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Pediatric Diabetes Professional Training

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Pediatric diabetes training for Healthcare Professionals in Europe: time for change

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Abstract

Background

Training for Healthcare Professionals in Europe who care for children and young people with Type 1 diabetes and their families is variable depending on the country. Building on the work of SWEET and using the German Certified Diabetes Educators curriculum, a European collaboration of pediatric diabetes experts aimed to 1) establish current core elements that should be included in a pediatric diabetes education training course and 2) create a template for a European Certified Diabetes Educator's training curriculum.

Methods

A qualitative methodology incorporating a survey questionnaire, focus group discussions, individual semi-structured interviews and workshops was employed to explore participants' experiences and opinions. Healthcare Professionals – pediatric consultants, diabetes nurses, dietitians and psychologists, national and local diabetes leads, academic and education leads and children and young people with diabetes and families took part in the study. The total number of participants equaled 186.

Results

A template for a European Certified Diabetes Educator Curriculum (EU-CDEC) was developed based on the themes that emerged from the participants' expertise and experiences. This provides a model for Healthcare Professionals' pediatric diabetes training provision.

Conclusions

There is a severe shortage of high quality, standardized training for Healthcare Professionals across the majority of European countries. Lack of trained Healthcare Professionals for children and young people with diabetes will result in the delivery of sub-optimal care and impact on health, wellbeing and clinical and psychological outcomes. The EU-CDEC template can be used to increase access to high quality training provision for all Healthcare Professionals across Europe and worldwide.

Key words: Type 1 diabetes; pediatrics; healthcare professionals; training; education.

Abbreviations

HCPs: Healthcare Professionals

CYP: Children and young people

T1DM: Type 1 diabetes melllitus

CDE: Certified Diabetes Educator

EU-CDEC: European Certified Diabetes Educators Curriculum

WP4: Work Package 4

Introduction

Availability of training for Healthcare Professionals (HCPs) in Europe who care for children and young people (CYP) with Type 1 diabetes mellitus (T1DM) and their families varies greatly across each European country. Training for HCPs is often not standardized, accredited or quality-assured (1,2). Of greatest concern is the adverse effect this may have on the care and education that CYP with T1DM receive, which may contribute to variations in glycaemic control and compromised health outcomes. Center differences in glycaemic control have been documented for several decades (3-7) followed by many examples of center and national programs (8-10) adopting international standards (11,12) to improve education, care and outcomes. Changing systems to improve outcomes is both challenging and complex. However, international guidelines accept that successful programs have shown that diabetes education for patients and HCPs is an integral part of effective change and consequently improvement in outcomes (8-10,13).

In 2008 a joint initiative of established national and European diabetes organizations (International Society for Pediatric and Adolescent Diabetes - ISPAD, International Diabetes Federation Europe, Foundation of European Nurses in Diabetes, Primary Care Diabetes Europe), 13 established pediatric diabetes centers of excellence, corporate partners and foundations with co-funding from the European Union, initiated the SWEET (Better control in Pediatric and Adolescent diabete**S**: **W**orking to cr**E**ate C**E**n**T**ers of Reference) European Union (EU) Project. Its primary aim was to raise standards of care for CYP with T1DM in Europe through the establishment of gold standard clinical practices within a holistic framework, one that considers the whole person and not simply their diabetes (14). SWEET established several work packages, one of which, Work Package 4 (WP4), examined in detail the training of HCPs across Europe and made recommendations for the future (2). Importantly, WP4 recommended the need to develop a structured, standardized and accredited, high quality core curriculum to ensure that Multi-Disciplinary Teams throughout

Europe were appropriately trained to deliver education to the same high standard to all CYP and their families regardless of where they lived.

Through the extensive work undertaken in the SWEET WP4 it was clear that accredited courses specifically for diabetes education were not available apart from the well-established German training program for Certified Diabetes Educators (CDE) that was part of a larger national program started by the German Diabetes Association in the late 1990s (13). Twenty years later, both the CDE role and training curriculum are well established in Germany with over 3700 trained CDEs practicing in 85% of diabetes centers nationwide (15). Due to the success of the German CDE program the SWEET Consortium decided to apply for a further grant from the EU (Leonardo da Vinci Transfer of Innovation Project), that specifically targeted projects that could 'Transfer Innovation'. Consequently, funding was allocated from the EU to apply the transfer of innovation principle, in this case use the German CDE Program as a template and adapt it to ensure it was current and fit for purpose for CYP with diabetes across all EU states at the time of the study.

