

Diabetes education for children and adolescents: challenges, concepts and practical implementation

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Summary

Structured education immediately after the diagnosis of type 1 diabetes and during follow-up care, is considered as an integral and essential part of long-term paediatric diabetes management. Structured education programs are intended to supply parents and children with the necessary theoretical knowledge, accompanied by a variety of practical skills. The programs are also intended to enhance self-management and to help all family members in coping emotionally with the disease. The present article presents a review of the concepts and curricula of the German language education courses that have been evaluated, focussing on nutritional advice, the support of balanced and age-appropriate eating behaviour, as well as the prevention of eating disorders. The programs are presented in the context of modern diabetes technology, such as insulin pump therapy, as well as changes in the social environment.

Keywords: Diabetes education, programs and courses, children and adolescents, nutritional counselling, social change

Introduction

During the last two decades, the quality of the metabolic control of children and adolescents with diabetes has improved, as a consequence of intensive forms of therapy and

structured education [1]. There have been clear reductions in daily stress with respect to lifestyle and therapy [2]. Despite these improvements, there has been little change during this time in the daily tasks that are required to live with diabetes. Children and parents still have to pay continuous attention to food intake, physical activity, frequent adjustments to insulin administration and the variability of diabetes [3].

Challenges for diabetes education in 2013

Although some new developments have helped to improve life with di-

abetes, the new challenges for diabetes education are mainly linked to the continual changes in the social environment.

Dealing with new technologies

Treatment options have been extended by innovative therapeutic concepts, such as insulin pump therapy (CSII), sensors for continuous glucose measurement (CGM) and various long and rapid-acting insulin analogues [3]. CGM makes it clear how large the fluctuations in glucose values are, particularly after meals. Parents who expect that their children are receiving optimum therapeutic management may be unsettled by the obvious and continuous fluctuations in blood glucose levels. This is exacerbated when there has been no education on the interpretation of the measured values and on different insulin types and doses at various times in the day. Education should include an understanding of the circadian rhythm of insulin sensitivity [3], as well as information on the influence of protein and fat on glucose metabolism [4].

Increasing incidence of diabetes in infants

For the last 20 years, the number of new cases of type 1 diabetes has been increasing annually by ca. 3–4 % [3]. This particularly affects infants and

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preschool children. For these young children, the education must provide information, as well as helping parents to maintain the balance between good diabetes management and appropriate upbringing in all areas of life, including eating habits and behaviour.

Continuous availability of energy rich foods

Many children and adolescents are now confronted with a vast number of different “children’s foods” and fast foods. There are self-service machines in the vicinity of schools and even in many paediatric clinics. These provide continuous access to sweets and other energy rich foods. Together with the reduced physical activity, the permanently available food contributes to the generally observed increase in the prevalence of overweight and obesity in children and adolescents in Germany [5]. Avoiding overweight is a particular challenge for girls and boys with type 1 diabetes [6].

Childcare outside the family

In Germany, an increasing proportion of children of all ages are no longer cared for by their parents, but in day care centres, full-time kindergartens, schools or in after-school care. Thus, diabetes management is no longer exclusively the responsibility of the parents, but of carers, who must also be informed about diabetes.

Children with psychosocial risks

About one third of all children and adolescents in Germany live in single parent, broken families, families in conflict, or grow up in precarious psychosocial circumstances. But even in nuclear families where both parents are in full-time employment, diabetes education must attempt to integrate diabetes therapy into both

family life and the parents’ professional careers [7]. Other challenges concern children with psychological disorders, such as ADHD (attention deficit-hyperactivity disorder), learning difficulties or eating or affective disorders, which can seriously impair everyday therapeutic behaviour [8]. Similar considerations apply if the parents suffer from severe physical or psychiatric diseases, such as depression, or are alcohol or drug dependent.

