

Original Article

Recommendations for age-appropriate education of children and adolescents with diabetes and their parents in the European Union

Martin D, Lange K, Sima A, Kownatka D, Skovlund S, Danne T, on behalf of the SWEET group, Robert J-J. Recommendations for age-appropriate education of children and adolescents with diabetes and their parents in the European Union.

Pediatric Diabetes 2012; 13 (Suppl. 16): 20–28.

Education is the keystone of diabetes care, and structured self-management education is the key to a successful outcome. Existing guidelines provide comprehensive guidance on the various aspects of education and offer general and organizational principles of education, detailed curricula at different ages and stages of diabetes, and recommendations on models, methods, and tools to attain educative objectives. The International Society for Pediatric and Adolescent Diabetes guidelines give the most elaborate and detailed descriptions and recommendations on the practice of education, which other national guidelines address on specific aspects of education and care. The aim of the work package on education developed by Better Control in Paediatric and Adolescent Diabetes in the European Union: Working to Create Centers of Reference (SWEET) project was not to generate new guidelines but to evaluate how the existing guidelines were implemented in some pediatric diabetes reference centers. The SWEET members have completed a questionnaire that elaborates on the many aspects of delivery of education. This survey highlights a profound diversity of practices across centers in Europe, in terms of organization as well as the practices and the content of initial and continuing education. A toolbox is being developed within SWEET to facilitate exchanges on all aspects of education and to establish a process of validation of materials, tools, written structured age-adjusted programs, and evaluation procedures for the education of children and adolescents with diabetes.

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Key words: education – guidelines – recommendations – SWEET – type 1 diabetes

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Submitted 5 April 2012. Accepted for publication 16 April 2012

The SWEET Project was established to raise the standards of care for children and young people with diabetes throughout the European Union. Several work packages have been established in order to identify the current situation pertaining to diabetes care, the current delivery of education to patients and families and of training to healthcare professionals, and establish criteria for Centers of Reference.

Guidelines in the field of pediatric diabetes, which have been published by International Society for Pediatric and Adolescent Diabetes (ISPAD) (1), the Australian Paediatric Endocrine Group (2), the National Institute for Clinical Excellence, UK (NICE) (3), the American Diabetes Association (4), and the German Diabetes Association (5), and other publications that provide useful insights on diabetes education (6–9), have been used as references to elaborate the evaluation of practices and recommendations on education in children and adolescents with diabetes.

These guidelines, which are evidence-based and referenced, provide general and organizational principles of education, detailed curricula at different ages and stages of diabetes, and recommendations on models, methods, and tools to attain educative objectives for children and adolescents with diabetes, but their similarities and differences deserve further evaluation and exploration. The ISPAD Guidelines (1) include a chapter ‘diabetes education’ with elaborate descriptions and recommendations on the practice of education in childhood diabetes. The NICE Guidelines (3) are often inspired by the ISPAD Guidelines 2000, some almost literally (universal principles of education, initial and continuing curriculum), but their specificity is the in-depth discussion on the evidence bases and on patients’ consultations giving a critical point of view on education practices (in-hospital/ambulatory care, education at diagnosis, and multidisciplinary healthcare team). The German Guidelines (5) propose recommendations on structured and age/diabetes duration appropriate education, evaluated education programs for initial in-patient and follow-up out-patient education, and structured trainings for educators on diabetes care, child psychology, and pedagogics. The Australasian Guidelines (2) have a very detailed chapter on diabetes camps and some other parts on education practices. The IDF Youth Charter and the DAWN Youth Call to Action (10, 11) highlight the critical importance of full integration of psychological and social aspects in pediatric diabetes care and education. Indeed, education should be referred to as an *ongoing* process of provision of individualized self-management and psychosocial support.

These various documents are a comprehensive guide to the various aspects of education in children and

adolescents with diabetes. They complement each other, and in many places they may overlap but they do not satisfy the needs of pediatric healthcare professionals for more practical guidance regarding the question: what are the most effective strategies and resources for the provision of initial and ongoing self-management education and support? Therefore, the aim of the SWEET work package on education was not to reformulate recommendations that already exist but to evaluate the real-life implementation of the existing guidelines in some European pediatric diabetes centers. Our approach has been to question the members of the SWEET program on the many aspects of education contained in the guidelines. The ISPAD Guidelines, which are very comprehensive, very recent, and based on an international consensus of clinical practice, have been used as the main reference for this evaluation.