Working in collaboration with SWEET partners the authors recognized the need to build on the findings of SWEET and use the German CDE curriculum as a framework to develop a curriculum focused specifically on the role of a CDE to be used across Europe. The qualitative and exploratory approach used in this study, across a wide range of relevant stakeholders/experts, updated the German CDE curriculum to ensure that it embedded key psychosocial principles that integrated diabetes education in the context of the individual child's environment. Therefore, the aims of this research were to:

1) Identify the core elements that should be included in a standardized CDE training course;

2) Create a standardised and accredited template for a paediatric CDE training curriculum.

Methods

Methodological approach

A consortium of European partners from the SWEET EU project took part in the study. All SWEET members work within large multi-disciplinary teams, have centers of more than 150 CYP with diabetes and are well established leaders in their field across the global ISPAD and SWEET network. All EU SWEET centers were invited to take part in the project and the collaboration included those from the Czech Republic, Germany, Greece, Portugal, Slovenia and the UK.

Phase 1: Establishment of a methodology

As part of the SWEET EU Project an extensive literature search was conducted to identify published guidelines around the training requirements in pediatric diabetes (2). The German CDE model was deduced to be the gold standard and equates to a well-established and standardized national strategy for HCP training, which is delivered in the context of a disease management educational program for CYP with T1DM (16). Furthermore, it is accredited by the German Diabetes Association (17). The underpinning pedagogy is based on the principles of holistic, family-focused, diabetes self-management education and support that is age/maturity appropriate and delivered as separate components to children aged 6-12 years, adolescents and parents (18). This model was used as the foundation for the development of the curriculum template, which the authors named the European Certified Diabetes Educator Curriculum (EU-CDEC). Following the literature search a qualitative methodology was developed which was deduced to be the most appropriate approach for the study given that the intention was to investigate the experiences and opinions of key diabetes stakeholders/experts and CYP and their families.

Phase 2: Assessment of the current status of HCP education.

The purpose of phase 2 was to identify the core elements that should be included in a standardized training course. This was achieved using:

1) A survey questionnaire;

2) Focus group discussions;

3) Individual semi-structured interviews.

A survey questionnaire

This was developed to build on the original findings of the SWEET EU Project WP4 (2) and gain a more up-to-date overview of the status of diabetes training and accreditation in each country represented by the six SWEET partners. The survey questionnaire was sent to each partner and then distributed within each country to HCPs (including pediatric consultants, diabetes nurses/educators, dietitians and psychologists), national and local diabetes leads (representation at a national and local level of recognized pediatric T1DM specialists) and academic and education leads (those responsible for delivering existing pediatric T1DM training in education establishments). The survey questionnaire was conducted in English as all partners agreed that HCPs, national and local diabetes leads and academic and education leads had sufficient mastery of the English language to be able to complete the survey questionnaire in English.

Focus group discussions

Alongside the survey questionnaire, separate focus group discussions were conducted with different population groups, namely HCPs, national and local diabetes leads, academic and education leads and importantly, CYP with diabetes and their families. The focus group discussions aimed to be representative of the different population groups and across the sample data saturation was reached. Focus group schedules were developed to explore in more detail generic key issues, as well as important points raised in the survey questionnaire in relation to the current status of, and future directions for, diabetes training. The focus group schedules were distributed to the six SWEET partners along with an information sheet and consent form. These documents were translated into the language of the appropriate country by the SWEET partner when required, for example, for CYP and their families.

Similarly, focus group discussions were conducted in the relevant language when necessary to ensure the essence of the lived experience was retained and to minimize the threats to validity. The same approach was adopted for the interviews and the workshops in Phase 4.

Individual semi-structured interviews

These were conducted with those who did not want to participate in, or were unable to attend, a focus group discussion.

Phase 3: Development of the curriculum template for an accredited pediatric EU-CDE training course.