Primary out-patient diabetes education

Initial education for children in Germany is almost exclusively in the in-patient setting and is usually performed by a multiprofessional team – paediatrician/diabetologist DDG, diabetes consultant DDG (certified diabetes educator), dietician, paediatric psychologist, as well as a social worker. In addition, financial support is usually provided for follow-up education sessions in the out-patient setting. Even though these education sessions are reimbursed in the context of the Disease Management Program (DMP) for Type 1 Paediatric Diabetes, there is hardly any financial support for the work of non-medical team members, such as dietitians, so education in this area is often inadequate [9].

Concepts of paediatric diabetes education

All current evidence-based guidelines on paediatric diabetes therapy agree that structured education of children and adolescents with type 1 diabetes, together with their parents, is an essential element of multi-professional management [3, 10–12]. For ethical reasons alone, it is absolutely essential that all family members should be informed in an appropriate manner of the correct application and possible risks of treatment. Parents and young people must be put in the

position of being enabled to live successfully with diabetes, with as much responsibility and independence as possible [13]. The education courses should provide children and adolescents with a basis for their physical, cognitive, mental and social development appropriate to their age. This means that parents should not only be informed about the therapy, but should also be advised on how they can combine this with their parental duties and a family life appropriate to their children [3, 12]. In addition, the education must help young people to cope with the diagnosis emotionally, together with the lifelong requirements of the therapy.

Structured education and diabetes management programs

Structured, paediatric diabetes education and treatment programs are characterized by a clear goal-oriented structure in the communication of the content of the education [10]. The essential information and objectives, as well as the methods and teaching procedures, are presented in a curriculum. Evaluated and target group-specific and specially adapted education documents must be provided to the education teams [10, 11, 14], as well as to the affected children, adolescents and their parents.

Education programs for elementary school children [16] and for adolescents [17] are currently accredited in the context of the DMP for type 1 paediatric diabetes [15]. Out-patient education according to these programs, as well as the teaching materials, are reimbursed by health insurance funds. A national evaluation has been performed for a corresponding education program for parents of children with type 1 diabetes [18, 19]. In-patient education of children and adolescents with type 1 diabetes, as well as their parents, is an integral component in Germany of multi-



modal complex treatment, in accordance with the Diagnosis Related Groups (DRG) (K60A = submission figure for complex treatment).

Individualised education as standard

Children and adolescents with type 1 diabetes cover a wide age range, with different phases of diabetes, major differences in the levels of education of their families and with different constellations of psychosocial risk. Thus, the education sequence must be individually adapted by experienced trainers [11, 12]. For this reason, the figures given for the time needed for an education se-

quence (e.g. ca. 30 teaching hours for the initial education of the parents [19]) are rough estimates, covering a wide range between the minimal and maximal requirements. Factors to be considered include habits, goals in life, family stress and special cultural features, as well as perceived levels of understanding and the emotional readiness to cope with diabetes and its consequences.

Graduated education courses

After the diagnosis of diabetes has been confirmed, the doctor discusses the situation with the children & young people and the parents. This initial educational approach influ-

ences long-term understanding and management. Parents often retain a highly emotional memory of this short discussion, which nurtures the initiation of a trusting cooperation between the family and the treatment team. This is the introduction to the initial detailed education of all family members by a multiprofessional diabetes team, which takes place in Germany during the time as an in-patient in a department of paediatrics, for an average of 12 to 14 days. In the following years, there are repeated follow-up education sessions, that are an integral component of continuous long-term treatment. Depending on the children's cognitive developmental status, specific curricula are designed for preschool children, elementary school children, adolescents in puberty and young adults, before they are referred for treatment to a physician in internal medicine [3, 12, 14]. The follow-up sessions may be planned for small groups of the same age or may be on individual themes, e.g. preparation for starting school [20] or starting insulin pump therapy (CSII) [17].

Diabetes education in practice

It would require more space than is available to present all the curricula of the different diabetes education courses. Reference is made to the following publications [3, 12, 14, 18]. We will now focus on nutritional counselling in the education courses [6].

