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Diabetes education in children and adolescents

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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. 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

Education is the key to successful management of diabetes (E). There is evidence that educational interventions in childhood and adolescent diabetes have a beneficial effect on glycemic control and on psychosocial outcomes (A).

To maximize the effectiveness of both conventional diabetes treatment and the advances in diabetes management and technology (especially self-monitoring of blood glucose, analog insulin, insulin pumps, continuous glucose monitoring), it is advisable that quality-assured structured education is available to all young people with diabetes and their carers (E).

An interdisciplinary education team sharing the same philosophy and goals and speaking 'with one voice' has beneficial effects on metabolic and psychosocial outcomes (B).

Health care professionals require appropriate specialized training in the principles and practice of teaching and education to implement successfully behavioral approaches to education designed to empower young people and carers in promoting self-management (E).

The content and delivery of structured education needs regular review to enable it to evolve to suit individuals, local practice and the changes in diabetes management and technology (E).

Educational interventions which have been shown to be most effective are most likely to:

- be based on clear theoretical psycho-educational principles (E)
- be integrated into routine clinical care (e.g., as an essential integral part of intensive insulin management) (A)
- be referred to as an ongoing process of provision of individualized self-management and psychosocial support (E)
- involve the continuing responsibility of parents and other carers throughout adolescence (B)
- make use of cognitive behavioral techniques most often related to problem-solving, goal setting, communication skills, motivational interviewing, family conflict resolution, coping skills, and stress management (A)
- use new technologies in diabetes care as one of the vehicles for educational motivation (A)

In the evaluation of structured educational programs it is essential to focus on outcomes such as the patient's achievement of self-selected diabetes-care goals, improved psychosocial adaptation, and enhanced self-efficacy in addition to glycemic control (E).

Education is the keystone of diabetes care and structured self-management education is the key to a successful outcome (1). National pediatric guidelines emphasize the importance of education, and most of them include specific chapters on education and educational principles (2–9). Publications which provide useful guidelines on diabetes education include the 'National Standards for diabetes self-management education (DSME)' (2), the 'Position statement on structured education' (10), the 'International Curriculum for Diabetes Health Professional Education' (11), the 'Recommendations for age-appropriate education of children and adolescents with diabetes and their parents in the European Union' (12), the 'Good practice recommendations on pediatric training programs for health care professionals in the EU (13), and 'The pediatric diabetes toolbox for creating centres of references' (14).

The following definition of Diabetes Education has been proposed: '*The process of providing the person with the knowledge and skills needed to perform diabetes self-care, manage crises, and to make lifestyle changes to successfully manage the disease*' (15). Education may be seen as an interface between clinical practice and research. Research into diabetes and educational methods is important in improving clinical practice (2–5, 7, 8), and this should be the responsibility of each nation/state and be a national priority (7, 8, 11–13).

Educational programs must be carefully planned, have specific aims, and learning objectives, which are shared with people with diabetes, their families, and other caregivers of young people with diabetes (2, 4, 5, 12, 14). It has remained contentious whether educational interventions *per se* are beneficial in diabetes care, particularly in children and adolescents because '*educational, psychosocial and psychotherapeutic interventions are frequently combined for the purpose of improving knowledge, skills and self-efficacy across various aspects of diabetes self-management*' (15). However, the success of an intensified insulin therapy in children and adolescents mainly depends on the knowledge, self-management skills, and on the motivation of the whole family (2, 3, 8, 12).

Nevertheless, systematic reviews of psycho-educational interventions conclude that such measures have small to medium beneficial effects on glycemic control (16–21) and a somewhat greater effect on psychological outcomes (22, 23). The effects are more pronounced for children than for adults (22). Educational efforts are most effective when integrated into routine care and are delivered with the involvement of parents. In addition, promoting empowerment principles, techniques for problem-solving, goal setting, and self-efficacy improve the efficacy of psycho-education (2, 4, 7–9, 12, 14, 16, 18, 24, 25).