Phase 3 of the research focused on the creation of a standardized and accredited template for a pediatric EU-CDE training course for HCPs. Components from the existing CDE training provision in Germany informed the development of the template. In addition, the findings from phase 2, principally the key themes that emerged from the experiences of participants in the survey questionnaire, focus group discussions and interviews, were collated and incorporated within the design of the EU-CDEC template.

Phase 4: Evaluation of the EU-CDEC curriculum template

Building on the prior work of SWEET and the collaborative development of the EU-CDEC template, the next stage in the research involved evaluating the template. In order to do this, workshops were conducted with CYP and their families and HCPs in each of the participating SWEET countries. The purpose of the workshops was to:

1) Check that the findings from phase 2 and the interpretations from the SWEET partners had been accurately incorporated in the draft template;
2) Insert any additions to the template;
3) Further refine the template to produce a final version of the EU-CDEC.

Subjects

Purposive sampling was conducted in each partner country to recruit HCPs (pediatric consultants, diabetes nurses/educators, dietitians and psychologists), national and local diabetes leads, academic and education leads and CYP with diabetes and their families, (see Table (i)). HCPs, national and local diabetes leads and academic and education leads were identified through the SWEET partner in each country and CYP and their families were subsequently identified through a combination of the SWEET partner and HCPs. The total number of participants equaled 186 with a representative range of CYP in respect of diagnosis period, age and gender.

Insert Table (i) here

Ethics and consent

Appropriate ethical approval was obtained. The focus group discussions, interviews and workshops were conducted by appropriately trained members from each of the SWEET partner countries and recorded with the participants' consent.

Data Analysis

The data from the survey questionnaire, the focus group discussions, interviews and workshops were transcribed in the appropriate language by the researchers in each of the SWEET partner countries and analyzed using a thematic approach (19). Data analysis involved generating categories and coding data so that common themes and links could be identified. At least two researchers were involved in the data analysis process, thereby reducing interpretation bias. Key themes from each partner were then translated into English where necessary and collated. In addition, the findings were translated back into the native language in order for participants to verify the themes as a means of establishing the reliability of the research findings.

Results

Firstly, we present the findings from the survey questionnaire, focus groups and interviews

that informed the content of the pediatric diabetes training program and secondly, the findings relating to the development of the template for a standardized pediatric CDE training program.

1. Factors to be incorporated in a standardized pediatric diabetes training program for HCPs. Six sub-themes were identified:

- experience;
- course standardization;
- developing the Certified Diabetes Educator program;
- the role of the Certified Diabetes Educator;
- realism: changing the mindset;
- individualized care.

Experience

All participants unanimously agreed that HCPs play an essential role in the education of CYP with T1DM. To do this effectively, HCPs needed to have proven prior experience of working in a pediatric diabetes unit. HCPs should possess appropriate skills, and must communicate effectively with CYP and families:

> "HCPs need to have a professional qualification, but then experience, knowledge and ability to communicate well with young people, before you start." [HCP]

Families mentioned that knowledge and skills were often lacking, especially amongst the wider Multi-Disciplinary Team. They reinforced communication and pedagogical skills as essential prerequisites in HCPs for effective knowledge transfer.

Participants felt that HCPs needed clinical experience but also it was imperative for HCPs to increase their experience and expertise by attending a relevant training program and ideally,

one dedicated to pediatric diabetes. The course should be widely recognized and constitute an essential component of the training pathway to work in pediatric diabetes. HCPs, and those responsible for appropriate staff training, needed to be clear about the proper route to becoming qualified and what this entailed:

> "It's not clear what training people should do. There needs to be a clear pathway for people who are interested in working with CYP with diabetes" [HCP]

Course Standardization

Differences in HCP practice within the pediatric diabetes clinics were apparent, both between the SWEET partner countries, as well as within individual countries and even individual pediatric diabetes units. In the absence of clear guidelines for education, a number of different protocols were in place:

> "Some HCPs know more than others, there is no consistent approach. We as parents have made ourselves complete experts …they've not had experience of living it and that shows sometimes." [Family member]

All participants referred to standardized training to ensure all families, regardless of where they lived, received the same high quality standard of care.

