate that peer group support and problem-solving can improve short-term glycemic control (162). Training in group coping skills improved glycemic control and quality of life for adolescents involved in intensive insulin regimens (163–165). Stress management, problem-solving, and coping skills training delivered in small groups of youths has reduced diabetes-related stress (166, 167), improved social interaction (168), and increased glucose monitoring and improved glycemic control (169).

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 (170, 171). Research indicates that early adolescence represents a high risk time for diabetes management, with worsening of adherence

observed over time (172), which may be due to decreased parental involvement.

Motivational interviewing appears to be a promising approach for adolescents, with initial studies showing improved glycemic control (173, 174). A larger multi-center randomized trial demonstrated that motivational interviewing with adolescents improved long-term glycemic control and quality of life (175). Another study targeting motivation with an individualized personal trainer showed improved glycemic outcomes in older but not younger adolescents (176). More recently it was demonstrated that this approach had long-term positive effects on glycemic control in older adolescents (177).

Several recent studies have examined coping skills training with younger, school-aged children. Results indicate that this approach had some favorable effects on life satisfaction and family functioning (178). 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 (179). 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 (116).

More studies have recently 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 (180). 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 (181). 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 as that for older children (182, 183).

Recent studies have 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 (184). This approach was particularly sensitive to diabetes management barriers with regard to social issues, time pressures, and dealing with emotions (185). 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 type 1 diabetes using the Internet (186).

A meta-analysis of intervention studies to promote regimen adherence in youth with type 1 diabetes was conducted and found 15 studies that met criteria for analysis (187). 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 (188).

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 to improve long-term glycemic control and psychosocial outcomes. There is growing evidence supporting the use of the Internet to deliver behavioral interventions.

### Conflicts of interest

The authors have declared no conflicts of interest.

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