

Original Article

A pediatric diabetes toolbox for creating centres of reference

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Introduction: ISPAD guidelines recommend age appropriate diabetes education concepts for young patients and their families as well as tools for nutritional management, psychosocial assessment, and psychological advice but their implementation in Europe is presently unknown.

Methods: On the basis of a structured survey among the European SWEET members information on established tools and programs in national languages were analyzed using an extensive literature and desk search. These were differentiated according to five age-groups and five target groups (young people with diabetes, parents, and other close relations, carers in school and nursery, and healthcare professionals).

Results: Responses and original tools were received from 11 SWEET countries reflecting the European status in 2011. More or less structured information for parents, close relations, and carers in school or nursery are available in all 11 participating countries. However, only two countries followed the recommendations of having published a structured, curriculum lead, and evaluated program for different age-groups and carers. One of these was evaluated nationwide and funded by the respective National Health Care System after accreditation. In addition a huge variety of creative tools, e.g., booklets, leaflets, games, videos, and material for educating children of different age-groups and their parents are available – but most of them are not linked to a structured education program.

Conclusions: Harmonizing and integrating these materials into quality assured structured holistic national education programs will be an important future task for the ongoing SWEET project. A comprehensive European diabetes educational toolbox is aimed to be published and continuously updated on the SWEET website.

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Diabetes education is a key element of pediatric diabetes care both at diagnosis, where there is no knowledge base and affected families are given first basic skills for controlling the disease, and throughout

the patients' lifetime. Education provides ongoing attention to self-management skills, prevention of acute and chronic complications and integration of knowledge into age-appropriate psychosocial development.

As diabetes management requires far-reaching lifestyle changes, it is indispensable that quality-assured education is delivered to the whole family and other carers of children and adolescents with diabetes.

The reports of the respective other SWEET work packages included in this Supplement issue demonstrate remarkable differences between European countries in structures, processes, and outcomes of pediatric care for young people with diabetes and their families. They point to significant differences in the content, provision, organization, delivery, and funding of pediatric diabetes education. In addition, there is currently no consensus on a curriculum for professionals' training programs and systems. Only a minority of European countries has established training but, for the majority, there was little standardization or a formal accreditation process for established diabetes professionals. On the other hand, all SWEET members strongly agree with the philosophy and content of the current ISPAD guideline on pediatric diabetes education (1) focussing on a structured quality-assured holistic concept of on-going patient education provided by a qualified multidisciplinary pediatric diabetes team.

The main objective of this SWEET work package was to create a first European toolbox with proven programs, concepts, devices and further material for education and care of young people with diabetes and their families. As a first step the core elements of age appropriate diabetes education concepts for young patients and their families needed to be collected among the SWEET partners. In addition central tools for nutritional management, psychosocial assessment and psychological advice among the national healthcare systems were compiled. On the background of proven material and tools, recommendations for qualified age appropriate patient education programs and materials will be developed for the service of Centres of Reference for Pediatric Diabetes. The inventory of existing materials and tools is supposed to be published and continuously updated on the SWEET website in detail. The present report gives a structured overview of the currently available programs in different European languages. In addition critical issues and challenges relating to national education materials and tools will be identified.

Methods

Four principle sources of information were applied to characterize the current status of pediatric diabetes education programs and materials in Europe. (i) Pubmed was searched using the terms 'diabetes, paediatrics, education, program, training, curriculum, children, adolescents, parents'. This yielded a small number of papers that were directly related to specific

education and training programs or material for pediatric patients and their carers. Furthermore, there were a huge number of publications pointing to the importance of age appropriate diabetes education as integral part of multidisciplinary pediatric diabetes care. These latter publications were not included in the result section below. (ii) Literature in English, French, and German language was extensively searched for current guidelines, standards, and recommendations for structured diabetes education programs. (iii) Furthermore, a desk search for published educational materials was done including books, booklets, websites of patient organizations, health insurance companies, and pharmaceutical companies all over Europe. (iv) Based on the discussion during a SWEET Members' Workshop in Malmoe during 2010 on existing and designated material and tools for diabetes education, a questionnaire was developed and sent to all SWEET participants from 14 European countries. This questionnaire consists of a matrix with 25 boxes: five (age groups) \times five (target groups: (i) children/adolescents, (ii) parents, (iii) other close relations, (iv) teachers and carers, (v) healthcare professionals – HCPs). In each box the existing programs, materials or other useful tools in local languages were collected and characterized by the SWEET partners. Each description includes the type of the tool, agenda and comprehensiveness, learning targets, instruction for use, curriculum, integration into a structured education concept, scientific background, access and financial effort for teams and families. In addition the SWEET members were asked to send one original example of the material to WP 5 center (Hannover team) and, – where applicable, to share information on the scientific evaluation of the material, published data and certification by health insurance companies, national associations or other organizations responsible for funding patient education nationally or locally.

