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Original Article

Harmonize care to optimize outcome in children and adolescents with diabetes mellitus: treatment recommendations in Europe

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Objective: Identify and evaluate current treatment recommendations in Europe for the care of children with diabetes in view of the European Union (EU) recommendations for Reference Centers.
Methods: A questionnaire was sent in 2008 to representatives of all EU countries and Norway, all known to be actively involved in pediatric diabetes care. Participants were asked whether specific guidelines were recommended and applied in their countries; when possible, they were invited to forward their national guidelines. As a second step, we evaluated the guideline mostly used in relationship to the recommendations of the EU.
Results: Information was obtained from all EU countries (including Scotland and Norway). National guidelines, as available, were forwarded for review. A 15/29 reported to use the International Society for Pediatric and Adolescent Diabetes (ISPAD) Clinical Practice Consensus Guidelines (CPCG), whereas 10 reported using national guidelines. These national guidelines were partly based on and/or compatible with ISPAD guidelines, but in most cases were far less detailed. The size and presentation differed (web based, booklet, page or chapter in adult guidelines). In four countries, no specific guidelines were used. As ISPAD CPCG were used most frequently, its content was evaluated within the EU Centres of Reference recommendations and minor changes were made in agreement with the ISPAD editor.
Discussion: Differences between guidelines may influence surveillance and quality of care in pediatric diabetes within Europe. Although a majority of countries is using or at least mentioning the ISPAD CPCG, their implementation as EU standard needs further endorsement. As language difficulties may hamper its implementation on a wider scale, further translation of the ISPAD guidelines should be endorsed to render it accessible to all healthcare professionals. With respect to the content, some changes were then made in agreement with the editors, adjusting them to the European context. For European Reference Centers, some further guidance on research may be included. Once implemented on an EU wide level, benchmarking of carefully defined robust quality of care and quality of life indicators will allow us to improve these guidelines on a regular basis ensuring an evidence-based care for all children with diabetes.

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Increased patient mobility, the request for cross border healthcare as well as the importance of patient's knowledge on quality and safety of the care, demands careful evaluation of the current situation and existing structures to care for children with diabetes in the different European Union (EU) countries. One of the recommendations to enhance EU wide collaboration and improve health care is the creation of European Reference Centres or European Reference Networks (1, 2). To facilitate further creation of reference centres for diabetes, a number of criteria were developed, which should be met by those European reference networks listed in Table 1 with the goal, of providing health professionals as well as patients within the EU access to high level, shared expertise in a given field. Although for a high level of expertise sufficient number of patients are requested, they must be able to obtain information in their own language near to where they live. This emphasises the need to balance any restriction in centre numbers to achieve a concentration of expertise against the need for local delivery of care.

The goal of the SWEET project is to harmonize care in an effort to optimize outcome in children and adolescents with diabetes mellitus. Differences have been identified throughout the EU, in access to care, the liability field, in the training of healthcare professionals, identification or recognition of reference centres and more as reported (3).

Use of a common treatment guideline may contribute to better harmonization in care.

Table 1. Criteria for a European Reference Centre (1)

- There should be sufficient activity and capacity to provide relevant services at a sustained level of quality.
- Each centre should be capable of providing expert advice, diagnosis or confirmation of diagnosis and, to produce and adhere to good practice guidelines and to implement outcome measures and quality control.
- Each centre should utilize a multidisciplinary approach.
- Each centre should demonstrate a high level of expertise and experience, as documented through publications, grants, or honorific positions as well as through teaching and training activities.
- There should be a strong contribution to ongoing research.
- Each center should strive for involvement in epidemiological surveillance such as registries.
- Close links and collaboration with other expert, national and international centres, and the capacity to network should be encouraged and maintained.
- Close links and collaboration with patient associations, where they exist, should be established and nurtured.
- There should be appropriate arrangements for patient referrals from other EU countries.
- There should be appropriate capacities for diagnosing, follow-up and management of patients with evidence of good outcome where applicable.

To gain more information on current clinical practice in the different EU countries, we investigated whether national guidelines were in place or whether EU wide recognized recommendations could be applicable which would be in line with the recommended criteria for centres of reference.