The DCCT provided unequivocal evidence that intensification of management reduces microvascular complications and that intensification requires effective diabetes self-management. Most importantly, effective self-management requires frequent and high levels of educational input and continuing support to young patients as well as to their parents and other caregivers (26, 27). Furthermore, health care professionals engaged in education who are perceived by young people as being 'motivating' may eventually encourage greater adherence to therapy (28). This high level of motivation and enthusiasm by those delivering the educational intervention is likely to improve biomedical outcomes by itself and makes interpretation of educational research a complex science (24, 29).

In contrast, those people who do not receive education or do not continue to have educational contacts are more likely to suffer from diabetes-related complications (2, 5, 29–31). It is a concern, however, that parents and adolescents often express satisfaction about services received even when there may be large gaps in education, psychological support, and self-management techniques accounting for relatively unsatisfactory and variable metabolic control (32).

Universal principles

Every young person has a right to comprehensive expert structured education which should empower them and their families to take control of their diabetes (1–8).

Children and adolescents, both of their parents (8, 14, 33), and other care providers should all have easy access to and be included in the educational process. Also care givers in nurseries or kindergarten and teachers in school should have access to an appropriate structured diabetes education (14, 34).

Diabetes education should be delivered by an interdisciplinary team of health care professionals with a clear understanding of the special and changing needs of young people and their families as they grow through the different stages of life (1, 2, 5, 8, 13, 14, 24). Diabetes education needs to be adaptable and personalized so that it is appropriate to each individual's age, stage of diabetes, maturity, and lifestyle, culturally sensitive and at a pace to suit individual needs (1, 2, 4, 5, 8, 12).

The priorities for health care professionals in diabetes education may not match those of the child and family. Thus diabetes education should be based on a thorough assessment of the person's attitudes,

beliefs, learning style, ability and readiness to learn, existing knowledge, and goals (1).

Educators (pediatric endocrinologist or physician trained in the care of children and adolescents with diabetes, diabetes educators, dieticians, psychologists, social workers, and other health care providers) should have access to continuing specialized training in current principles of insulin therapy, new diabetes technologies, advances in diabetes education, and educational methods (2, 4, 5, 8, 12–14, 24).

Diabetes education needs to be a continuous process and repeated for it to be effective (2–14).

Content and organization of education programs

It is widely accepted that diabetes cannot be successfully managed without behavioral modification (35, 36). Health professionals need to understand that education alone focusing only on acquisition of knowledge is unlikely to alter behavior particularly in those individuals where diabetes appears to be overwhelmingly difficult. Thus the diabetes team needs training not only in the principles of teaching and structured education but also in behavioral change management including counseling techniques (2, 35, 36).

The importance of structured education (12, 14) programs has been emphasized in a variety of contexts. Evidence comes mainly from adult diabetes that it is more effective than informal unstructured education in improving metabolic control (15, 17, 37, 38). In pediatric diabetes, systematic studies of structured educational programs are rare and research has focused more on psychosocial interventions. However, there are ethical and methodological limitations of performing randomized-controlled trials (RCTs) on initial diabetes education at onset. The evidence for efficacy of these interventions comes from studies performed mainly in North America, Australia, and Europe and has been extensively reviewed in various publications (14, 15, 17–21, 39, 40).

There are four key criteria which characterize a structured educational program (10, 12):

1 it has a structured, agreed, written, and evaluated curriculum
2 it uses trained educators
3 it is quality assured
4 it is audited

Moreover, to put this into practice it has been recommended that (1–14):

- Structured education should be available to all people with diabetes at the time of initial diagnosis, or when it is appropriate for them, and then as required on an ongoing basis, based on a formal, regular individual assessment of need.
- Education should be provided by an appropriately trained interdisciplinary team. The team should have a sound understanding of the principles governing teaching and learning.
- Interdisciplinary teams providing education should include, as a minimum, a pediatric endocrinologist/diabetologist or a physician trained in the care of children and adolescents with diabetes, a diabetes specialist nurse/diabetes educator and a dietician. Furthermore, a psychologist and a social worker are recognized as mandatory in the interdisciplinary team (12).
- Sessions should be held in a location accessible to individuals and families, whether in the community or the inpatient center.