Results

The Pubmed search yielded few relevant documents addressing specific education programs or tools for children, adolescents or parents. Some meta-analysis on the effectiveness of pediatric diabetes education for children and adolescents on metabolic control and psychosocial outcomes primarily focussed on randomized controlled trials and some observational studies with a variety of interventions for different groups of patients or parents (2–5). Three types of interventions were distinguished, those providing general diabetes-related education and skills training, those addressing psychosocial issues, and those with an explicit behavioral and self-management component. Some studies are targeting young people in poor metabolic control, others newly diagnosed children

at onset or adolescents starting self responsible diabetes management. Successful interventions were heterogeneous and included cognitive behavior therapy, family therapy, skills training as well as general diabetes education. The majority of educational interventions were successful in improving various psychosocial outcomes. The results of two studies examining refinements to intensive therapy education suggest that educational interventions may enhance the effects of intensive diabetes management in reducing HbA1c (6, 7). In summary, however, the authors of the meta-analyses state, that 'due to the heterogeneity of the included interventions, the variety of outcome measures and duration of follow up, and the small sample sizes, there is insufficient evidence to identify a particular intervention that is more effective than standard care to improve diabetes control or quality of life or to reduce short-term complications' (1). Compared to the high number of publications on distinct educational intervention data on some specific material or tools, e.g., self-study material to prevent severe hypoglycemia (8, 9) or structured education programs are rare (10, 11). As the education material and tools are usually implemented as an integral part of a holistic multidisciplinary education and care concept, the effectiveness of these single parts is scientifically difficult to verify.

The majority of publications on diabetes education underline its' relevance as a keystone of successful pediatric care and families' diabetes self-management. Several national, e.g., UK (NICE 2004) (12); (Diabetes UK 2010) (13); Germany (DDG 2009) (14) and (DDG 2011) (15); USA (ADA 2005) (16) (ADA 2010) (17); and international guidelines (Australasian Paediatric Endocrine Group (APEG 2005) (18), International Diabetes Federation (IDF 2008) (19) ISPAD (1) DAWN Study Group (2007) (20) include comprehensive chapters on targets, structures, contents, and practices of pediatric diabetes education. All guidelines assemble recommendations and guidance for diabetes education in pediatric long-term care. They emphasize the importance of age-appropriate coordinated education and material for children, their parents and other carers at disease onset and as follow-up until adulthood. Knowledge about practical aspects of the current therapy, skills for coping with everyday life, empowerment, development of self management skills and psychological support are some of the key topics. Furthermore, structured curricula, experienced and trained educators and education as an integral part of the long-term care are strongly requested.

In most instances the guidelines include detailed key recommendations for pediatric diabetes education. Particularly, the ISPAD guidelines (2009) and the German evidence-based guidelines (2009), accentuate most similar recommendations concerning key criteria

of education and didactic principles on structure, processes, and objectives of diabetes education at diagnosis ('survival skills') and follow-up ('secondary continuing educational curriculum'). The ISPAD Clinical Practice Recommendations (2009) define well-structured education programs according to four key criteria: a qualified program (i) has a structured, agreed, written curriculum; (ii) uses trained educators; (iii) is quality assured, (iv) is audited. The author of the ISPAD guideline state:

Evaluation of educational programs 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 glycaemic control. The Multidisciplinary Diabetes Team is supposed to provide formal and content standards of education programs with a written adapted curriculum for several age ranges and duration of diabetes disease. The several modules contain models, strategies including the tasks of diabetes education and objectives of knowledge as well as skills for managing the diabetes of children, adolescents and their carers.

On this background the authors of preceding work-packages of SWEET on guidelines and professional education have summarized the current status of diabetes education for patients and their families as well as the training for the members of multidisciplinary pediatric teams. This reveals that even specialized pediatric diabetes centers such as the SWEET members are hardly able to realize ISPAD recommendations for structured and quality assured education. One of the important challenges was identified in the provision of structured age-appropriate and evaluated self-management education for patients, parents, other close relations, and teachers. Comparisons between the SWEET members' current healthcare professional training practices highlighted a great diversity of a multitude of different factors. A minority of countries had a well-established, highly organized approach to accredited training for all team members, e.g., Germany and Sweden, whereas the current situation of most of the other countries is less well defined. There were differences in the accrediting bodies, ranging from academic bodies and health systems to diabetes associations. This diversity and lack of standardization makes it a complex task to have transferable education concepts and qualifications across European borders.

