Optimizing Outcomes in Adolescents with Type 1 Diabetes and Their Families

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Abstract

- **Objective:** To critically evaluate the evidence related to interventions designed to meet the challenge of optimizing outcomes in adolescents with type 1 diabetes and their families and to discuss implications of these findings for clinical management.
- **Methods:** A MEDLINE, PSYCHLIT, and CINAHL search identified articles published between January 1986 and November 2003 relating to education or psychosocial interventions for adolescents with type 1 diabetes and their families.
- **Results:** 29 studies were included in the review and were categorized as education, psychosocial, or family intervention. Education interventions increase diabetes knowledge but are not consistently helpful in improving metabolic outcomes. Psychosocial interventions such as coping skills training and behavioral family systems therapy have demonstrated improvements in metabolic control, self-efficacy, diabetes stress, quality of life, and parent-adolescent conflict. Intervention studies that target families of adolescents with diabetes suggest that involvement of the family in the intervention can have a positive impact on metabolic control and interpersonal relationships.
- **Conclusion:** Education interventions remain the mainstay of treatment for adolescents with type 1 diabetes. Psychosocial interventions show promise for improved psychosocial and metabolic outcomes. Family interventions are emerging as a positive way to improve interpersonal relations and assist the adolescent in transitioning from family-management toward self-management of their diabetes.

Type 1 diabetes mellitus is a major health problem in the United States, affecting over 151,000 persons younger than age 20 years [1]. It accounts for 5% to 10% of all diagnosed cases of diabetes and is characterized by alterations in carbohydrate, protein, and fat metabolism due to a lack of insulin production [2–4]. Management of type 1 diabetes is complex and requires insulin administra-

tion, blood glucose monitoring, carbohydrate counting, and exercise [4]. Diabetes remains the sixth leading cause of death in the United States, and adolescents diagnosed with type 1 diabetes are twice as likely to die prematurely from complications than adolescents without type 1 diabetes [3]. The Diabetes Control and Complications Trial [5] demonstrated that intensive management and improved metabolic control as measured by glycosolated hemoglobin (HbA1c) could reduce diabetes complications by 27% to 76% [5].

Intensive management of type 1 diabetes can be difficult and demanding, particularly for the adolescent who is in the midst of emotional, psychological, physiological, and social change [6]. According to Erickson [7], the task during adolescence is to achieve ego identity and avoid role confusion. Cognitively, adolescents are developing a skill level of formal operations where they can deal efficiently with complex problems, think abstractly, and plan realistically for the future [8,9]. Influence by peers steadily increases throughout childhood and peaks in early adolescence. During this time, parental support is viewed less favorably, and relationships between the parent and adolescent become less cohesive [10]. The shift from parental support to peer support is normal but can place the adolescent at an increased risk for psychological difficulties. Diabetes-specific family conflict and general family conflict have been associated with lower rates of adherence in adolescents [11]. The demands of adolescence may take precedence over the intensive diabetes management routine [6]. However, the shift from parental to peer support is not absolute [12], since a majority of adolescents continue to seek guidance from their parents; thus, adolescents with type 1 diabetes should be encouraged to maintain close, supportive relationships with parents, adults, and friends [10].

Adolescents face internal conflict when considering whether to share information about their diabetes with their friends. Needing to be the same as one’s peers and not be treated differently is characteristic of early adolescence. There is a strong fear of nonacceptance by the peer group and exclusion from peer activities, which may make the adolescent

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reluctant to disclose his or her diagnosis [13]. This fear often causes adolescents to deliberately miss glucose tests, insulin injections, or boluses and eat additional foods without taking the appropriate insulin, which can cause a decline in metabolic control. However, supportive relationships from peers and adults can help to buffer the negative effects of such challenges [14].

Since the majority of intensive management is provided at home, diabetes education for parents and adolescents has been the mainstay of treatment [4,15–18]. More recently, research involving psychosocial and family interventions for adolescents with diabetes has been reported in the literature. We conducted a review to examine the research literature on education and psychosocial interventions for adolescents with type 1 diabetes and their families. The questions we sought to answer included the following: What interventions have been used with adolescents with type 1 diabetes and their families? What outcomes have been studied? What are the findings of these studies?