SWEET survey on diabetes education for children, adolescents, and families

The data presented here were obtained by means of a questionnaire, aimed at giving some insight of the practices in diabetes education offered to children, adolescents, and their families, in European pediatric diabetes reference centers. The questionnaire was developed and validated by members of the SWEET working group, and it focuses on (i) the interdisciplinary team involved in care and education; (ii) the organization of education (settings: hospital/ambulatory; modalities: face-to-face/group; and location); (iii) the practices of education (definition, guidelines, model, strategies, and curricula); (iv) the materials, tools, and published and evaluated programs; and (v) the structure of on-going education at diabetes onset and follow-up.

The questionnaire was sent to 14 centers participating in the SWEET project. All are among the leading centers in their respective countries, with more than 400 pediatric patients with type 1 diabetes ($n = 10$), two centers with 250–400 patients and two centers with 150–250 patients in continuous care. In contrast to the survey utilized for other SWEET work packages, the questionnaire on education was not disseminated to centers or countries outside the SWEET core group. A wider diffusion of the survey through ISPAD was considered; however, the authors thought that this process would also lead to a complex self-selection of specialized pediatric diabetes centers from a wide range of settings, and it was judged that this would not guarantee that the survey results to be more reliable or representative. Thus, the figures that are presented here must only be considered as a picture of educative practices in a limited number of reference centers, possibly in optimal environments. Despite these limitations, the survey clearly shows the great diversity of

practices in education and highlights important challenges and opportunities in relation to implementation of the existing recommendations for diabetes education. The survey provides a foundation for improving future evaluation and sharing of educative practices and resources with the purpose of improving diabetes education for European children and adolescents with diabetes.

The interdisciplinary education team

Existing guidelines recommend that 'education should be provided by an appropriately trained (in childhood/adolescent diabetes) *interdisciplinary team* ...' (1, 2, 5), which 'should include, as a minimum, a diabetes specialist nurse and a dietician' (1) or 'the patient and his/her family; pediatric endocrinologist or physician trained in the care of children and adolescents with diabetes; diabetes educator; dietitian; and psychologist/social worker' (2, 5). The teams in the participating SWEET centers include: pediatric diabetologists/endocrinologists or pediatricians/MDs with special interest in diabetes; diabetes nurses specialized in pediatric diabetes (pediatric/adult practices in some centers); dietitians; and psychologists, sometimes psychiatrists; only two centers had a social worker.

The survey suggests that a psychologist should be a mandatory member in the SWEET reference centers. Conversely, only two centers had a social worker but considered his/her role as essential and not interchangeable with the psychologist's (2, 5). Thus, guidelines should emphasize the specific roles of each of the professionals involved, social workers being not just a help in the difficult practical tasks that families of new onset diabetic children or families of adolescents are confronted with, but 'a help to individuals, families, or groups who are experiencing difficulties, in order to help engender their social well-being, insertion, and autonomy,' and to manage complex social issues, which is crucial in a number of families for attaining optimal glycemic control. For the SWEET teams, the role of non-health professionals such as associations, teachers or play specialists, and peers (in camps) is common.

Another SWEET report describes the great disparities among centers in terms of the *numbers of health professionals* related to the number of patients, which some centers judged insufficient or poor, and it proposes recommendations on the minimum health professional to patient ratio required to deliver optimal care and education to young people with diabetes, their family, and other care givers.

The *child/adolescent with diabetes* (1–3, 5) is the center of the care and educative process and is an integral member of the team as well as *the family* (1–3, 5) and *other care providers* (1–3, 5). For the

SWEET members, children and parents are educated 'always' or 'most of time' at diagnosis and at follow-up (fathers not as regularly at follow-up). Siblings are included in the educative process in nearly all centers; grandparents and other family members in fewer centers. This highlights the crucial role played by family members in care and education; however, guidelines often do not name siblings as such and grandparents are only seldom mentioned (2). Most centers do education/training at school, some on a regular basis, while interventions in sports settings occur only occasionally.

Education organization and practices

The IDF International Standards for Diabetes Education (6) recommend that 'an *effective communication system* be implemented to ensure that information is shared with all team members and that all members of the team speak with one voice'. However, the communication between team members on patient education is mainly based on informal exchanges in nearly all the teams. Team meetings on diabetes education occur in about two thirds of them; files and patient's follow-up notebooks specific for patient education occur in about half. Structured training for the diabetes education team is implemented in two countries where evaluated programs were developed focusing on communication skills, practical training, and family support as well as self-management in diabetes therapy.