Methods

In 2008, a questionnaire was sent to at least one representative of all EU countries, Scotland and Norway. The contact person was either an ISPAD member or a person with a specific interest in childhood diabetes. They were asked whether national pediatric diabetes guidelines existed and/or what other guidelines would be applicable in their country. Wherever possible/available they were invited to send these guidelines to the study coordinators.

With this information, we evaluated whether these recommendations covered the criteria for European Reference Centers.

Results

Information on available pediatric diabetes guidelines was received from all EU countries together with Norway and Scotland. They are summarized in Table 2. ISPAD Clinical Practice Consensus Guidelines (ISPAD-CPCG) are the most frequently mentioned as reference guideline (in 15/29 countries). These consensus guidelines have been published after peer review and are based on an international consensus among pediatric diabetes healthcare professionals (4). Some countries have national recommendations for diabetes, but do not specify guidelines for different age groups. Four countries do not use specific pediatric guidelines, whereas 10 countries do report having national pediatric diabetes guidelines. The pediatric specific recommendations vary in size (half a page – book), presentation (paper format, page in a booklet, referenced papers or online.) and content. Although their concordance with ISPAD CPCG is frequently mentioned, most guidelines include less detail in almost all domains. Treatment targets differ as well, whether one considers the process of care targets (frequency of visits, screening for associated illnesses and complications, education, etc.) or outcome targets (glycemic targets, HbA1c targets in different age groups). Finally, very limited information is available on the implementation of the guidelines (4–7).

As most countries refer to the ISPAD-CPCG, these guidelines were used as the basis for the EU recommendations and we analyzed these as a second step within the European context. Most of the requested criteria for European Reference Centers mentioned

Table 2. Identified National Pediatric Diabetes Guidelines

Country	Guidelines
Austria	Currently in preparation
Belgium	No national guidelines ISPAD/ESPE guidelines in some centres, ULB with specific recipe
Bulgaria	Small leaflet, mainly ISPAD Guidelines
Cyprus	N/A
Czech Republic	Web-based national guidelines
Denmark	Website based, specific information on DKA, CSII, hypoglycaemia and intercurrent infections
Estonia	No national published pediatric guidelines
Finland	Defined by the Finnish Diabetes Association, not published
France	Clinical Guidelines HAS, very global, AJD, ISPAD
Germany	National published guidelines, DDG
Greece	No national guidelines, Mainly ISPAD, except for DKA (ADA based)
Hungary	No pediatric standard of care guidelines, adult and ISPAD
Italy	National general pediatric guidelines, not yet really implemented Health structure Guidelines
Ireland	ISPAD , BSPED, ADA
Latvia	No pediatric standard of care published
Lithuania	ISPAD guidelines
Luxemburg	Mainly ISPAD guidelines, except for DKA
Malta	Diabetes UK and ADA guidelines
Netherlands	Web-based national guidelines currently evaluated by the Dutch Diabetes and Endocrinology group, based on ISPAD
Poland	National Diabetes Guidelines with one chapter on pediatric diabetes
Portugal	ISPAD
Romania	Mainly ISPAD, no national guidelines
Slovakia	ISPAD, Slovak Diabetes Association
Slovenia	Mainly ISPAD guidelines
Spain	No national pediatric standard of care published
Sweden	Published guidelines (book) defined by the Pediatric Society for Endocrinology and Diabetes, Swedish
UK	ISPAD, BSPED, NICE
Scotland	Partly ISPAD, partly individualised approach
Norway	Short clinical guideline, paper version

in Table 1 are covered, although some aspects need further specification within the EU, especially when discussing harmonization and mobility of patients and healthcare professionals.

With respect to the structure of care, the multidisciplinary teams are the cornerstone of diabetes care. In the ISPAD CPCG guidelines, different team members are identified without specification of professional qualifications. Within the EU, no harmonized training curriculum is recognized for the different healthcare professionals, thus hindering the mobility of healthcare professionals. This needs to be addressed at the EU level. In the paper 'Heterogeneity in the systems of pediatric diabetes care across the European Union' (pages 5–14 of this issue), the staff currently available in the EU centers is reported, which is clearly differing between centers. This information was used to propose recommendations with respect to the number of health professionals needed per 100 patients as presented in the guidelines and summarised in Table 3.