Methods
Primarily, research focusing on improving metabolic control and psychosocial outcomes were evaluated. Education interventions were defined as those concentrating on increasing knowledge about diabetes and competence to perform self-care behaviors. Psychosocial interventions included those that primarily focused on improving metabolic control and adjustment or adaptation to the disease. Family interventions were defined as those whose primary target was the family of the adolescent with diabetes.

The English-language MEDLINE, PSYCLIT, CINAHL databases were searched using the following key words: insulin-dependent diabetes, adolescents, education, psychosocial, and family intervention. The focus was on published literature from January 1986 to November 2003. No attempt was made to search for unpublished works. The search yielded a total of 76 potential manuscripts for inclusion. An additional search of relevant journals (Diabetes Educator and Diabetes Care) was conducted to assure that no manuscripts were missed. Manuscripts were retrieved and reviewed for inclusion using the following criteria: (1) a study reporting the results of an intervention; (2) adolescents with type 1 diabetes and/or their families; (3) publication between 1 January 1986 and 1 November 2003; and (4) published in English. All 76 manuscripts were located for review. Forty-seven manuscripts did not meet inclusion criteria, leaving 29 manuscripts for review.

Education Interventions
The American Diabetes Association [4] and International Society for Pediatric and Adolescent Diabetes (ISPAD) [18] recommend diabetes education as the standard approach for patients with type 1 diabetes and their families to meet treatment goals. Diabetes education interventions are designed to teach knowledge related to diabetes management, such as monitoring blood glucose levels; problem-solving for blood glucose highs, lows, and sick days; medication taking; eating; physical activity; reducing risks of diabetes complications; and living with diabetes.

General Education
Several studies took place during summer diabetes camps, targeting outcomes such as knowledge and problem-solving regarding blood glucose testing, insulin administration, dietary information, and exercise. Misuraca and colleagues [19] reported that 256 children and adolescents (mean age, 10.0 years; range, 8–16 years) who attended a 10-day summer camp with 3 monthly meetings post-camp had a reduction in HbA1c levels (P < 0.01) and increased knowledge (P < 0.01). Similarly, Kemp et al [20] studied intensive management and diabetes education during a 2-week summer camp over 2 consecutive years with 42 children and adolescents aged 8 to 16 years. HbA1c levels initially improved, but then from year 1 to year 2, HbA1c levels increased from 8.1% to 10.1%, demonstrating only short-term efficacy. Lastly, the effectiveness of feedback instruction on self-monitoring of blood glucose over 2 summers was studied [21]. Subjects were randomly assigned to routine education (n = 19) or routine education plus individualized feedback on technique (n = 20). Marginal differences were found between the 2 groups. All of the studies used convenience camp samples, 2 of the 3 studies had no control group, and 2 studies had small sample sizes, which makes it difficult to draw conclusions.

Two pre-experimental studies (nonrandomized, nonblinded) focused on evaluation of diabetes education programs. Anderson [22] conducted an evaluation of a diabetes education program for children and adolescents in Canada. Twenty-two subjects (aged 13–17 years) returned satisfaction questionnaires, and a chart audit was conducted on 100 subjects. The respondents liked learning, problem-solving, and the support they received. The majority had received appropriate screening for complications, but only 17.5% had reached metabolic treatment goals. A study in India [23] evaluated whether an education program increased knowledge in 37 children and adolescents (aged 8–18 years) enrolled in a 2-day program that consisted of general diabetes education and individual sessions on injections, monitoring, and dietary counseling. Using a 1-group pre-post test design, at 3 months there was demonstrated improvement in general knowledge about diabetes, insulin, injections, and hypoglycemia but no differences in diet, exercise, or monitoring knowledge. These small studies with pre-experimental design suggest that general diabetes education may improve diabetes knowledge. However, these studies must be interpreted with caution.
Structured Education