A 'protected environment conducive to learning' is important (1) and described precisely by the IDF International Standards for Diabetes Education (6), because 'the quality and availability of physical space and educational resources affect learning ...' (6). All SWEET centers have a specific *location for education*, but the available number of rooms/space for education varies enormously. Eight centers receive full or frequent support from their hospital for education, and a national governmental plan for diabetes education exists in only four countries.

ISPAD guidelines clearly distinguish educative objectives and methods for initial (at diagnosis) and continuing education: 'methods ... will depend on local experience and facilities'; preliminary education 'will be dominated initially by individual (family, in-hospital) teaching'; and 'continuing education will take place most often in an ambulatory setting'. Other guidelines discuss the 'controversy' (3) between *in-hospital and ambulatory settings* (2, 3). For the SWEET centers, education at diagnosis is mainly in-hospital: 5–12 d hospitalization ($n=9$) or 2–5 d plus consultations or home interventions ($n=2$). It is ambulatory in three centers: consultations, day care hospitalizations, and home interventions. 'Initial diabetes education is usually (face-to-face) with the

educator' (2, 5), often with group education in some centers, while continuing education is mainly practiced face-to-face in all centers, with structured group education in only half of them.

All centers use the *ISPAD Guidelines* as reference, along with some guidelines established by national committees or associations. They use a variety of *educative models, strategies, methods, and tools* as recommended (1, 10–14). The most commonly used educative models (by more than half the centers) are patient centered. They take into account the beliefs, conceptions, and representations of the patient, include psychosocial education strategies, such as family communication and coping support. Motivational interviewing and behavioral interventions that require specific educative and psychological skills are used by fewer centers. The SWEET centers use different methods, mostly interactive and a variety of materials or tools, with few differences between children and parents; the 'new technologies' are far behind the more traditional ones, paper, pictures, slides, questionnaires... (Table 1).

'Evaluation of educational programs is essential ...'

(1). Most SWEET centers use various methods to evaluate the patient's knowledge, skills, attitudes, quality of life, and satisfaction. However, fewer than half of the centers have a procedure for evaluation (parents and children) at the end of initial education; fewer than half submit their programs to audit, review, or regular modifications; only two centers evaluate the structure and the process (attendance or participation in study groups). The evaluation is most often informal, with very variable criteria, but all together the centers use eight different questionnaires (Table 1), mostly local but one is a nationally validated questionnaire of knowledge, and in one country psychosocial and physiological outcomes of programs for children, adolescents, and parents have been evaluated in nationwide multicenter long-term studies (15). Although limited, this picture suggests that even centers of reference have not fully integrated evaluation into the routine of diabetes education, and there appears to be room for improvement in terms of establishing common standards for such evaluation.

Education at diagnosis

No study has evaluated the *content of education programs* (3), but most guidelines list specific objectives for initial and continuing education (1, 3). Questions to the SWEET members have made it possible to compare their education programs to those recommendations. More than 80% of the educative objectives are covered in the programs for newly diagnosed diabetes in all centers, except one which includes only 7 of 19 ISPAD objectives in the initial education (Table 1). Some

objectives are not considered to be 'survival skills' by all respondents (Table 2). Conversely, more than 80% of the ISPAD Continuing Education objectives are part of the program for newly diagnosed patients in half the centers; fewer than half of the educative objectives (nine and five items from a total of 23) are covered in only two centers (Table 3). Overall, the number of both initial and continuing ISPAD objectives dispensed in initial education varies from 12 to 42, and six centers include more than 90% of the 42 items (Tables 2 and 3) in their program, which shows that initial education often covers much more than 'survival skills' (1).

The questions on some practical aspects of the *delivery of education at diagnosis* have shown that: children between 3 and 9 yr are included in the educative process; 12 centers have a written curriculum and/or schedule for initial education; and all centers have documents for parents, many of them for children (half age-adjusted, with 12 different documents for 6–18 yr old). The documents are often produced locally, but one was elaborated and validated by a National Pediatric Diabetes Association. The organization of initial education varies enormously: 2–12 d of education (<1 wk in half the centers), 4–14 sessions, 1–4 sessions per day, 4–20 educative hours, 0.8–4 h of education per day, and 0.7–4 h per session. Educative objectives seem to be the most consistent part of the educative organization, but they represent 1–8 objectives per hour (≥ 4 in six centers), 2–6 objectives per appointment, and 2–12 objectives per day. Such variability may depend on 'the child's or young person's age, maturity, culture, wishes, and existing knowledge within the family' (3), or on 'local experience and facilities' (1). This raises several questions: how can these activities be better evaluated? Do the educative objectives at diabetes onset correspond to ISPAD 'survival skills' (1) or do they need to be extended as in many of the SWEET centers? Should we recall that 'some young people with type 1 diabetes felt they were given too much information at the time of diagnosis' (3).