Table 1. Principles and practice of education in children, adolescents, and their parents/primary care givers

1. Motivation	- The learner needs to and/or have a desire to learn
2. Context	- Where is the learner now? - Where does the learner want to be later?
3. Environment	- Learner-centered, comfortable, trusting - enjoyable/entertaining/interesting/'open'
4. Significance	- Meaningful, important, links, or joins up - reward or gain
5. Concepts	- Simple to complex in gentle steps *(short attention span)*
6. Activity	- Constantly interactive - practical *(fitting into real life)* - goal setting and problem-solving
7. Reinforcement	- Repetition, review, summarize
8. Reassess, evaluate, audit	
9. Move forward *(continuing education)*	

Educational programs should use a variety of teaching techniques, adapted – wherever possible – to meet the different needs, personal choices, learning styles of young people with diabetes and parents, as well as local models of care.

Table 1 summarizes the philosophy of education in children, adolescents, and parents with diabetes (2, 14, 39–41; Table 1). In addition, the generally accepted principles which govern quality in teaching should also be recognized by diabetes educators (41) (Table 2).

Primary (level 1) education

The following topics are recommended at diagnosis as a comprehensive basis for successful therapy and positive emotional coping from onset on throughout lifetime for young patients and their families:

1 Explanation of how the diagnosis has been made and reasons for symptoms
2 Simple explanation of the uncertain cause of diabetes. No cause for blame or feelings of guilt

Table 2. Qualities looked for by UK Office for Standards in Education – OFSTED (39)

- Lessons should be purposeful with high expectations conveyed
- Learners should be given some opportunities to organize their own work *[over direction by teachers needs to be guarded against]*
- Lessons should elicit and sustain learner's interest and be perceived by pupils to be relevant and challenging
- The work should be well matched to learner's abilities and learning needs
- Learner's language should be developed and extended *[teachers' questioning skills play a part here]*
- A variety of learning activities should be employed
- Good order and control should be largely based on skillful management of learner's involvement in the lesson and mutual respect

3 The need for immediate insulin and how it will work
4 What is glucose? – normal blood glucose (BG) levels and glucose targets
5 Practical skills

- insulin injections/pump therapy if indicated/insulin dose adjustment
- blood and/or urine testing and reasons for monitoring, CGM (continuous glucose monitoring) if indicated

6 Basic dietetic advice inclusive carb counting, healthy eating
7 Explanation of hypoglycemia (symptoms, prevention, management)
8 Diabetes during illnesses. Advice not to omit insulin – prevent DKA, monitoring ketones
9 Diabetes at home or at school including the effects of exercise
10 Identity cards, necklets, bracelets, and other equipment
11 Membership of a Diabetes Association and other available support services
12 Psychological adjustment to the diagnosis (parents and children)
13 Integration of diabetes self-management therapy into family life and social activities
14 Details of emergency telephone contacts and continuous long-term care

Some guidelines discuss the 'controversy' (6, 8) between in-hospital and ambulatory education at diabetes onset. Owing to the heterogeneity of health care systems and funding of diabetes care and education there is evidence supporting both alternative approaches (40, 42–46).

Methods of delivering primary levels of education and the use of educational resources will depend on local experience, facilities, and the respective national health care system (12, 14). It will be dominated initially by individual (family) teaching, but specific age appropriate curricula for children of different cognitive levels and adolescents as well as special curricula for parents are developed and evaluated in some countries (12, 14, 39, 40).

Health professionals should learn to incorporate and deliver the education using behavioral approaches which are learner-centered and not didactic (35, 47, 48). All team members should follow a common philosophy and common goals in diabetes education (24).