Results of SWEET questionnaire on national/local education material

Pediatric centers from 11 European SWEET – members (Czech Republic (CZ), France (FR), Germany (GE), Greece (GR), Italy (IT), Luxembourg

(LUX), Poland (POL), Portugal (POR), Romania (RO), Sweden (SW), and United Kingdom (UK) responded to the questionnaire and reported about local education materials. These consisted mainly of books, booklets, picture folders, leaflets, journals, DVDs, references to websites, games or cards and devices for practical skills training. Almost all education materials and tools are available in the national languages, in Luxembourg bilingual in German and French. In 9 of the 11 responding countries material and tools in English language are also provided to parents and HCPs. In addition, some of the French education tools are translated into Arab.

Education tools for children younger than 5 yr. Specific education materials for the youngest children (<5 yr) are available in nine of the responding European countries, e.g., education films, colorful booklets, and picture books. The chronic disease and the therapy are explained age appropriately on a simple basic level. All materials stress the importance of parents' or HCPs' support. In most cases the materials are designated also for preschool children 5–6 yr old. Because of the limited cognitive maturity and responsibility of this younger age group, a proper evaluation of this type of education is most difficult. The main objectives of these tools are to reduce children's fears and to support their acceptance that the daily therapy is managed by their parents. Accordingly no published data on any outcome measure or efficacy of these tools could be identified. Currently no material for this age group is evaluated and/or certified as part of a structured education program. Nevertheless, the SWEET members explicitly agree on the notion that even these young children should be informed about their disease and therapy appropriately.

The materials and tools are mainly published and distributed free of charge to the families by pharmaceutical companies or National Diabetes Associations (CZ, FR, GE, GR, IT, LUX, PO, SW, UK). The booklet of Luxembourg is especially addressed to children from 2 to 6 yr and their parents in two languages (French and German). In this booklet parents get ideas on how they can playfully explain diabetes to their children (21). One other education tool is a child appropriate and colorful animated video cartoon (DVD) that is easy to understand even by young children with diabetes (CZ). It is provided for basic diabetes education in combination with the ring binder 'My diabetic first diary.' (22).

Education tools for preschool children (5–6 yr). In nine countries, age-specific education materials and tools are available for these preschool children. In 8 of 10 countries the education material and tools

focus on age appropriate information on diabetes and diabetes treatment at onset. For example, books, booklets, websites, or videos with basic information on type 1 diabetes therapy were developed. The essentials are simply explained focussing on pictures, fancy, or real-life stories. All these materials suppose parents' or HCP support in explaining the disease and the necessity of therapy. In most cases, the materials are developed not only for children 5–6 yr but for the primary school children as well. The cognitive maturity of this age group impedes a structured evaluation of this type of education. In most of the countries the materials and tools are not evaluated or certified as part of a structured education program. The majority of the materials and tools are provided free of charge to the families by pharmaceutical companies or National Diabetes Associations (CZ, FR, GE, GR, LUX, IT, PO, SW, UK). In all European SWEET countries, there is a high agreement that preschoolers are able to acquire some basic information and competences in diabetes treatment. To prepare preschoolers about to start primary school a unique structured 2-d training curriculum 'Fit for school' was developed and evaluated in Germany for this subgroup (23).

Education tools for children 7–9 yr. In all countries participating in this survey age-specific materials and tools are available for primary school children. Most of them focus on simple basic information, e.g., about etiology, symptoms, insulin therapy, hypo- and hyperglycemia, nutrition, carb counting and blood glucose self measurement according to the ISPAD 'survival skills'. The books, booklets, leaflets, games and websites, or videos differ widely in comprehensiveness. While in some countries CSII and MDI are standards of insulin therapy and education (CZ, GE, PO, LUX, SW), in other countries the focus of therapy is on a conventional insulin regimen with two or three injections per day. Furthermore, some books or booklets impart primary knowledge while other structured programs and curricula support emotional coping, self-management, and practical problem solving skills via group sessions. Beyond this, CSII manufacturer provide creative child-appropriate information about their devices, e.g., DVDs, storybooks, booklets, and games.

The education for primary school children is supposed to be evaluated according to knowledge, practical skills, quality of life, and metabolic control. Currently, there are published data on the acceptance and efficacy of one structured education program and a corresponding book in one country (GE) (24, 10). "Les CAHIERS de l'AJD" includes a book and a comprehensive website for education at onset of diabetes type 1 with the basic information about

diabetes therapy and care in French (25). It is based on a structured curriculum (26). In two countries, the programs and materials are nationwide certified (FR and GE). Both programs include written curricula with age-appropriate materials and tools. In the other European countries, the materials and tools are not yet evaluated and/or certified as part of a structured education program. Most of the tools mentioned above are provided by pharmaceutical companies or National Diabetes Associations free of charge for the families (CZ, FR, GR, IT, LUX, POL, POR, RO, SW, UK). Other material is reimbursed by the Health Insurance Companies as part of a qualified education course (GE).