Continuing education

The keywords for continuing education in the ISPAD and other guidelines (1, 3, 5) are ambulatory, patient-centered, interactive, [with] new technologies, [in] groups, and eventually associations and camps. Responses from SWEET healthcare professionals show that an estimated 60–100% of patients attend continuing education programs. There are established curricula available for education at diagnosis, pump (all centers), insulin adjustment, diet and carbohydrate counting (CHO) ($n=13$), continuing education ($n=10$), annual age-specific education ($n=8$), transfer to adult team ($n=4$), and type 2

Table 1. Educative strategies/methods, educative materials, and evaluation tools

	For children/adolescents	For parents
Strategies/methods		
Practical works – technical handling	13	12
Sports (activity holidays)	13	
Oriented discussion	12	8
Shared experiences	11	10
Free discussion	11	9
Problem solving	11	9
Games	5	
Materials/Tools		
Brochures, handouts	9	11
Overhead, slides, powerpoint	8	9
Questionnaires	5	8
Picture folder	7	6
DVDs	5	3
Computer software	3	3
Games or cards	5	3
Evaluation		
Technical skills	11	One local grid One local and one national questionnaire for pump
Clinical outcomes	10	Parameters from e-files
Knowledge	10	One local questionnaire for pump One national validated questionnaire
Attitudes	9	One local questionnaire
Quality of life	8	Hvidoere SG; DAWN (rare in routine)
Educative needs	7	One education file
Behavior change	5	
Satisfaction	5	Hvidoere SG; one local questionnaire
Anxiety	5	Hvidoere SG

Number of SWEET centers using each method/material/tool (of those proposed in the questionnaire).

diabetes ($n = 5$). A detailed description of the content and organization of 24 different written structured group education programs (Table 4) has been reported by 10 centers (1–12 per center), covering many of the ISPAD educative objectives: 12 for ‘general’ children’s education (8 age-specific); 5 for pump treatment; 3 for school; and 4 for family members (parents of new patients, of children <5 yr, grandparents, and siblings). Most programs include the children and their parents. Descriptions of the programs include: recruitment of the participants; schedule of the programs (number/frequency of sessions); settings (ambulatory/in-hospital); and modalities (individual/group).

For the SWEET members, structured group education has many positive points including good attendance of children and parents; increasing knowledge; skillfulness; training; motivation; self-esteem and awareness on specific aspects of life with diabetes; progressive learning; age-appropriate language; contacts and interactions between patients; and less acute complications. However, there are barriers to developing and delivering such programs such as insufficient resources, a lack of time for professionals and parents or other care givers, low motivation in teenagers, difficulty accommodating very young children, creating age groups, suitable times

in which all participants can gather on the same day, and creating real-life conditions (gymnasium and swimming pool).

Guidelines provide a rather comprehensive coverage on *diabetes in camps* (1, 2, 5), and responses from the SWEET members show that diabetes camps are organized in 13 centers/countries, but their size and organization vary widely: 1–2 sessions per year (20–60 children) in seven centers (or countries); 2–5 sessions ($n = 100–200$) in four; 15 sessions ($n = 400$) in one country; and 27 sessions ($n = 1200$) in one country. Sessions last 2–7 d (eight centers); 1–2 wk ($n = 2$); and 2–3 wk ($n = 2$), and parents participate in six centers/countries. The camp staff includes 5–10 (<100 patients), 10–25 ($n = 100–200$), and 250 people ($n = 1200$). The SWEET centers are entirely or partly involved in the organization of camps, associations, societies, or parents in four cases. The camps are funded by different and often multiple contributors from ministries of health to parents, foundations, and industry.