Developing the Certified Diabetes Educator program

Participants representing HCPs, national and local diabetes leads and academic and education leads advocated a structured CDE program that includes:

- a standardized diabetes national curriculum;
- theoretical and practical training plus comprehensive coverage of key diabetes topics;
- psychosocial wellbeing;

- pedagogical skills and communication techniques.

Organization and delivery of the course needed to incorporate face-to-face, e-learning and blended learning methodologies. A modular approach would be more flexible to accommodate individuals' work commitments:

> "The time commitment is important. It might be better doing it (training) as separate modules and then building it up to a full MSc, because it is difficult to get released for that amount of time." [HCP]

The role of the Certified Diabetes Educator

HCPs stated CDEs do not have to have an autonomous role for diabetes education since a whole range of HCPs could deliver the educational component. However, they emphasized that CDEs should be responsible for the organization of education programs, act as the link between the Multi-Disciplinary Team and CYP and their families and educate other members of the Multi-Disciplinary Team:

> "To be a CDE you should be prepared for change, encourage the whole team, have leadership qualities…have the skills to educate the other members of the MDT." [HCP]

Furthermore, CDEs needed an incremental approach to education, starting with the basics and building on this knowledge as and when appropriate, together with refresher courses at regular intervals in key diabetes topics.

All participants regarded the CDE role as absolutely essential to address the challenges of T1DM and particularly managing T1DM as part of everyday life:

> "What could be better is more in-depth knowledge about how to practically put diabetes into life… experts need to know what they're talking about, but also how to put that into life and get good results as well." [Family member]

Realism: changing the mindset

Many participants stated that the underpinning philosophy needed to include greater inclusivity. CYP and families wanted to be involved in decisions and believed HCPs should consider the bigger picture rather than simply focusing on HbA1c outcomes:

> "You can feel that you're walking in to get a 'ticking off' if that number has gone high and if it's gone low it's a sort of pat on the back and we would prefer it to be open and less of a school teacher thing." [Family member]

Families thought that 'how' education was delivered was equally important as 'who' delivered education. CYP and families were hungry to learn about their diabetes and valued a shared decision-making approach rather than a didactic approach:

> "No one has talked to us about exactly why and how we're doing what we're doing…and even now we're doing it, but we're none the wiser." [Family member]

This was reiterated by the HCPs, stating CYP and families should be encouraged and empowered to self-manage their diabetes:

> "There is this big shift towards educating them so that they learn more and understand more because in the past it was very much, 'you do this and you do that', as opposed to actually understanding why they're doing it and engaging them to self-manage. I think if we can change that mindset we may get better results out of our young people." [HCP]

Individualized care

Participants highlighted the importance of individualized care and access to a CDE who understood age-related and cultural differences. In some countries a 'one size fits all' approach rather than a personalized care plan seemed to be the norm:

> "I think HCPs struggle… they do a really good job when it comes to talking to the parents, but they have a challenge when it comes to young people… the challenge for them is being able to give information to everyone who walks through the door." [Family member]

Above all, CYP and families felt that the CDE was there to inform, answer questions and enable CYP and families to self-care and have a positive approach to life with diabetes.

2. A standardized and accredited template for a pediatric CDE training program for HCPs.

The template was created from the findings from phases 1-4 and a comparison with the CDE curriculum in Germany. Importantly, the template was designed ensuring flexibility for each partner to create content fit for purpose and took into account the wide range of specialist teaching, learning and assessment materials unique to individual countries.

Three key principles guided the pedagogical framework of the template:

- empowerment philosophy and patient-centered care;
- professional knowledge rooted in practice and not simply academic achievement
- previous personal and professional experience valued as a foundation for managing the CDE learning process and the application of advanced diabetes practice.

In terms of content, the EU-CDEC template embedded the key components of a pedagogic framework. This formed the basis of a standardized training platform and was divided into three main sections:

- Healthcare process;
- Guidance, consultancy, coaching and education;
- Interdisciplinary work within the diabetes team.

Healthcare process

This involves an exploration and assessment of the health status of the CYP and incorporates what the participants termed the ‘diabetes basics’. It includes the essential information that CYP and families need to know about their diabetes, for example, phases of diabetes and principles of insulin therapy. In addition, management of the condition including nutrition and hypoglycaemia and an assessment of the individual’s overall health, for example, age-appropriate care, practical skills in blood glucose monitoring and insulin adjustment and emotional well-being, are covered.