Education tools for children 9–12 yr. All of the participating countries are reporting of age-specific education material for secondary school children, e.g., textbooks, colorful books with stories, online computer games, websites, booklets, DVDs, journals, and games including basic information about type 1 diabetes. The education resources are knowledge-centered and focus on techniques of insulin therapy (CSII and MDI), blood glucose self measurement, coping with hypoglycemia, healthy eating and carb counting. Four countries provide their age appropriate structured written material with a stepwise adjusted curriculum (FR, GE, LUX, SW). There are published data on the acceptance and efficacy of these tools in one country (GE). In the other countries, the material and tools are not yet certified as part of a structured education program. One education program is nationally certified for children 8 to 14 yr old and their parents including pump therapy (FR).

The majority of the material and tools is provided by pharmaceutical companies or National Diabetes Associations (CZ, FR, GR, IT, LUX, POL, POR, SW, UK). The structured treatment and education program for children with type 1 diabetes (GE) was certified by the German Diabetes Association and by the Federal Social Insurance Office (BVA) and is reimbursed by all of the German Health Insurance Companies.

Education tools for adolescents 13–18 yr. All SWEET members reported of having several education materials and tools for these young people with diabetes in their country. The books and other tools are mainly information documents [websites, booklets, leaflets, videos, journals, and games (cards, online)] providing essential basic information about type 1 diabetes. On top of this, special information and workbooks for pump users are available in Czech, English, Polish, Swedish, and German language.

Three countries are providing several age-appropriate education material and tools as part of a

national curriculum of a structured education program. Two of these countries are using nationally certified structured education programs (FR, GE). One of these national education programs is scientifically evaluated in a multicenter study (27). Data on the acceptance and efficacy of this material and the structured courses are published (28). The most comprehensive programs include all topics mentioned in the ISPAD secondary continuing education curriculum. In addition training of social competence, self-management skills, aspects of social integration and psychological advice are integrated in a didactic manual captured on a CD-ROM (29).

Summary of published patient education programs and tools

In all of the European countries participating in the SWEET project there is educational material for children and adolescents with diabetes (examples are shown in Fig. 1; details and access: www.sweet-project.eu). While some are developed for specific age groups and patients' needs others address all young people without differentiating according to cognitive maturity and developmental tasks. In some countries there are several leaflets with basic survival information, in others comprehensive books and curricula for education courses have been developed. In the majority of European countries participating in this survey, structured, age-appropriate and evaluated programs, and curricula as recommended by ISPAD and other guidelines are still missing. Thus, the working group came up with the following recommendations for Centres of Reference regarding the education of children and adolescents.

Recommendations on child and adolescent education for centres of reference

- For children and young people developmental maturity appropriate material, tools, and a structured curriculum (program) according to the different age groups should be developed and provided at diabetes onset and regularly as follow-up education.
- The programs have to cover all types of insulin therapy, especially intensified insulin therapy with pens (MDI) or insulin pump (CSII).
- The programs have to cover all survival skills in an age appropriate manner. They have to focus on knowledge as well as on practical skills and on successful age-appropriate psychosocial coping with the disease in everyday life.
- The programs for the young people have to be adapted to the programs for parent and caregiver education.



Fig. 1. Examples of education programs and tools in different European countries.

- All members of the pediatric diabetes team should be trained to use the programs adequately and to give structured – but individualized - education to children and their families.
- On the long run, the programs should be evaluated according to feasibility, acceptance and satisfaction of patients and to metabolic and psychosocial outcome parameters in longitudinal studies.

Education material for parents of children and adolescents with diabetes

In all responding SWEET centers several education material and tools for parents and other primary caregivers are available: mainly books, a diversity of booklets, colorful and creative brochures, leaflets, journals, DVDs, or websites. The material and tools focus on essential information about diabetes at onset. Most of the education material is not specifically aimed at parents but for older children, young people, and HCPs also. Age specific topics on child care and family life and parental tasks are included as separate chapters in some of the programs. Table 1 summarizes the main educational tools for parents recommended by the SWEET teams of 11 countries.

The majority of these tools are independent from a proper structured curriculum or holistic education programs. In two countries, the educational material for parents is part of a structured education program (FR, GE). One of the two countries provides a treatment and education program and training courses for parents. The comprehensive textbook is a medical and psychological guide for parents and also a stepwise written curriculum for 30h training course at disease

onset (30). Data from a multicenter study on the acceptance and effectiveness of this education program and material are published (31).

Beyond this a variety of printed information on healthy eating, carb counting, cooking, insulin therapy adjustment, hypoglycemia, DKA, and many aspects of everyday life with diabetes are provided free of charge by pharmaceutical companies or National Diabetes Associations (CZ, FR, GE, GR, IT, LUX, POL, POR, RO, SW, UK) or available in bookstores. Despite the availability of various printed information for parents of children or adolescents with diabetes in nearly every European country participating in this survey, structured, age-appropriate, and evaluated comprehensive programs as recommended by ISPAD and other guidelines are still missing in the majority countries. Likewise, the financing of these services of the pediatric diabetes teams in many countries is unclear. Thus, the working group came up with the following recommendations for Centres of Reference regarding the education of parents.