Conclusions

The survey performed on education within the SWEET program was limited to a small number of specialized pediatric diabetes centers. Despite this

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Table 2. ISPAD 'primary (level 1) education. At diagnosis: survival skills'

1.	Explanation of how the diagnosis has been made and reasons of symptoms	13
2.	Simple explanation of the uncertain cause of diabetes. No cause for blame	13
3.	The need for immediate insulin and how it will work	14
4.	What is glucose	
	Normal blood glucose levels	14
	Glucose targets	13
5.	Practical skills	
	Insulin injections	13
	Blood testing	14
	Urine testing	13
	Reasons for monitoring	13
6.	Basic dietetic advice	14
7.	Simple explanation of hypoglycemia	13
	Simple explanation of hyperglycemia	13
8.	Diabetes during illnesses. Advice not to omit insulin – prevent diabetic ketoacidosis	13
9.	Diabetes at home or at school	11
	Including the effects of exercise	12
10.	Identity cards, necklets, bracelets, and other equipment	9
11.	Membership of a diabetes association and other available support services	11
12.	Psychological adjustment to the diagnosis	13
13.	Details of emergency telephone contacts	12

ISPAD, International Society for Pediatric and Adolescent Diabetes.

Number of SWEET centers using each ISPAD educative objective for the education of children and adolescents with newly diagnosed diabetes.

obvious limitations, the survey reveals a great diversity of educative practices across centers and countries. The wide range of educative approaches and issues identified in this survey was considered by the authors to provide a reasonable basis for attempting to further facilitate and harmonize educative practices. The survey reveals that even these very specialized and relatively well-resourced pediatric centers can hardly implement the existing recommendations for education. Limitations were seen even in relation to the very important aspects such as providing structured education programs and the systematic evaluation of programs.

The survey highlights the fact that the growing field of education, also referred to as therapeutic education or self-management education or support, is still a relatively young specialty area where local customs and cultural differences play a tremendous role in determining the preferred and optimal educational format and content. The inherent humanistic nature of education and its dependence on a range of cultural and individual factors appear to make harmonization more complex than when dealing with medical treatment guidelines and procedures.

Table 3. ISPAD 'secondary (level 2) continuing educational curriculum'

1.	Pathophysiology, epidemiology, classification, and metabolism	12
2.	Insulin secretion, action, and physiology	12
3.	Insulin injections, types, absorption, action profiles, variability, and adjustments	13
	Pump (used in two cases)	12
4.	Nutrition – Food plans	13
	Qualitative and quantitative advice on intake of carbohydrate, fat, proteins, and fiber	13
	Nutrition: coping with special events and eating out	11
	Growth and weight gain	9
	Diabetic foods, sweeteners, and drinks	13
5.	Monitoring, glycated hemoglobin	13
	Cleared (agreed) targets of control	10
6.	Hypoglycemia and its prevention, recognition, and management	14
	Hypoglycemia: glucagon	13
7.	Intercurrent illness, hyperglycemia, ketosis, and prevention of ketoacidosis	13
	Blood testing ketone	10
8.	Problem solving and adjustment to treatment	9
9.	Goal setting	9
10.	Micro- and macrovascular complications; prevention. Need for regular assessment	11
11.	Exercise, holiday planning, and travel	10
12.	Smoking, alcohol, and drugs	8
13.	School, college, employment, and driving vehicles	5
14.	Sexuality, contraception, pregnancy, and childbirth	4
15.	Updates on research	7

ISPAD, International Society for Pediatric and Adolescent Diabetes.

Number of SWEET centers using each specific ISPAD educative objective for the education of children and adolescents with newly diagnosed diabetes.

Overall, the survey provides an important new understanding of the breadth of educational approaches and tools used today in pediatric diabetes. Although we should be cautious about being too prescriptive in our recommendations regarding the use of particular techniques based on this survey, also considering the scarcity of unequivocal clinical evidence regarding differential effectiveness of the different educational approaches reported in the survey, the richness of the collected experience, information, and tools developed provide a remarkable opportunity for creating a toolbox of educative practices and resources that all pediatric centers in Europe should be able to benefit from. Such a toolbox can be supported by a general and culture-independent framework for education but should as a main purpose provide access to a range of proven resources, better practices, and educational tools that may suit the individual needs of different pediatric care teams to various extents whether it is in relation to improving the organization,

Table 4. Written structured education programs currently used in SWEET centers

General aim	Number	Specific objectives
Continuing education	3	ISPAD objectives, on demand; psychological support
	1	Re-motivation (individual or group)
	1	Annual check-up
Age-adjusted	7	Age-adjusted objectives:
		Age-adjusted ambulatory
		6–11 yr
		>11 yr
		5–6 yr group + parents
Insulin pump	3	Theory, practical skills, diet, exercise, and prevention of acute events
		Pump and physical activity
		Pump in newly diagnosed
School	3	Education and collaboration with the school staff
Diverse	4	Experience sharing and education in group:
		Parents of new patients
		Parents of <5 yr
		Siblings
		Grandparents: acquire skills to take children safely

ISPAD, International Society for Pediatric and Adolescent Diabetes.

quality assurance, delivery, or evaluation of diabetes self-management education.

