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Diabetes education in children and adolescents

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Education is the keystone of diabetes care and structured self-management education is the key to a successful outcome. Adapted from (1)

National pediatric guidelines emphasise the importance of education, but do not include specific chapters on education and educational principles (2–5).

Publications which provide useful guidelines on education in diabetes include "National Standards for diabetes self-management education (DSME)" (6), "Position statement on structured education" (7), "Guidance on the use of patient-education models for diabetes" (8), the "International Curriculum for Diabetes Health Professional Education" (9) and a recent description of paediatric diabetes education in Germany (10). See end of text.

A 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". (11)

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, 6, 11, 12) and this should be the responsibility of each nation / state and be a national priority (7, 10, 13).

Educational programmes must be carefully planned, have specific aims and learning objectives, which are shared with people with diabetes, carers and their families (8, 10).

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"* (14).

Nevertheless, systematic reviews of psycho-educational interventions conclude that they have small to medium beneficial effects on glycemic control (14, 15) and somewhat greater effect on psychological outcomes (16). The effects are greater for children than adults (16), and are most effective when integrated into routine care, when parents are involved, empowerment principles are involved, problem-solving, goal setting and self-efficacy is promoted (10, 15, 17).

The DCCT provided unequivocal evidence that intensification of management reduces micro-vascular 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 (6, 10, 11, 12, 18, 19). Related to this is evidence that health care professionals engaged in education who are perceived by young people as being "motivating" may encourage greater adherence to therapy (20). This high level of motivation and enthusiasm in educational intervention is likely to improve biomedical outcomes by itself and

makes interpretation of educational research a complex science (21).

In contrast, those people who do not receive education or do not continue to have educational contacts are more likely to suffer diabetes related complications (6, 19, 22, 23) **B**. It is a concern, however, that parents and adolescents often express satisfaction about services received (5) even when there may be large gaps in education, psychological support and self-management techniques accounting for relatively unsatisfactory and variable metabolic control (24).

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, 5, 7)

- Children and adolescents, their parents and other care providers should all have easy access to and be included in the educational process (5)
- Diabetes education should be delivered by 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)
- Diabetes education needs to be adaptable and personalised 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, 10)
- 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 (doctors, nurses, dieticians and other health care providers) should have access to continuing specialised training in diabetes education and educational methods (2, 6, 7, 9, 11)
- Diabetes education needs to be a continuous process and repeated for it to be effective (2, 4, 5, 8–11)

Content and organisation of education programme

It is widely accepted that diabetes cannot be successfully managed without behavioral modification (25, 26). Health professionals need to understand that education *per se* with acquisition of knowledge is unlikely to alter behavior particularly in those individuals where diabetes appears to be overwhelmingly difficult. There is therefore a need for training the diabetes team not only in the principles of teaching and structured education but also in behavioral change management including counselling techniques (25–27).

The importance of structured education (7) programmes is considered in a variety of contexts and there is evidence, mainly from adult diabetes, that it is more effective than informal unstructured education in improving metabolic control (12, 14–17, 28, 29). In pediatric diabetes, structured educational programmes have been less well publicised and because of the nature of the problems have focussed more on psychosocial interventions. The evidence for efficacy of these interventions, nearly all from North America, has been extensively reviewed in various texts (14–17) but others have developed more recently (10, 30).

There are four key criteria which characterise a structured educational programme (7):

(1) has a structured, agreed, written curriculum
(2) uses trained educators
(3) is quality assured
(4) is audited

and to put this into practice it has been recommended that (1–8):

- 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 on-going 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 diabetes specialist nurse and a dietician
- Sessions should be held in a location accessible to individuals and families, whether in the community or the inpatient center
- 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.

The following principles of education in children have been adapted from discussions with teachers and reference (30) (Table 1).

Moreover the principles which govern quality in teaching should be recognised by diabetes educators (30, 31) (Table 2).

Specifically in diabetes care, the following guidelines (1) may act as a template on which to develop an appropriate educational curriculum and indeed they have been quoted extensively elsewhere (2, 4, 5, 10)

Table 1. Principles & practice of education in children

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-centred, 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, summarise
8. Reassess, evaluate, audit
9. Move forward *(continuing education)*

Primary (Level 1) education

At diagnosis: Survival skills

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
3. The need for immediate insulin and how it will work
4. What is glucose? - normal BG levels and glucose targets
5. Practical skills - insulin injections
   - blood and/or urine testing and reasons for monitoring
6. Basic dietetic advice
7. Simple explanation of hypoglycemia
8. Diabetes during illnesses. Advice not to omit insulin—prevent DKA
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
13. Details of emergency telephone contacts.

Methods of delivering primary levels of education and the use of educational resources will depend on local experience and facilities. It will be dominated initially by individual (family) teaching. Health professionals should learn to incorporate and deliver the education using behavioural approaches which are learner-centred and not didactic (25, 32, 33).

- Initial learning should be reinforced by written guidelines and booklets which should be appropriate to the child's age and maturity (see resource appendix)
- 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)

Secondary (level 2) continuing educational curriculum

Continuing curriculum

1. Pathophysiology, epidemiology, classification and metabolism
2. Insulin secretion, action and physiology
3. Insulin injections, types, absorption, action profiles, variability and adjustments
4. Nutrition—food plans; qualitative and quantitative advice on intake of carbohydrate, fat, proteins and fibre; coping with special events and eating out; growth and weight gain; ''diabetic foods''; sweeteners and drinks
5. Monitoring, including glycated hemoglobin and clear (agreed) targets of control
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
9. Goal setting
10. Micro and macro-vascular complications and their prevention. The need for regular assessment
11. Exercise, holiday planning and travel, including educational holidays and camps

Table 2. Qualities looked for by UK Office for Standards in Education - OFSTED (30, 31)