Initial education of the parents

As diabetes is relatively rare in children and adolescents, the initial education of both parents and possibly other primary caregivers is provided on an individual basis. Practical sessions ("learning by doing") are particularly effective [12–14, 21]. This is consolidated by the education

Age-specific nutritional themes for parents
babies and preschool children: Advice on breast-feeding and help in estimating the carbohydrate content of the milk meals
suitable supplementary diet in the first year of life, evaluation and assessment of ready-to-use products, ideas about the preparation of basic foodstuffs
selection and procedure with sweeteners within the family (saccharose, sugar substitutes, sweeteners) caution: early habituation to the sweet taste
evaluation of "children's foods", "products for diabetics", "diet products"
possible treatments for hypoglycaemia in the child caution: sweets
fluid supply and suitable foods during infections, which are frequent in this age group
adaptation of the quantity of food to the different levels of physical activity, when it is (no longer) possible to adjust the insulin dose
planning regular meals for the whole family
educational counselling when there is repeated conflict or tantrums with small children at mealtimes [21, 22]
procedure and availability for sweeteners in the whole family caution: unique position relative to brothers and sisters
ideas how preschool children can participate in the selection and preparation of simple meals
counselling on how children can independently select foods appropriate to their age
preparation of meals in the kindergarten, agreement with educators, participation in outings and (birthday) celebrations
age-appropriate supply of fat, protein, carbohydrates, vitamins and minerals, everyday practical advice, e.g. using the DGE nutritional pyramid

Table 1: Age specific nutritional themes for the parents of babies, infants and preschool children with diabetes [18]

book for parents [18]. The parents' own successes in treating their child should make it clear that they are not passively at the mercy of diabetes, but can make an active contribution to their child's wellbeing. This experience of self-efficacy also makes it easier to cope with the diagnosis emotionally.

The education curriculum for parents includes all themes relevant to understanding the therapy: physiology/pathophysiology, principles of differentiated insulin therapy (basal and prandial insulin), nutrition, metabolic self-control, hypoglycaemia and hyperglycaemia, physical activity and sport, insulin therapy in acute diseases, therapeutic goals, secondary complications and psychological, didactic and social medical issues [3, 11, 12]. As almost all children under 6 years are now given insulin pump therapy, their parents must learn how the boluses of insulin can be flexibly adapted to the child's nutrition and physical activity.

Nutritional counselling includes food science and, especially, suggestions about planning meals suitable for children and for solving conflicts typical of this age group. ♦ Table 1 summarises themes for the parents of infants and preschool children with diabetes [22, 23]. The main problem for parents is to help their children to eat in a normal manner, under the control of hunger and satiation, and in spite of the many demands of diabetes management. The quantity of food consumed by the child should not be determined by diabetes, but be "flexible under the protection of insulin", in accordance with the treatment philosophy of Prof. Karl STOLTES (1939) [24].

Parents of schoolchildren have the task of preparing their children for independent diabetes management. This means that they should offer

Age-specific nutritional themes for parents

regular meals together, to practice matching the insulin dose and carbohydrate content of the meal
adjustment of the quantity of food to different levels of physical activity, if it is (no longer possible) to adjust the insulin dose prior to exercise
practical suggestions to assist the assessment of carbohydrate during the course of the normal day
estimation of the protein and fat content of a meal/snack and selection of the most appropriate bolus in the CSII, (the bolus may be delayed) [4, 25]
preparation of suitable meals for the time spent in school
visiting the school canteen and discussion with relevant school staff
suitable foods for physical activity, sport and stress
depending on the child's age, involvement and independence in preparing food
supply of fat, protein, carbohydrates, vitamins and minerals as appropriate to age
everyday practical advice, e.g. with help of the DGE nutritional pyramid
basic information on changes in height and weight in school age children (percentile curves)
early nutritional counselling after excessive weight increase
after diagnosis of celiac disease, comprehensive counselling on suitable and unsuitable foods, sources and practical cooking techniques

Table 2: **Age specific nutritional themes for parents of elementary schoolchildren with diabetes** [18]
CSII = Insulin pump therapy

their children balanced nutrition and serve as an example.