Recommendations on parent education for centres of reference

- For parents of children with type 1 diabetes appropriate material, tools and a structured curriculum (program) according to the different parental tasks should be developed and provided at diabetes onset and regularly as follow-up education.
- The programs have to follow the developmental maturity of the children, their developmental tasks and their competences, and limitation of self management.

Table 1. Comprehensive education material for parents of children with diabetes in European languages recommended by the SWEET members

Czech Republic

Lebl J, et al. Abeceda diabetu (ABC of Diabetes), 3rd edn. Praha: Maxdorf, 2008: 1–184.

Lebl J, Burgerová R. Velká diaknička o jídle (Big Book About Eating with Diabetes), 4th edn. Foundation “Children with Diabetes”, 2009: 1–54.

France

Les DOSSIERS de l’AJD (book) is an advice for young people and their parents managing their diabetes (parents of children with diabetes 5–18 yr). (<http://www.ajd-educ.org>)

The education material is nationally certified and evaluated. The structured education material includes an age appropriate pedagogic sequences: Les CAHIERS de l’AJD (book).

Germany

Hürter P, von Schütz, Lange K. Kinder und Jugendliche mit Diabetes: Medizinischer und psychologischer Ratgeber.

(Children and Adolescents with Diabetes: Medical and Psychological Guide), 3rd edn. Heidelberg: Springer, 2011: 1–384.

A comprehensive textbook with medical and psychological advice. The structured treatment and education program with a curriculum for parents is nationally evaluated and data are published (31).

Greece

Gika H, Thymelli I. Νεανικός Διαβήτης. Ποιος είναι αυτός ο νέος συγκάτοικος της ζωής μου. (Diabetes in the Youth. Who is the New Roommate in My Life?) Athens: AGIRA, 2005: 1–159.

Gerasimidi-Vazeou A, et al. Οδηγός διατροφής για τη ρύθμιση του διαβήτη (Nutritional Guide for Diabetes) Athens: Anathesis Creative Publications, 2008: 1–208 (www.ede.gr/public/)

Italy

There are some individual booklets developed by specific pediatric diabetes centers for parents, (e.g., Centro di Riferimento Regionale per la Diabetologia Pediatrica, Università e USSL 20 di Verona).

Luxembourg

Association Luxembourgeoise du Diabète (ed.) The Treatment of my diabetes. (3 booklets). Luxembourg: Association Luxembourgeoise du Diabète, 2012: each booklet 1–158.

The booklets are addressed to children and their parents from 2 to 6 yr, 7 to 12 yr, and 13 to 18 yr in French and German language (www.adl.lu).

Poland

Noczyńska A. Wiadomości o cukrzycy typu 1. (News About Type 1 Diabetes). Opole: Almamedia Press, 2010: 1–198.

Noczyńska A. Edukacja w cukrzycy typu 1. (Diabetes Education Type 1). Gdansk: Via Medica, 2009: 1–108.

Szypowska A, Lipka M, Prochner-Czaplińska M, Trippenbach-Dulska H. Mam cukrzycę typu 1. Poradni dla pacjenta i jego rodziny. (I have Type 1 Diabetes. Guide for Patients and Their Families. Published by Bayer Company. www.bayerdiabetes.pl)

Hanas R. Cukrzyca typu 1 u dzieci młodzieży I dorosłych. [Type 1 Diabetes in Children, Adolescents and Adults: How to Become an Expert on Your Own Diabetes]. London: Class Publishing, 2008: 1–400.

Portugal

On the website of the portuguese patient organization (Associação Protectora dos Diabéticos de Portugal) several material and information for parents are available www.apdp.pt/

Romania

Serban V. Diabetul zaharat tip 1 al copilului si tanarului. Ghid Practic (Type 1 Diabetes Mellitus in Children and Young People. A Practical Guide.). Timisoara: Brumar, 2007, 1–120.

Sweden

Hanas R. Type 1 Diabetes in Children, Adolescents and Young Adults: How to Become an Expert on Your Own Diabetes, 5th edn. London: Class Publishing, 2012: 1–400.

Dahlqvist G. Diabetes hos barn och unga. [Diabetes in Children and Adolescents.] Gothia: Bauer bok, Växjö, 2008: 1–84.

UK

Cook E., ed. Tots to teens – a parent’s complete guide to diabetes. London: Diabetes UK, 2009: 1–71.