Within the process of care, some simplifications of the ISPAD CPCG have been proposed for EU implementation to render supervision easier (8). With respect to care, a recent report on dyslipidemia has led to a treatment change, which has been proposed as well for the ISPAD CPCG (9).

Table 3. Recommendations for the multidisciplinary specialized pediatric diabetes team members per 100 patients in the optimal, moderate, and minimal setting (E, 8)

	Optimal	Moderate	Minimal
	Per 100 patients		
Nurse	1.0 FT	0.6	0.5
Doctor	1.0	0.8	0.5
Dietitians	0.5	0.3	0.3
Social worker	0.2	0.2	0.1 (access to)
Psychologists	0.3	0.2	0.1 (access to)

Finally, the EU recommendations include a contribution to epidemiology and research as one of the relevant tasks of the diabetes units. As the ISPAD CPCG are clinical guidelines, they provide no further guidance on research.

Discussion

Development and continuous evaluation of best practice in diabetes mellitus remains one of the major objectives in diabetes care, possibly allowing a delay in and/or prevention of later complications

(10, 11). Within the EU, equal care for children is sought for all inhabitants and this may be achieved through comparable recommendations of care. As mentioned in Table 1, these recommendations should include guidance on structure, process, and outcome of care.

We investigated whether guidelines were available in the member states and observed that in the majority of EU countries, the ISPAD CPCG were recognized. Although large scale evaluation of the implementation of these guidelines are lacking, a current problem in applying these guidelines in some countries may be based on language difficulties. A short version of the guidelines was prepared within Work Package 2 of the SWEET study which may serve as a shortened version of the CPCG. The translation of the ISPAD CPCG may solve this problem and should be endorsed.

With respect to the European Reference Center Criteria, some further questions arose when analyzing the recommendations of the ISPAD CPCG. The multidisciplinary team is considered to be the backbone of the care provision. Improved mobility of patients and healthcare professional would suggest the need for a core training curriculum for the various team members.

Currently, there exists no unanimity within the EU concerning the training received by healthcare professional with a specialty in diabetes. A common curriculum is needed because the optimal functioning of a healthcare team requires clear identification and definition of the duties of all the participants, with a clear focus on the child at the centre of care. Translation in ideal numbers has been discussed and is summarized in Table 3. As this may vary by country, depending on local circumstances, we differentiated the requested staff into optimal, moderate, and minimal numbers. Long-term benchmarking will allow further adjustment to obtain best practice and cost-effective functioning. In addition to the need for harmony within a family, harmony and consistency of philosophy within the diabetes team will facilitate clear identification of therapeutic targets (12). Efficient communication within the team, as well as good communication with and within families, has an effect on outcome and necessitate sufficient attention (13, 14).

Careful observation of chronic complications should be guaranteed on a regular basis. To facilitate this follow up, the frequency has been simplified in the EU centers as compared with ISPAD.

As the ISPAD guidelines focus on clinical care, they do not include any information on research procedures, e.g., Good Clinical Practice.

Within the EU, new regulations have established a system of obligations and rewards around the development of new medicinal products. This has been done to improve the information available on drugs used in the pediatric population and to ensure that the drugs applicable for the pediatric population are subject to ethical research of the highest quality (15). Some guidance on research practices would be relevant and should be pursued in the next revision.

Within this paper, we have only collected information on the available guidelines, and their compatibility with the requested criteria to improve health care within the EU.

The second step is the long-term evaluation of achieved clinical targets, including quality of care and the quality of life of the patients. Only with benchmarking over time, the optimal guidelines become available and best practice may become general practice.

Through a continuing registry, including robust comparable data on process and outcome indicators, the current approaches and guidelines can be evaluated, where needed adjusted, updated and tested and in this way allow continuous improvement of care.

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Conflict of interest

The authors declare no conflict of interest.

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