Several studies have examined structured education programs that focused on specific aspects of diabetes care, such as nutrition, exercise, or blood glucose monitoring. Challener et al. [24] studied adolescents (mean age, 14.8 years; mean duration of diabetes, 5.8 years) who attended 2 education sessions on self-monitoring blood glucose followed by the use of a meter with memory. Findings demonstrated improvement in glycemic control and frequency of self-monitoring of blood glucose. In another study [25], 6 adolescents (mean age, 14.5 years) received three 45-minute education sessions on improving blood glucose awareness, while a control group (n = 9) received usual care. The accuracy of glucose estimation improved (P < 0.02), but there was no improvement in mean blood glucose control. Lastly, the effects of exercise training in children and adolescents (no improvement in mean blood glucose control). Lastly, the effects of exercise training in children and adolescents (mean age, 11.9 years; mean duration of diabetes, 4.7 years) was studied over a 3-month period [26]. Fitness measured by VO2 and pedaling time improved in the experimental group (n = 16), but metabolic control (assessed by blood and urine glucose levels) did not improve. These 3 studies had small sample sizes, and 2 of the 3 studies did not have a control group. Therefore, these studies must be interpreted with caution.

Several researchers studied new technology such as computer-assisted management, telecommunications, outpatient management, and anchored instruction (AI) using videodisks. AI stresses the importance of learning within a meaningful, problem-solving context. The effects of a computer-based system on control, adherence, and behavioral change in adolescents was studied [27]. The Diabetes in Self-Control (DISC) program stores blood glucose data and uses computer diabetes education with problem-solving and goal setting to improve metabolic control. Twenty adolescents (12–19 years) who were matched on grade, gender, race, HbA1c, and knowledge were randomized to the DISC program or to receive written materials for 15 weeks. Post-testing showed no differences between the 2 groups in HbA1c levels, but there were differences in blood glucose levels at lunch and dinner. The DISC group performed significantly more blood glucose self-monitoring tests, but there were no differences between the groups in both general and problem-solving knowledge as measured by the Test of Diabetes Knowledge [28].

Pichert and colleagues [29–32] conducted several studies using AI. Sixty-nine campers (aged 9–15 years) were studied to examine the effectiveness of 2 AI videodisks designed to teach problem-solving for sick day management and dietary adherence. In all studies, the researchers found that the experimental groups performed better on tests of knowledge and diabetes management. Long-term follow-up was conducted with the sick day management study, which indicated that differences in knowledge persisted, and the experimental group reported more sharing of management responsibilities during sick days than the control group [30]. Effects on metabolic control were not reported.

An experimental evaluation of the efficacy of using a telecommunications system (Data-Link® modem with meters, biweekly transmission of results, protocol for telephone follow-up to achieve mean blood glucose level of 140 mg/dL) was conducted [33]. After 1 year, there were few differences between the experimental and control groups in telephone follow-up of HbA1c levels or hospitalizations and emergency department use documented by chart audit. Nurse practitioners spent less time per call with those in the experimental group to achieve the same outcomes.

In another study [34], a video game in which characters have diabetes and engage in self-care diabetes management was tested over a 6-month period. The control group (n = 28) received another video with no health connections. Parents in the experimental group (n = 31) reported that their children’s communication about diabetes (P < 0.025) and levels of self-care (P < 0.003) increased, but self-efficacy, knowledge, urgent medical visits, and HbA1c levels showed no significant differences. Three of the 4 studies had a 2-group design and sample sizes were small to moderate. Caution should be used in interpreting the findings until more rigorous studies can be conducted.

Delamater and colleagues [35] conducted a randomized controlled trial (RCT) to evaluate an education program designed to teach decision making in insulin adjustments and compared this program with supportive counseling focusing on psychosocial adjustment. The Self-Management Training program consisted of 7 sessions over 4 months. Subjects included 36 children and adolescents (mean age, 9.3 years; range, 3–16 years). Results demonstrated that self-management training significantly improved metabolic control at 1 and 2 years compared with conventional follow-up but not compared with supportive counseling. This RCT had a small sample size and early findings were promising, but further study is needed to have confidence in the findings.