International (ISPAD) and national guidelines emphasize the importance of on-going age-appropriate education for children and adolescents with diabetes and their families. Educational concepts covered in the guidelines include (i) detailed curricula and educative objectives for different age groups and stages of diabetes; (ii) organizational principles and recommendations for providing information and support; and (iii) recommendations on models, methods, and tools and evaluation of educative programs for different target groups. All SWEET centers agree in referring to the current ISPAD Guidelines (1), a recent international consensus with the most elaborated and detailed description and recommendations on education in relation to childhood diabetes.

Recommendations

National Guidelines should refer to the ISPAD Guidelines and add country-specific aspects to implement qualified education to all young people with diabetes and their families.

The role of the interdisciplinary team in care/education is fully recognized, and the SWEET survey has shown that:

- all the SWEET centers have care teams, which include a psychologist, rarely a social worker, and emphasize the importance of integrating psychosocial aspects in the process of education;

- the role of each member of the team is not always clearly identified;
- often the exchange of information within the team should be optimized;
- the child, the adolescent, and the parents are considered full members of the care/education team by the healthcare professionals;
- siblings, grandparents, the school staff, peers, and associations are also considered part of the care team for most centers.

Recommendations

The psychologist should be recognized as mandatory in the interdisciplinary team.

The specific role of each team member in care and education, particularly the psychologist and the social worker, should be clearly defined and evaluated.

A patient-centered psychosocial approach should be the foundation for all educational activities, including a well-structured approach for integrating psychosocial evaluation into standard care and the development of individualized self-management support plans.

Members of the team should be trained in communication, the principles and delivery of education, and in the psychosocial aspects of diabetes.

Siblings, grandparents, and the school staff should be part of the educative programs, and the role of other partners in care/education should be better considered and evaluated.

Specific recommendations should be established on the minimum requirements for optimal school integration and diabetes management (16, 17).

Lessons from the SWEET survey on organization and practices in education are the following:

- Education is mainly dispensed in-hospital, is seldom ambulatory, and experiences in group education are still rather limited.
- Not all SWEET centers consider the need to develop a specific location that is 'conducive to learning', nor do they receive local or national support to optimally develop education.
- A variety of educative models, strategies, methods, materials, and tools are used, but the use of new technologies and evaluation is still rather limited.

Concerning the content and programs for initial and continuing education:

- The guidelines define quite precisely the content of initial (at diagnosis) and continuing education, but the practice of initial education does not follow the guidelines in most SWEET centers.
- Individual experiences with structured written programs of education are still rather limited, but all SWEET centers have written documents for parents and children (some age-adjusted) and all the programs together present consistent material to make the development of educative activities feasible.

And for camps:

- Camps are recognized as important for the care and education of children and adolescents with diabetes, and their parents.
- Recommendations exist concerning the goals, principles, and the organization of camps, but their implementation is extremely variable between countries.

Recommendations

Guidelines should emphasize the need for support from governmental and local authorities to organize and develop patient education.

Existing recommendations on the contents of initial education should be evaluated. The question is whether current practices respond to the needs of the child/family at diagnosis and whether the wide range of psychosocial challenges is sufficiently integrated into current educational practices.

International procedures and/or studies should be developed:

- to better define the educative competencies/objectives at various ages or stages of diabetes;
- to facilitate exchanges and evaluate the numerous settings, models, methods, tools, and programs to dispense education (including camps);

- to validate tools for their evaluation.

Educative programs should be written, so that may be known and evaluated.

All children and adolescents with diabetes should be offered an individual needs assessment for self-management education and support on a regular basis. These should include assessment of knowledge, skills and behavior, as well as psychosocial factors such as quality of life, mental health, and support from family and school.

The SWEET toolbox will aim at collecting existing educative (and evaluation) tools and programs in order to help implement these recommendations.

Conflict of Interest

The authors declare no conflict of interest.

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