Further brochures, videos (“Type 1 diabetes: journey of a life time”) and other printed information on www.diabetes.org.uk

- The programs have to cover all types of insulin therapy, especially intensified insulin therapy with pens (MDI) or insulin pump (CSII).
- The programs have to cover all survival skills and on knowledge as well as on practical skills and on successful age appropriate coping with the disease in the family.
- The programs for the parents have to be adapted to the programs for children and adolescents.
- All members of the pediatric diabetes team should be trained to use the programs adequately and to give structured – but individualized - education to parents and other primary caregivers.
- On the long run the programs should be evaluated according to feasibility, acceptance, and satisfaction of parents and to metabolic and psychosocial outcome parameters of the children in longitudinal studies.

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Education material for other close relationships of patients

Nine countries are reporting about education material and tools for other close relationships, e.g., siblings or grandparents, of children with diabetes. In most instances the material and tools are the same as for young patients or parents, e.g., books, booklets, brochures, leaflets, handouts, DVDs, and web-based material (see above). In one country a structured education material for grandparents was developed (FR). The curriculum is specially aimed at grandparents of children up to 12 yr. The program is nationally certified and evaluated (26). Siblings of children with diabetes are often invited to participate in education courses together with their newly diagnosed sister or brother. Thus, the working group came up with the following recommendations for Centres of Reference regarding the education of close relatives.

Recommendations for centres of reference

- Family members like siblings or grandparents should be invited to education courses for children with diabetes or their parents.
- The programs and materials for these groups should focus on their special needs while caring for the child with diabetes.

Educational material for teachers in nursery and school

In 10 European participating countries education material for nurseries and teachers is applicable, in 8 of them the material and tools are specifically developed for nurseries and teachers. There is a lot of printed or web-based material primarily focused on provision of basic knowledge on care, e.g., booklets, brochures, papers, or DVD are applicable with general information about diabetes at diagnosis, treatment, and advice for help at acute complication or in case of emergency. The content of the information material depends on the countries' legal (insurance) situation of diabetes care in school and nursery.

Most of the tools are provided by pharmaceutical companies or National Diabetes Associations (CZ, FR, GE, GR, LUX, IT, POL, POR, SW, UK). In Germany, for example, a DVD in combination with a booklet was developed by the pediatric diabetes association (AGPD) with real-life examples of young children with diabetes in school, information on the legal background of diabetes care in school, and experiences of teachers. The DVD also includes videos for a lesson about diabetes in primary and secondary school (32). Currently, there are no data published

on the acceptance and effects of any of this material and tools. Thus, the working group came up with the following recommendations for Centres of Reference regarding the children in school and kindergarden.

Recommendations for education of teachers in nursery and school

- Children with diabetes have to be supported by teachers and classmates. Diabetes education has to prepare them to successfully talk about their diabetes in school and ask for help in case of emergency.
- Teachers in school and nursery need comprehensive diabetes information to support children with diabetes age appropriately. If parents are not able to inform the teachers adequately, a member of the diabetes team should be able to educate these teachers.
- Information material for teachers should support the social integration of children with diabetes, prevent stigmatization, and motivate teachers to assist children in the management of their diabetes therapy in school.

Education material for HCPs

All SWEET members reported of education material and tools for HCPs in their country. In some countries (FR, GE, GR, IT, LUX, POL, POR, ROM, SW, UK) education material or tools for HCP are the same as for parents (Table 1). Other countries propose comprehensive textbooks in local languages [CZ (33), GE (34)] or provide national evidence based guidelines with detailed curricula for different age groups and parents (14). Beyond these all SWEET members refer to the curricula published in the ISPAD Clinical Practice Recommendations on pediatric diabetes education (1).

In contrast to the recommendations for the education of professionals, only few printed materials, instructions, or curricula on the process of education (didactics, practice of education, and psychosocial care) of HCPs are published in the SWEET countries included in the present survey. As described in detail elsewhere in this supplement, the majority of HCPs does not have a standardized training in pediatric diabetes education. The lack of standardization may result in team members not cooperating as a cohesive integrated multidisciplinary diabetes team. Structured age-adjusted curricula for HCPs are provided only in two countries (FR, GE). Nationally accredited training courses are delivered to all members of the diabetes teams in Germany. They contain knowledge, skills, and competences required to use the accredited programs effectively. The courses are mandatory for reimbursement of education and certified by the

National Diabetes Association and Federal Insurance Office. Thus, the working group came up with the following recommendations for Centres of Reference regarding the education of HCPs.

Recommendations for education tools for HCPs

- Many European countries lack of structured accredited programs for the multidisciplinary diabetes teams. Defined core and full curricula that can be delivered to all team members should urgently be developed.
- Existing training courses for HCPs educating children and their families should be quality assured and accredited nationally.
- As funding or facilities for training are not available in the majority of countries structures to sufficiently fund the education of the educators should be aimed for on a European scale.

Other significant tools for education

All European centers recommended several practical tools and materials that are meaningful to educate young patients with diabetes and their parents. Some of them are independent of languages, e.g., devices or soft toys; others focus on local food or national legislation, e.g., information on driving license, social help or diabetes care in school. The tools summarized in Table 2 are recommended by the members of pediatric diabetes teams for practical everyday life oriented training (details and access: www.sweet-project.org). On the long run, these useful and close to the everyday life material should to be integrated into structured curricula for all age-groups and carers of children with diabetes.