In another study [36], 142 families (family member and adolescent [mean age, 11.4 years; mean duration of diabetes, 4.5 years]) were randomized to the intensive therapy (IT) group or to usual care. Before randomization, patients received a score for diabetes self-management competence (SMC) that reflected diabetes knowledge, treatment adherence, and health care interactions and were then divided into 3 groups: low, moderate, or high SMC. All 3 SMC groups who received IT had similar HbA1c levels (7.7%–7.9%) at the end of the study. Of patients who received usual care, the group with low SMC levels saw a steady increase in HbA1c levels (9.6%) over the 18-month treatment period. HbA1c levels did not change significantly among the moderate and
high SMC groups that received usual care. Compared with their usual care counterparts, the low SMC IT group realized greater glycemic benefit from IT than did the moderate or high SMC IT patients.

In summary, educational studies have been conducted with children and adolescents with diabetes, but the majority focused on adolescents who demonstrate poorer management of their diabetes [37]. Outcomes studied included knowledge, metabolic control, psychosocial status, and health care utilization. The majority of studies used a small convenience sample and a 1-group pre-post design with no control group. Therefore, these findings should be interpreted with caution until evaluated in more rigorously designed studies.

**Psychosocial Interventions**

Psychosocial interventions include coping skills training (CST), psychotherapy, and stress management training (SMT). Outcomes measured include metabolic control, self-efficacy, quality of life, parent-adolescent conflict, barriers, and adherence.

**Coping Skills Training**

CST is a group intervention designed to increase competence and mastery by retraining nonconstructive coping styles and patterns of behavior into more constructive behaviors. CST for adolescents with diabetes is based on the premise that improving coping skills will improve the ability of adolescents to solve problems and manage their diabetes. CST consists of role-playing various difficult situations (eg, managing food choices, diabetes care around friends, making decisions regarding drugs and alcohol, and independence/independence conflicts) so that the trainer can model appropriate coping behavior [28]. The scenarios assist adolescents in role-playing difficult situations. Emphasis is placed on problem-solving, social skills training, cognitive behavior modification, and conflict resolution [38].

Massouh and colleagues [39] studied the effects of a social learning group intervention on metabolic control in 34 adolescents (aged 12–16 years) who attended a summer camp. They were randomly assigned to the experimental or control group. Both groups received a 1-hour daily diabetes educational session, and the experimental group received an additional 40-minute social learning intervention with a psychologist who demonstrated role-modeling behaviors for dealing with peer pressure. The experimental group demonstrated a slight decrease in HbA1c levels at 3 months, while the control group remained unchanged. In another study, the effects of SMT designed for adolescents with diabetes was evaluated [40]. Subjects were randomly assigned to the experimental group (n = 9), which received SMT training (10 sessions over 3 months), or the control group (n = 10), which received standard care. Diabetes management stress decreased significantly in the experimental group, but there were no differences in HbA1c levels, coping styles [41], self-efficacy [42], or adherence [28]. Although these are randomized trials, samples are small, making generalization difficult.

Grey and colleagues [43–45] conducted an RCT to determine the effects of a group CST intervention on metabolic control and psychosocial outcomes. In the study, 65 adolescents aged 13 to 20 years (mean age, 15.5 years; mean duration of diabetes, 8.1 years) who were receiving IT were randomly assigned to an experimental group with CST and a control group without CST. The CST intervention consisted of 6 small-group sessions taught by a master’s-prepared nurse. Skills taught included social problem-solving, cognitive behavior modification, and conflict resolution. Results demonstrated that adolescents who received CST had lower HbA1c levels (P < 0.001), had greater diabetes (P < 0.02) and medical (P < 0.01) self-efficacy, found it easier to cope with their diabetes (P < 0.01), were less upset about their diabetes (P < 0.001), and had improved quality of life (P < 0.001) when compared with the control group. These effects were maintained at 6-month [45] and 12-month follow-up [43]. This well-designed clinical trial used a convenience sample of mostly middle-class youth, limiting generalizability.