Initial learning should be reinforced by written guidelines and curricula. It should be accompanied by quality-assured education materials (books, booklets, leaflets, DVDs, websites, games, and others) which should be appropriate to the child's and adolescent's age and maturity (12, 14). All materials should follow common therapeutic goals and a shared holistic approach.

Written materials for parents should use appropriate language and a style that is easily comprehensible (it is suggested that this should be at the level of a popular local or 'tabloid' newspaper). An integrated education concept for parents combines knowledge, practical self-management skills with psychological advice on parental tasks, and emotional support (2–14). For parents with limited literacy and/or poor numeracy special material focusing on diagrams, drawings, video clips, and other visual media are recommended (49, 50).

Secondary (level 2) continuing educational curriculum

Core topics of the continuing curriculum are:

1 Pathophysiology, epidemiology, classification, and metabolism
2 Insulin secretion, action, and physiology
3 Insulin injections, types, absorption, action profiles, variability and adjustments, insulin pump therapy with different boluses and bolus calculation
4 Nutrition – food plans; qualitative and quantitative advice on intake of carbohydrate, fat, proteins, and fiber; coping with special events and eating out; growth and weight gain; 'diabetic foods'; sweeteners and drinks, prevention of disordered eating
5 Monitoring (glucose, ketone), including glycated hemoglobin and agreed targets of control, use of CGM (if applicable)
6 Hypoglycemia and its prevention, recognition, and management including glucagon
7 Intercurrent illness, hyperglycemia, ketosis, and prevention of ketoacidosis
8 Problem-solving and adjustments to treatment in everyday life, motivation and coping with unexpected glucose fluctuations
9 Goal setting

10 Micro- and macrovascular complications and their prevention. The need for regular assessment
11 Exercise, holiday planning, and travel, including educational holidays and camps
12 Smoking, alcohol, and drugs
13 Nursery, kindergarten, school, college, employment, and driving vehicles
14 Sexuality, contraception, pregnancy, and childbirth
15 Updates on research.

Continuing education will take place most often in an ambulatory (outpatient, domiciliary, and community) setting (2–14, 51). Where staffing levels, expertise and local circumstances do not permit this, educational programs may be carried out in the hospital environment, either by individual teaching or in groups and whenever possible in a protected environment encouraging to learning (43, 51).

The educational program should utilize appropriate patient-centered, interactive teaching methods for all people involved in the management of diabetes, particularly the affected child or adolescent (2–14).

A realistic understanding of self-management is a prerequisite for higher levels of diabetes education as both educational and psychosocial issues are important determinants of success (2, 12, 15, 39, 40).

Newer technology may be attractive to young people including videos, CDs, computer games, text messaging for information (52), web 2.0 portal (53), telephone reminders, and support (54) but is used most effectively in interactive modes (5, 15, 19, 55).

Group education may be more cost effective and the educational experience may be enhanced by peer group (37, 38, 51) or school friendships (39). However, there is evidence that education directed at the specific needs of individuals is at least equally effective as group education (56).

There is some evidence that benefit might be gained from participation in organized Diabetes Association meetings and in holiday or camping experiences (57, 58).

Evidence from group discussions with young people suggests that education using these newer technologies is attractive for them, and there is further scientific data to support their widespread use (53, 55).

Education should be viewed as an important factor in empowerment for both parents (33, 42), as well as children and adolescents. This empowerment approach should enable young people to use knowledge and practical skills in problem-solving and self-care, and to be in control of goal setting for better care. In essence, the patients need to experience that they have influence over their own lives in making informed decisions about their diabetes (2–14, 47, 48).

Matching and adjusting insulin profiles to quantified food intake and exercise levels are an important part of any intensified diabetes management. More complex modern therapeutic regimens with multiple daily injections, use of different insulins and insulin analogs, continuous subcutaneous insulin infusion (CSII, insulin pumps), as well as wearing continuous glucose measurement devices require appropriate education. Higher levels of education and understanding are required for these interventions to be successful and require more time, skill, and greater resources from the educational team (2, 8, 9, 14, 59–61). Changing from one form of insulin regimen to another as the only means of intervention does not improve metabolic control (16, 24, 32). In contrast, by addressing the total management package using comprehensive structured education, the likelihood of success is greater (2–8, 16, 24, 61, 62), especially if the educators are highly motivated (29).