- Lessons should be purposeful with high expectations conveyed
- Learners should be given some opportunities to organise 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 skilful management of learner's involvement in the lesson and mutual respect

12. Smoking, alcohol and drugs
13. 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, community) setting (2, 4, 5, 34). 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 conducive to learning (34, 35)
- The educational program should utilise appropriate patient-centred, interactive teaching methods for all people involved in the management of diabetes, particularly the affected child or adolescent (34).
- Higher levels of diabetes education should be grounded in a realistic understanding of self-management as both educational and psychosocial issues are important determinants of success (14, 30, 34).
- Newer technology may be attractive to young people including videos, CDs, computer games, text messaging for information (36), telephone reminders and support (37) but is used most effectively in interactive modes (5, 8, 14, 17)
- Group education may be more cost effective and enhanced by peer group (28, 29, 34) or school friendships (30), although there is evidence that education directed at individual needs is equally effective as group education (5, 8, 38)
- There is anecdotal evidence that benefit may be gained from participation in organised Diabetes Association meetings and in holiday or camping experiences (39, 40).

Evidence from group discussions with young people suggest that education using these newer technologies is attractive but there is little scientific evidence to support its widespread use (5). In contrast, traditional intensive individualised outpatient education in specialised clinics has been shown in some situations to produce excellent results in terms of glycemic control (41, 42).

When education is viewed as an important factor in empowerment, both for parents and adolescents, it should enable young people to use knowledge and practical skills in problem solving and self-care, to be in control of goal setting for better care and to have influence over their own lives in making informed decisions about their diabetes (32, 33, 43, 44).

Matching and adjusting insulin profiles to quantified food intake and exercise levels have become an important part of modern intensified management with multiple injection treatment, the availability of analogue insulins and infusion pumps. Higher levels of education and understanding are required for these interventions to be successful and requires more time, skill and greater resources from the educational team (10, 42, 45, 46).

Changing insulin regimens per se does not improve metabolic control (12, 24). In contrast, by addressing the total management package utilising comprehensive structured education there is more likelihood of success (6, 7, 14–19, 28, 29, 47), especially if the educators are highly motivated (21).

Education and age group

Diabetes education needs to be adaptable and appropriate to each individual's age and maturity (1, 48).

Infants and toddlers

- Total dependence on parents and care providers for injections, food and monitoring and the requirement of a trusting attachment between infant and caregivers (49)
- Mothers may feel increased stress, diminished bonding and depressive feelings (49, 50) but this applies to many chronic diseases (51)
- Unpredictable erratic eating and activity levels
- Difficulties in distinguishing normal infant behaviour from diabetes-related mood swings (50)
- Injections and BG checks seen as pain inflicted by caregivers (50)
- Hypoglycemia is more common. Severe hypoglycemia may be more harmful (see chapter on hypoglycemia). Education on prevention, recognition and management is therefore a priority. Age specific targets for BG should be discussed (see chapter on monitoring).

There is conflicting evidence on the behavioural characteristics of preschool children with diabetes (49, 52) and whether diabetes outcomes depend on education per se. But parents report the importance of education and non-judgmental support from a team (50, 53)

School age children

- Adjusting to the change from home to school, developing self-esteem and peer relationships (48, 54)
- Learning to help with and developing skills in injections and monitoring
- Progressive recognition and awareness of hypoglycemic symptoms (55)
- Increasing understanding and self-management
- Adapting diabetes to school programs, school meals, exercise and sport (54)
- Including monitoring of BG levels and injections in the school setting

- Advising parents on the gradual development of the child's independence with progressive stepwise hand-over of appropriate responsibilities (1, 48)

School age children have expressed dissatisfaction that health professionals talk to parents and not to them (5). There is some evidence that focussed age appropriate educational interventions are effective in children and families (5, 14–17, 48, 56).

Adolescents

(See chapter on 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
- Understanding that knowledge about diabetes in adolescence is predictive of better self-care and (metabolic) control but the association is modest
- Discussing emotional and peer group conflicts
- Teaching problem solving strategies for dealing with dietary indiscretions, illness, hypoglycemia, 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
- Understanding that omission of insulin is not uncommon. The opportunity should be grasped for non-judgemental discussion about this
- Developing strategies to manage transition to adult services.

Summary and recommendations

- Education is the key to successful management of diabetes (1–11) **E**
- There is evidence that educational interventions in childhood and adolescent diabetes have a modestly beneficial effect on glycemic control and a stronger effect on psychosocial outcomes (14–17) **A**
- To maximise the effectiveness of both conventional diabetes treatment and the advances in diabetes management and technology (especially self monitoring of blood glucose, analogue insulins and insulin pumps) it is advisable that quality assured structured education is available to all young people with diabetes and their carers (2, 4, 5, 7) **E**
- Health care professionals require appropriate specialised training in the principles and practice of teaching and education (25, 27, 30, 31) to implement successfully behavioral approaches to education designed to empower young people and carers in promoting self-management (25, 32, 33) **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 (2, 6, 7, 10, 11, 17) **E**
- Educational interventions which have been shown to most effective are most likely to:
  - be based on clear theoretical psycho-educational principles (14–17) **E**
  - be integrated into routine clinical care (e.g. as an adjunct to intensive insulin management) (14, 15, 17, 45, 46) **A**
  - involve the continuing responsibility of parents and other carers throughout adolescence (4, 5, 30, 34, 56) **B**
  - make use of cognitive behavioral techniques most often related to problem solving, goal setting, communication skills, family conflict resolution, coping skills and stress management (14–17) **A**
  - utilise new technologies in diabetes care as one of the vehicles for educational motivation (14, 17, 36, 37) **A**
- Evaluation of educational programmes is essential and should 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 (14–17) **E**

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