**Psychotherapy**

The use of psychotherapy is based on previous studies that have suggested that anxiety, depression, and conflict related to adaptation to diabetes management is common in adolescents with type 1 diabetes [46–48]. Wysocki and colleagues [49–51] reported on a behavioral family systems therapy (BFST) intervention for families of adolescents with type 1 diabetes and the short-term and maintenance of treatment effects. In this RCT, 119 families (adolescent [mean age, 14.3 years; mean duration of diabetes, 4.8 years] and a family member) were randomized to 10 sessions of BFST, 10 sessions of education and support, or current therapy. BFST targets parent-adolescent conflict by focusing on family problem-solving and communication skills. Education and support focuses on diabetes education and social support. In an early report from this study, the BFST group scored higher on 13 of 20 items on an evaluation questionnaire, suggesting family conflict was appropriately targeted. At 3 months, short-term effects [50] demonstrated that the BFST group had improvement in parent-adolescent relationships (P < 0.05). At 6- and 12-month follow-ups [51], the BFST group continued lasting improvements in parent-adolescent relationships (P < 0.013) and had less conflict (P < 0.04). This well-designed trial of BFST selected families who were having conflict for inclusion in the study. It is difficult to know if similar findings would occur in a less high-risk population.
**Stress Management**

Stress management has been used as a method for improving diabetes care and outcomes in several relatively small studies. Mendez and Belendez [52] examined the effects of a behavioral intervention on treatment adherence and stress management in adolescents using a quasi-experimental pre-post test design with a nonequivalent control group. The experimental group \((n = 18)\) received 12 group sessions that covered blood glucose training, role-playing, relaxation exercises, and problem-solving strategies. The control group \((n = 18)\) received routine care. At 13 months’ follow-up, the experimental group demonstrated more knowledge regarding glucose management with established validity and reliability. There was only one RCT using CST [43-45], which was a methodologically rigorous study in which significant differences in metabolic outcomes were found. However, Wysocki and colleagues’ trial of BFST [49-51], targeting parent-adolescent conflict, used a 3-group RCT design with an adequate sample size and a theoretical base to link the interventions and outcomes, which allowed for testing of the intervention effects.

**Family Interventions**

Family-based diabetes management is important at diagnosis and as the child and adolescent advances towards young adulthood. The majority of conflict around diabetes care emerges during adolescence. Anderson and colleagues [11] conducted an RCT that tested an office-based intervention aimed at maintaining parent-adolescent teamwork in diabetes management tasks without increasing diabetes-related family conflict. Eighty-five subjects aged 10 to 15 years (mean age, 12.6) were randomly assigned to a teamwork intervention, attention control (AC), or standard care. This individual teamwork intervention group focused on conflicts that could interfere with parent-adolescent teamwork around managing daily diabetes self-management, such as high and low blood glucose levels, realistic expectations for glucose levels and behavior during adolescence, and the responsibility of the parent in maintaining involvement in their adolescents’ insulin regimen and glucose testing in a positive manner. The AC group received equal attention from a research assistant and received traditional diabetes education. The standard care group received routine diabetes care. Results of this well-designed study showed no major deterioration in parent involvement in insulin administration in the teamwork group, in contrast to a 16% decrease in the AC and standard care groups. No teamwork families demonstrated a major decline in parental involvement with glucose monitoring versus an 11% drop in the comparison groups. Teamwork families reported significantly less conflict at 12 months, and HbA1c levels over 12 to 24 months showed more adolescents in the teamwork group (68%) than in the comparison groups (47%) improved their metabolic control.

In a follow-up investigation, Laffel and colleagues [54] studied the impact of an ambulatory family-focused team-work intervention on glycemic control. Subjects \((n = 105)\) were randomly assigned to either the teamwork group or the standard care group. The mean age was 12.1 years, mean duration of diabetes was 2.7 years, and mean HbA1c level was 8.36%. At 1 year, HbA1c levels decreased from 8.4% to 8.2% in the teamwork group and increased from 8.3% to 8.7% in the standard care group \((P < 0.05)\). Both groups were similar in frequency of blood glucose monitoring and insulin dosages. Families in the teamwork group maintained or increased involvement when compared with the standard care group \((P < 0.05)\). The teamwork group and the frequency of daily blood glucose monitoring significantly predicted \((P < 0.05)\) HbA1c levels. Results support that the teamwork intervention stabilized and maintained the expected deterioration seen in youth with type 1 diabetes receiving standard care.