Education and age group

Diabetes education needs to be adaptable and appropriate to each individual's age and maturity (1, 14, 63). Specific curricula and appropriate education materials and tools are recommended for children and adolescents of different age groups (3–5, 5–6, 7–9, 9–12, 13–18 yr, and for young adults as part of a structured transition process) as well as for parents and other primary care givers of young people with diabetes.

Infants and toddlers

- Total dependence on parents and other care providers for injections/management of pumps, food and monitoring and the requirement of a trusting attachment between infant and caregivers (63)
- Mothers may feel increased stress, diminished bonding, and depressive feelings (64–67) but this applies to many chronic diseases (68)
- Unpredictable erratic eating and activity levels
- Difficulties in distinguishing normal infant behavior from diabetes-related mood swings, e.g., due to hypoglycemia (64–67)
- Injections, catheter insertion, and BG checks seen as pain inflicted by caregivers
- Hypoglycemia is more common (see chapter on hypoglycemia). Long standing hyperglycemia may be even more harmful. Education on prevention, recognition, risk, and management are therefore a priority (69, 70).
- Care in nursery and kindergarten

There is conflicting evidence on influencing behavioral characteristics of preschool children with diabetes through education (64, 68) and whether

their diabetes outcomes depend on them being part of the educational approach. But parents report the importance of education and non-judgmental support from a team (24, 25, 40, 61, 65)

School age children

- Adjusting to the change from home to school, developing self-esteem, and peer relationships (34, 55)
- Learning to help with and developing skills in injections, pump use, and monitoring
- Progressive recognition and awareness of hypoglycemic symptoms
- Increasing understanding and self-management
- Adapting diabetes to school programs, school meals, exercise, and sport
- Including monitoring of BG levels, injections, giving boluses in the school setting
- Advising parents on the gradual development of the child's independence with progressive stepwise hand-over of appropriate responsibilities (1, 63)

School age children have expressed dissatisfaction that health professionals talk to parents and not to them. There is some evidence that focused age appropriate educational interventions are effective in children and families (17–20, 23, 25, 71–74).

Adolescents

(see chapter on Diabetes in Adolescence for references)

- Accepting the critical role of continued parental involvement and yet promoting independent, responsible self-management appropriate to the level of maturity and understanding (72, 74)
- Understanding that knowledge about diabetes in adolescents is predictive of better self-care and (metabolic) control but the association is modest
- Discussing emotional and peer group conflicts
- Discussion weight control and preventing disordered eating (75, 76)
- Teaching problem-solving strategies for dealing with dietary indiscretions, illness, hypoglycemia, blood glucose fluctuation due to puberty, sports, smoking, alcohol, drugs, and sexual health
- Negotiating targets, goals and priorities and ensuring that the tasks taken on by the adolescent are understood, accepted, and achievable (77)
- Understanding that omission of insulin is not uncommon. The opportunity should be grasped for non-judgmental discussion about this
- Developing strategies to manage transition to adult services (78).

In conclusion, age-appropriate, quality-assured structured diabetes education needs to be available to all young people with diabetes and their carers to maximize the effectiveness of both conventional diabetes treatment as well as more advanced diabetes management and technology.

Conflict of interest

KL has received lecture honoraria from Abbott, Bayer Vital, Lifescan, Lilly Deutschland, Menarini, Merck Serono, NovoNordisk, Roche diagnostics, and Sanofi. Furthermore, she received research support from Menarini, Novo Nordisk, and Roche. TD has received honoraria from NovoNordisk, Lilly, Sanofi, Medtronic, Biodel, Becton Dickinson, Boehringer, and Roche. EW and PGFS have declared no conflict.

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