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Psychological care of children and adolescents with diabetes

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A substantial research base developed over the past four decades provides evidence for the significant role of psychosocial factors in the management of type 1 diabetes in children and adolescents (1–6). This chapter reviews the main findings from the 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 research base for the psychological care of young people with type 2 diabetes is sparse. Therefore, this chapter does not address type 2 diabetes specifically.

The International Society of Pediatric and Adolescent Diabetes (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 (7):

- (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.

These general recommendations remain appropriate and are amplified below with more specific recommendations for psychological care.

Psychological adjustment and psychiatric disorders

Research findings indicate that children with type 1 diabetes are at risk for adjustment problems during the initial period of adaptation after diagnosis (8, 9) (B). When adjustment problems exist, children are at higher risk for continued adjustment difficulties (9–11) (B). There is growing evidence, particularly from North America, that young people with diabetes appear to have a greater incidence of psychiatric disorders (12–14) (B). In a 10-yr prospective study from 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) (B). Children with recurrent diabetic ketacidosis (DKA) are more likely to have psychiatric disorders than children in good metabolic control (15) (B). Depression has been associated with poor glycemic control and increased hospitalizations (16–19) (B); although, more study of this issue is needed. Studies also indicate that behavioral

problems are associated with poor glycemic control (20, 21) (B). While a recent longitudinal study of young adolescents did not reveal group differences in psychosocial adjustment, social difficulties and eating disturbance among youth with type 1 diabetes emerged over time (22) (B).

There is also evidence that adolescents with diabetes, especially girls, have a higher incidence of eating disorders, and that eating disorders are associated with poor glycemic control (23–25) (B). It is estimated that 10% 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 (24) (B). Without intervention, disordered eating and insulin manipulation may worsen over time and increase the risk of serious health complications (26) (B). Even at subclinical levels, glycemic control has been observed to worsen with increasing symptoms of eating disorder (27, 28) (B). However, in one recent study, although eating disorders were common in young girls with type 1 diabetes, there was no relationship observed between eating disturbance and glycemic control (29) (B).

Poor metabolic control has been associated with a number of other psychosocial problems including anxiety and poor self-esteem (30) (C). When psychological adjustment problems persist into late adolescence, there is evidence indicating greater risk for poor diabetes management during early adulthood (31, 32) (B).

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 (33, 34) (B) and history of severe hypoglycemia (35–37) (B). Research also indicates that diabetic youths are more likely to have learning problems, with such problems more frequent among boys than girls (38, 39) (B). Academic achievement and school performance are lower in children with poor metabolic control (40) (C).

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 (41) (B). Such problems were predicted by early onset of diabetes (prior to the age of 4 yr), which was related to poorer visuospatial functioning, and both recurrent severe hypoglycemia and hyperglycemia, which was related to decreased memory and learning capacity (42) (B). Study of neuropsychological functioning 6 yr after diagnosis found that children with diabetes performed more poorly on measures of intelligence, attention, processing speed, and long-term memory than the

control children. Children with early diabetes onset (before the age of 4 yr) showed weaknesses in attention, processing speed, and executive functioning, while those with recurrent severe hypoglycemia had lower overall intellectual abilities (43) (B).

A recent study examining school experiences of students with diabetes found better glycemic control and quality of life when school personnel and friends had received some training in diabetes and its management (44) (C).

Family functioning

The research literature has consistently demonstrated that family factors are integral to the management of diabetes in children. The findings from a number of cross-sectional and prospective studies have shown that high levels of family cohesion, agreement about diabetes management responsibilities, and supportive behaviors 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 (30, 45–52) (B, C). Significant family dysfunction for the majority of families has been observed in clinical studies of adolescents with recurrent DKA [(15) (B), (53, 54) (C)].

Studies have also shown that socio-demographic factors such as single parenthood (55–57) (B) and lower income and ethnic minority status in the USA (58–61) (B) 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. 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 (62) (C). 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 posttraumatic stress disorder 6 wk after their child had been diagnosed (63) (C). Another study found that psychological maladjustment of fathers predicted poor glycemic control in children 5 yr after diagnosis (64) (C).

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 (50, 65) (C). It was also noted

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that levels of diabetes-specific family support were inversely related to youngsters' age (older children and adolescents report significantly less family support for diabetes). Youths may receive instrumental support from their families and also considerable emotional support from their friends (50) (C). 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 (66) (B).

Stress and coping

Studies have shown that children with high life stress tend to have worse glycemic control (49, 67, 68) (C). Diabetes-specific stress has also been linked to poor glycemic control (66) (B). Research examining attributional and coping styles has indicated that youths in poor metabolic control are more likely to use the learned helplessness style (69) (C) and engage in avoidance and wishful thinking in response to stress (70, 71) (C), while youths in good glycemic control have high levels of self-efficacy (72) (C) and engage in active coping (71) (C). Maladaptive coping has also been associated with poor regimen adherence (73) (C).

The health belief model has been studied in adolescents. Findings 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 (74–76) (B, C). 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 (77) (B). Personal model beliefs about diabetes were also shown to mediate the relationship between personality variables (emotional stability and conscientiousness) and self-care behaviors (78) (B). Studies of health risks associated with diabetes indicate that youth underestimate their own risks while acknowledging greater risks of diabetes attributed to other youths (79) (C).