Tools for psychological screening

The ISPAD Consensus Guidelines 2000 (35) stated that ‘psychosocial factors are the most important influences affecting the care and management of diabetes’. On this background Delamater in ISPAD Clinical Practice Recommendations for psychological care of children and adolescents with diabetes (36) stated three general recommendations:

- (i) Social workers and psychologists should be part of the interdisciplinary healthcare team.
- (ii) Overt psychological problems in young persons or family members should receive support from the diabetes care team and expert attention from mental health professionals.
- (iii) The diabetes care team should receive training in the recognition, identification, and provision

of information and counseling on psychosocial problems related to diabetes.

As a consequence, standardized assessment of the developmental progress in all domains of quality of life (e.g., physical, intellectual, academic, emotional and social development) should be conducted on a routine basis. Psychosocial adjustment problems, depression, eating disorders, and other psychiatric disorders should be identified as early as possible by structured qualified assessments. Finally, the interdisciplinary team should aim to provide an assessment of general and diabetes-related functioning (communication, parental involvement, and burden of disease). As basic elements of the SWEET toolbox some selected validated psychometric instruments are proposed by the SWEET members (Table 3).

While some of these questionnaires are linguistically translated and validated in several European languages, e.g., the KIDSCREEN and PedsQLTM instruments, others are only available in English or some single languages. To better harmonize the evaluation of psychosocial care for children and adolescents in Europe some psychometric core instruments should be selected and linguistically translated into the languages of all SWEET members. In the future these instruments can be used to compare important psychosocial outcome parameters such as quality of life, psychological health, behavioral difficulties, treatment satisfaction or burden of diabetes in everyday life between pediatric diabetes centers.

Discussion

The survey among the SWEET members and the literature and website search revealed an impressive number of creative tools and materials for educating children of different age groups, adolescents and their families in European countries in daily diabetes management. While the materials teaching the principles of insulin therapy differ only slightly between the centers, tools, and tables with information on healthy eating, nutritional aspects and carbohydrate counting are more diverse reflecting country-specific cultural aspects. This diversity is even greater if it comes to information on legal aspects such as driving license issues, career choices, social services and access to medical care or devices for diabetes treatment. These are difficult to be standardized among the SWEET members. Although the survey was limited to a small number of specialized pediatric diabetes centers from 11 European countries it can be assumed that almost all nationally accredited and qualified education programs and concepts were mentioned by these experienced local teams. In contrast, local activities of single centers may not be included in the present paper.

Table 2. Tools and devices for practical skill education, patient-centred training, and psychosocial support of families recommended by the SWEET members for centres of reference

Nutrition advice and carb counting.

- Carbohydrate exchange lists (booklets, tables, software, apps).
- Lists of ingredients of convenience products (websites of manufactures).
- Lists of protein, fat, and carbohydrates of local food.
- Realistic photos of local meals (games).
- Games (cards, computer) for estimating carbs.
- Kitchen scale to train to reliably estimate carbs.
- Packages of local food with detailed information on ingredients.

Insulin substitution and (blood) glucose measurement.

- All devices for training (different syringes, pens, pumps, catheters, meters, sensors).
- Soft toys and special dolls for injection and catheter/sensor insertion.
- Stencils for systematically changing injection areas.
- Latex skin model with integrated 'lipoma'.
- Insulin curves (plastic models) to illustrate the effects of different insulins.
- Bolus and basal insulin calculator (tables, devices, and software for pumps and meters).
- Log books, diaries, software to collect blood glucose data systematically.

Prevention of acute complication.

- ID-cards, necklaces with information on first aid.
- Hypo-boxes with glucose.
- Glucagon kits.
- Printed information on hypos and first aid for trainers and teachers.
- Printed short instruction to manage DKA securely.
- Printed information on alcohol consumption and diabetes.

Social integration and psychosocial advice.

- Conversation Map™ education tool as basis for sharing experiences among families and interests-centered education.
 - Comprehensive brochure and/or videos for teachers and caregivers about diabetes and help at acute complications.
 - Printed information or websites on national social rights and financial aid for families of a child with a chronic disease.
 - Printed information on national legislation (driving license, health insurance, occupation for young people with diabetes).
 - Printed information on traveling world wide with diabetes (legal aspects, insurances, insulin, and devices during flights).
 - Information on patient organizations (websites).
 - References to national/local diabetes-journals for children, adolescents, and parents.
 - Printed information on access to local social and psychological advice.
-

But it's unlikely that these tools or programs are scientifically evaluated or nationally accredited because no published data was retrieved.