♦ Table 2 lists some relevant education themes, that are consolidated in a practically orientated advisory discussion or in practical exercises and experiences. The following teaching materials can be used: food packages, specific foods, photos of dishes in the original size, cookbooks, family recipes, training tools from the German Nutrition Society (www.dge.de) and the Federal Centre for Health Education (www.bzga.de), as well as analyses of finished products on the manufacturers' websites. Other essential elements are carbohydrate exchange tables (either printed or as an app) and other tables, e.g. calories consumed or the corresponding apps, or Fddb-App, in order to be able to estimate the effects of various dishes and drinks on blood glucose levels.

Children of elementary school age learn very quickly how to estimate the carbohydrate content of basic foods. However, they may find ready-to-serve meals difficult to estimate, e.g. in the school canteen, and need to be helped by adults. Counselling should therefore include pragmatic approaches to support the children when their parents are not present. In spite of simple insulin administration through a pump, children with diabetes – just like healthy children – have to learn how to limit the consumption of rapidly absorbable carbohydrates, in order to prevent malnutrition or obesity. To achieve this, parental education techniques need to be established to develop a positive relationship with the child and to introduce rules for behaviour that can be transferred to specific situations. The Delfin program is one example of how parents can lovingly and consistently de-

mand that rules/guidelines for dealing with diabetes are kept [26].

Initial education for elementary schoolchildren

Schoolchildren (aged about 6 to 12) are first informed in an appropriate manner about their disease, the treatment and the correct behaviour in special situations, e.g. during hypoglycaemia. In HÜRTER et al.'s [16] diabetes program for this age group, a 10-year old boy reports on 1) the causes of diabetes, 2) insulin therapy, 3) his nutrition, 4) metabolic control and 5) hypoglycaemia. In the sixth chapter for older children, the principles of intensive insulin therapy are presented. This curriculum requires ca. 8 theoretical and 18 practical teaching units. These education units are adapted to how elementary schoolchildren typically think and their developmental stage. Exces-

sively complex theoretical material is dispensed with, in favour of many practical exercises. As regards nutrition, children learn to distinguish between foods that contain a lot of carbohydrate compared with foods with little or no carbohydrate. Practical exercises of weighing out the quantity corresponding to one carbohydrate unit and selecting suitable carbohydrate-free drinks is useful. They also learn which foods, in which quantities, can be used in the event of hypoglycaemia. Other themes are participation in (birthday) parties or outings, behaviour in difficult situations with contemporaries, planning sweets and how children can request help from their parents or other adults.

Initial education for adolescents

When diabetes first develops, adolescents must be provided with detailed

information about their metabolic disorder. The certified education program for this age group consists of four workbooks and a guideline for pupils [17]. Book 1 provides basic information on diabetes; book 2 consolidates the principles of intensive insulin therapy; book 3 covers the issues of sport, hobbies and travel, weight regulation, identity, contraception, wishes for young people, future and secondary complications, school, choice of career and legal questions; book 4 contains the curriculum for insulin pump training. The material is orientated towards the specific situation and problems of 13- to 18-year olds. Issues addressed include independence from the parents, body image, nutrition and eating behaviour, dealing with the typical conflicts of adolescence, exchanging information about diabetes with contemporaries, development of personal perspectives in life and the transition to diabetes facilities for adults. The most important nutritional themes are summarised in ♦ Table 3.

One chapter is entitled "Look good and feel good" and is mainly intended for young women [27]. This answers questions about normal body weight. The pressure to be slim is questioned and the negative consequences of strict fasting are explained. It is also explained how overweight in diabetes can be prevented or slowly reduced, without unfavourable consequences for metabolic control. There is additional information on the first signs of eating disorders and the available counselling. At the end of the chapter, it is discussed how young people can be encouraged to develop favourable self-image and wellbeing. The education documents are intended to support active education or coaching. Suggestions about how to make the education interesting and worksheets are summarised in a teaching guideline with a CD for education teams [17].