Quality of life

Some research findings indicate that the quality of life is lower among youths with diabetes compared with healthy children (80, 81) (B), particularly when parents rate their child's quality of life (81–83) (B). There is also some evidence that quality of life is lower in girls and youths with shorter disease duration (84) (C) and in those with diabetes-related family conflict (85) (B). Less favorable quality of life also appears to be related with youths' perceptions that diabetes is upsetting, difficult to manage, and stressful and is related to higher levels

of depression (86) (C). Another study found lower quality of life was associated with depression and lower socioeconomic status (87) (C). 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 (87–91) (B, C). Quality of life does not appear to be adversely affected by use of the insulin pump (92) (B). In general, when diabetic youth rate their own quality of life, they tend not to rate themselves very differently from their healthy peers (81–83, 85, 91, 93) (B, C).

Psychosocial and behavioral interventions

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 (1–4, 94) (A); although, this literature is not without some methodological limitations (95, 96) (A). 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 (97, 98) (A). In addition, these interventions have improved the parent–adolescent relationship (97, 99–101) (A) and improved regimen adherence (101) (A). Recent studies of behavioral family systems therapy with diabetes-specific tailoring have shown improvements in family conflict and regimen adherence (102) (A) as well as improved glycemic control over 18 months (103) (A).

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 (104, 105) (C). Psychoeducational 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 (106) (A). Other trials involving psychosocial intervention after diagnosis showed improved family functioning without improved glycemic control (107, 108) (A).

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 (109) (B). 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 youngsters' 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 (110) (A). A psychoeducational 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 (111) (A).

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 (112) (C). The results of a recent larger trial indicated that this approach improved frequency of blood glucose monitoring, reduced inpatient admissions, improved glycemic control, and reduced medical costs (113, 114) (A).

Peer group interventions have also been evaluated and indicate that peer group support and problem solving can improve short-term glycemic control (115, 116) (A). Group coping skills training improved glycemic control and quality of life for adolescents involved in intensive insulin regimens (117–119) (A). Stress management, problem-solving and coping skills training delivered in small groups of youths has reduced diabetes-related stress (120, 121) (A), improved social interaction (122) (A), and increased glucose monitoring and improved glycemic control (123) (A).

It is crucial to maintain consistent 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 significant problems with metabolic control (124, 125) (B). It is also important to note that early adolescence represents a high-risk time for diabetes management, with worsening of adherence observed over time (126, 127) (B), which may be because of decreased parental involvement.

Motivational interviewing appears to be a promising approach for adolescents, with initial studies showing improved glycemic control (128, 129) (C). A recent multicenter randomized trial demonstrated that motivational interviewing with adolescents improved long-term glycemic control and quality of life (130) (A).

In summary, the results of controlled intervention research have shown that family-based interventions utilizing positive reinforcement and behavioral contracts, communication skills training, negotiation of diabetes management goals, and problem-solving skills training have led not only to improved regimen behaviors and glycemic control but also to improved family relationships (A). Group interventions for young people with diabetes targeting coping skills

have also shown positive effects on regimen adherence, glycemic control, and quality of life (A). Individual interventions with adolescents have shown motivational interviewing to improve long-term glycemic control and psychosocial outcomes (A).

Recommendations

The following recommendations build upon the ISPAD 2000 Guidelines (7) and are consistent with recent statements and guidelines issued by the American Diabetes Association (131), Australia (Australasian Paediatric Endocrine Group Clinical Practice Guidelines, www.nhmrc.gov.au/publications), Canada (www.diabetes.ca/cpg2003), and the UK (www.nice.org.uk/pdf/type1diabetes).

- 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 and social workers.

- (i) 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).
- (ii) There should be easy access to consult psychiatrists for cases involving severe psychopathology and the potential need for psychotropic medications (E).
- (iii) All mental and behavioral health specialists should have training in diabetes and its management (E).
- (iv) The interdisciplinary diabetes health care team should strive to 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 or by email (B, E).
- (v) 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 (B, E). Quality of life can be reliably measured with good clinical utility (132) (A). It is especially important to monitor the school performance of children who developed diabetes before the age of 5 yr and with a history of significant hypoglycemic episodes at early ages (B). These children, as well as all children experiencing learning difficulties at school, should be referred for a psychoeducational 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).

- (vi) 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).
- (vii) Identification of psychosocial adjustment problems, depression, eating disorders, and other psychiatric disorders should be conducted at planned intervals by mental health professionals (B, E). These assessments are particularly important in young people not achieving treatment goals or who exhibit chronically poor metabolic control (high hemoglobin A1c and recurrent DKA) (B, E).
- (viii) The interdisciplinary team should aim to provide preventive interventions for patients and families (include 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).
- (ix) The interdisciplinary team should aim to provide an assessment of 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 (B, E).
- (x) 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, and E).
- (xi) 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 (133) (A).

- (xii) Adolescents should be encouraged to 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 between adolescents, their parents, and the adult diabetes team well in advance of the actual transfer to adult care (E) (see Guideline on Adolescence).

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