Compared to the high quality standards claimed in national and international guidelines (1, 12, 14, 18, 19) on diabetes care and education only a minority of countries offer comprehensive and well-coordinated education structures. Program development and on-going funding is usually not provided by the respective national healthcare systems. As described in the other reports of SWEET work packages there is a significant lack of evaluated concepts of education that are integrated into holistic care of young people with type 1 diabetes in the majority of European countries. Furthermore, there is a lack of quality assured education of the multidisciplinary pediatric team members on introducing such programs and tools to patients and caregivers. Adequate concepts of education for educators need to be developed based on proven experience already available in some European countries. They need to be adapted to specific cultural and regional characteristics but generally harmonized among the European healthcare systems to allow cross-border healthcare when needed.

Our evaluation of education programs and tools revealed another scientific challenge evaluating these approaches. Classical RCT double-blind methodologies are most difficult to apply on tools and concepts that are an indispensable part of qualified integrated diabetes care as they focus on individualized team-family communication (2, 4, 37). Well-designed longitudinal observational studies that address patients' and parents' satisfaction, quality of life, burden of disease, social integration, and metabolic control should be considered as alternative methodological approaches on an European level. Harmonizing, translating into local languages and integrating proven education programs into quality assured structured holistic education concepts will be an important future task for the SWEET project. The SWEET project wishes to invite all those involved in pediatric diabetes education to join forces to cooperate in this network.

Many of the small, but effective and proven tools collected in Table 2 are professionally designed, produced, and distributed free of charge by pharmaceutical companies. Also the majority of qualified education programs wouldn't have been developed

Table 3. Selected psychological screening instruments and questionnaires for children, adolescents and parents (recommended by the SWEET members)

Generic quality of life

KIDSCREEN Instruments child report/proxy report/translated into several European languages; <http://www.kidscreen.de>
The PedsQL Instruments child report/proxy report/translated into several European languages; <http://www.pedsql.org/>

Disease-specific quality of life

DISABKIDS Diabetes Module (DM) child report/proxy report/translated into several European languages;
<http://www.disabkids.de/>

The PedsQL Condition-Specific Modules/diabetes child report/proxy report/translated into several European languages;
<http://www.pedsql.org/>

DQOLY-SF 2006: Hoey H, McGee HM, Skinner TC, Skovlund SE – translated into several European languages;
www.dawnstudy.com

Burden of diabetes

Hood K, Butler D, Anderson B, Laffel L. Diabetes family conflict scale (updated and revised). *Diabetes Care* 2007; 30: 1764–1769.

de Wit et al. MY-Q, 2009. www.dawnstudy.com

Polonsky. PAID (Problem areas in diabetes questionnaire) (www.dawnstudy.com) adolescents and adults, 1995.

Markowitz et al. PAID-PR (Problem Areas in Diabetes Survey – parent revised version). *Diabetic Medicine* 2012; 29: 526–530.

Gonder-Frederick et al. Hypoglycaemia Fear Survey, HFS-II. *Diabetes Care* 2011; 34: 801–806.

Behavior and emotional problems in children

Goodman. SDQ (Strengths & Difficulties Questionnaires), 1997. (available from <http://www.sdqinfo.com/>)

Achenbach. CBCL (Child Behavior Checklists), 2012. (available from <http://www.aseba.org/>)

Screening instruments for psychological well-being and disorders

Morgan JF, Reid F & Lacey JH. The SCOFF questionnaire: screening tool for eating disorders. *BMJ* 1999; 319: 1467.

Markowitz JT et al. Diabetes Eating Problem Survey (DEPS-R). *Diabetes Care* 2010; 33: 495–500.

Beck JS, Beck AT, & Jolly JB. Beck Depression Inventory for Youth (BDI-Y), 2001.

Kovacs M. Child Depression Inventory 2 (CDI 2), 2011.

Lang M, Tischer M. Children's Depression Scale (CDS), 3rd edn. Acer Press, 2004.

Bech P. WHO-Five Well-being Index (WHO-5), 2004. <http://www.who-5.org> Screening for emotional well-being and depression in parents and adolescents.

Kroenke K et al. Patient Health Questionnaire (PHQ). The Patient Health Questionnaire Somatic, Anxiety, and Depressive Symptom Scales: a systematic review. *General Hospital Psychiatry* 2009; 32: 345–359.

and evaluated without the generous funding by these companies. In contrast, nearly no funding of this central part of pediatric diabetes therapy is supported by national or European healthcare authorities or insurance companies. This introduces a potential bias in the information given and needs to be publicly addressed when discussing National Diabetes plans that are currently under development in most European countries. New concepts of independent sourcing of quality assured diabetes education for all children and adolescents affected in Europe should become another mid- to long-term goal of the SWEET initiative toward improving the equality and access to modern pediatric diabetes care across the continent.

Conflict of interest

The authors declare no conflict of interest.

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