Altersspezifische Ernährungsthemen
Age-specific nutritional themes
calculating prandial insulin after large meals, allowing for protein and fat content [4, 24]
insulin dosage for protracted meals (e.g. brunch, parties at night, grill evenings)
assessment of ready-to-use meals and fast food products / how to interpret the information on ingredient lists
helpful strategies to counteract uncontrolled consumption of sweets
effects of various alcoholic drinks, cocktails, energy drinks
basic information on changes in height and weight in adolescents (percentile curves)
objective discussion of peer pressure and support of a positive self-image
healthy strategies to prevent overweight
healthy long-term strategies to reduce weight in overweight young people
sensitive presentation of the risks from extreme dieting, hunger phases and insulin dose reduction (purging)
caution: attacks of intense hunger, binge eating and eating disorders
If required: information on counselling centres and therapeutic help if eating disorders are suspected
If celiac disease has been diagnosed: comprehensive counselling about foods and meals that are suitable or unsuitable outside the home, at school and during eyes

Tab. 3: Age specific nutritional themes for adolescents with diabetes and their parents [17, 18]

Follow-up education during long-term diabetes management

Follow-up education is recommended at regular intervals, in order to adapt the therapy to new circumstances, the children's physical development and the course of the diabetes. These may be in groups of 4 to 8 participants for parents, school-children or adolescents. Education is provided to develop practical skills for implementing therapy in daily life. New therapeutic principles are explained. Experiences are exchanged and the independence and the social skills of the children and adolescents are supported. The special nutritional themes are as listed in ♦ Tables 1–3.

School children benefit from structured follow-up education, in which they learn the basic principles of diabetes treatment together with contemporaries and under realistic conditions. In the structured education course "Fit für die Schule" [Fit for School] [20], children who will shortly start school learn how to inject themselves with insulin or how to administer insulin with an insulin pump, as well as how to measure and classify their blood glucose values, how to react appropriately to hypoglycaemic episodes and how to deal self-confidently with their condition.

Diabetes coaching in a group of contemporaries is also expedient for adolescents who developed diabetes as children and who have been cared for by their parents. The aim of this education is to consolidate their knowledge of intensive insulin therapy in daily life and to exchange experiences. But the adolescent young person must also find their own way to cope effectively with the problems of their age group in spite of diabetes. Possible themes include injections or wearing a pump in public, alcohol consumption, con-

flicts with their parents about diabetes therapy, holidays without their parents, the behaviour of fellow pupils and strangers, partnership or dealing with worries about the future.

Conclusion

Structured diabetes education in Germany for children and young people with type 1 diabetes and their parents has been well established and quality assured for over two decades in comparison with other European health systems [14], a key element for success being the highly skilled accredited members of the multi-professional team. This has helped to improve the situation and prognosis of children and adolescents with diabetes. New technologies, such as continuous glucose measurement (CGM), should be integrated in the future into the education of team members and into patient education on nutrition – in a structured manner and accompanied by quality assurance. The precondition for this is that CGM is reimbursed by the health insurance funds.

Individualised out-patient education in small groups have been found to be effective in long-term care. There are however no financial plans to employ the necessary number of dieticians as part of integrated care – both for out-patients and in-patients. The structural conditions for multiprofessional out-patient education is a matter of urgency for all involved professional associations and scientific societies.

Other technical aids – such as apps – are now being continuously developed on a variety of nutritional themes. These are practical aids in everyday work, but are not capable of replacing motivational counselling adapted to the individual's situation.

Other research issues include valid

diagnostic testing for eating disorders in diabetes, as well as effective concepts for their prevention and therapy. Finally, we have not discussed one increasingly important high risk group: adolescents with type 2 diabetes. Research is urgently needed on drug therapy, training and long-term lifestyle modification for this group of patients.

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Conflict of Interest

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