Satin and colleagues [55] conducted an experimental study in which 32 families were randomly assigned to a multifamily intervention of support and guidance, a multifamily intervention plus parent simulation of diabetes, or a standard care control group of adolescents and their family members. The intervention consisted of 6 weekly sessions that included both the adolescents and their parents with group therapy, guidance, and support provided. The parents in the simulation group simulated having their children’s diabetes and performed diabetes self-care for 1 week. The results demonstrated that the multifamily interventions with a simulation group had the best improvement in metabolic control.

In another study, Svoren and colleagues [56] conducted an RCT to examine the reduction of acute adverse outcomes in youths over a 2-year period. The youths (mean age, 11.9 years; mean duration of diabetes, 5.2 years) and their families were randomly assigned to the either the Care Ambassador (CA) group, the Care Ambassador plus psychoeducation (CA+) group, the Care Ambassador plus psychoeducation (CA+) group.
group, or the standard care group. The Care Ambassadors encouraged youth and their family members to seek medical advice from their health care team and followed up on appointments. Both the CA (7.3) and CA+ (7.5) groups had significantly (P < 0.001) more medical visits than the standard care (5.4) group. In addition, the CA+ group had 25% fewer hypoglycemic events and 40% fewer emergency department visits than the other 2 groups. The estimated annual cost savings was $80,000 to $90,000.

In summary, intervention studies that target families of adolescents with diabetes suggest that psychosocial outcomes, metabolic control, and parent-adolescent conflict may be amenable family interventions and may have a positive impact on metabolic control. The 4 studies reviewed were all RCTs and had adequate sample sizes. The primary goal of all family interventions is to optimize glycemic control through family work.

Summary and Guidelines for Clinical Management

This review evaluated the evidence relating to interventions used to optimize outcomes in adolescents with type 1 diabetes and their families. The following evidence-based clinical management guidelines are suggested for health care providers who are involved in the care of adolescents with type 1 diabetes and their families:

Diabetes education remains the cornerstone of effective diabetes management. Each patient and family member should meet with a Certified Diabetes Educator at diagnosis and be consistently followed so that foundational diabetes education is provided. The ISPAD consensus guidelines for the management of type 1 diabetes mellitus in children and adolescents should be used to guide diabetes management [18]. Diabetesspecific psychosocial outcomes such as diabetes stress, anxiety and diabetes quality of life needs to be closely monitored in adolescents with type 1 diabetes. Psychosocial interventions with demonstrated efficacy, such as CST and BFST, should be available to adolescents and their families. Family interventions utilizing both education and psychosocial interventions may be successful in addressing parent-adolescent conflict. The primary goal of family interventions is to optimize glycemic control, improve communication, and decrease diabetes specific stress. Family interventions designed to prevent or modify adolescent decrease of metabolic control and psychosocial outcomes may ultimately reduce morbidity and mortality if introduced into routine care.

Directions for Future Research

Management of type 1 diabetes in pediatric and adolescent populations is difficult, and efforts to establish interventions to optimize outcomes and reduce health care costs are vital. To advance our understanding of the efficacy of interventions, studies need to be theoretically based with the intervention design and outcome measures linked. Reliable and valid measures must be used, which would allow evidence across studies to be combined. Education, psychosocial, and family interventions have little overlap. Developing collaboration and looking across interventions may advance the science. Some areas to examine might include the benefits of individual, group, or family-based interventions; the level of parental involvement; defining which adolescent age-group would be most amenable to intervention studies; the best location to deliver interventions; integrating interventions into current medical care; and the cost-benefit analysis of interventions in reducing morbidity and mortality. In summary, theoretically driven interventions with outcomes-based research that are designed to improve clinical practice and decrease cost of care by improving quality of life and decreasing morbidity and mortality are needed for adolescents with type 1 diabetes.

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