Guidance, consultancy, coaching and education

This focuses on the psychology and pedagogy of diabetes education. It includes planning, designing and reflection using case studies and scenarios and incorporates cognitive and behavioral techniques in diabetes care, communication and coaching skills. An evaluation of current educational programs, an awareness of education in practice and the development of practical skills are regarded as essential components. Observational placements and reflective practice portfolios are just two examples of learning strategies that are used.

Interdisciplinary work in the diabetes team

This is dedicated to the role of the CDE and includes the philosophy within the team, the CDEs professional role and behavior, quality assurance, case management and evidence-based practice.

Content is divided into three modules as outlined above, to provide all students with the required CDE knowledge, skills and competencies. The course is designed to promote a

questioning approach to healthcare and facilitate critical analysis, based on a model of reflective practice. Consequently, student educators acquire an understanding of shared challenges amongst CYP and families, and colleagues, providing them with an opportunity to reflect on their beliefs and diabetes practices. See Table (ii) for the CDE Curriculum Template.

Insert Table (ii) here

Discussion

Differences in the delivery of care and outcomes for CYP with T1DM are apparent throughout Europe and globally (2-7,20-24). Whilst a significant number of CYP receive a high standard of care from appropriately skilled and trained HCPs, it is unacceptable that there are others who, because of inadequate HCP training, are failing to receive the highest levels of diabetes care available and are disadvantaged health-wise because of inequitable training provision compared with international standards (11,12).

European colleagues have recognized for many years the need for an investment in standardized training for all pediatric diabetes HCPs. Unified communication and agreement on goals are crucial for effective education (25,26). Therefore, a common training program with all team members adhering to standardized guidelines has been hailed as the way to drive improvements in diabetes outcomes, rather than an overreliance on therapeutic strategies alone (3,11,14,15,26,27). The EU-CDE template developed and presented here demonstrates that progress is being made towards achieving this goal.

The EU-CDEC template represents an important milestone and provides a model for pediatric diabetes training provision that can be adopted throughout Europe and globally. The German CDE program formed the basis of the EU-CDEC template because of its recognized gold standard curriculum. This has evolved over many years and throughout the time since its inception it has been evaluated and refined in light of diabetes outcome measures for CYP and their families in Germany. Now the EU-CDEC template has been developed which retains many similarities with the German model, but has been updated to include key psychosocial principles that respect the child’s individual diabetes education needs in the context of their environment. This is consistent with the philosophy to continually evaluate and produce a training program that is dynamic and evolves to meet the needs of HCPs, CYP and their families.

Limitations

Whilst diabetes teams across Europe are beginning to realize the importance of the CDE role, we acknowledge that there is still a long way to go. The authors recognize that before the final EU-CDEC template can be implemented throughout Europe and with potential for global use, there are resource implications that need to be considered. Specific constraints, for example, culture, language and finance, operate in individual countries, which dictate exactly how the EU-CDEC template would be implemented and in what way students are assessed. Whilst the EU-CDEC template can serve as a framework, if it is to be successful, it may be more realistic in certain countries to divide the course into shorter training modules focused on specific themes.

The data presented here solely reflects the views of the participants and may not be representative of those individuals in the participating European countries who were not involved in the study. Equally, the findings are not necessarily generalizable to pediatric diabetes communities in other European countries outside of the consortium. Nevertheless, the salient themes highlighted in this study, based on six SWEET European countries, are likely to be pertinent to pediatric diabetes units, professional training institutions and diabetes organizations worldwide.

Conclusions

Based on our partners' and all stakeholders' commitment to develop the CDE role and the strength of the collaborative working of SWEET, now an international network of 58 members, together with the support of ISPAD, there is real added value to ensure the EU-CDEC template is firmly recognized as the established training course for the professional diabetes community globally and not just in Europe. The implications of this are far reaching. With an established, standardized EU-CDEC in place, firstly, education and training will be aligned according to evidence-based practices and current global health policy and guidelines (12,17,27-30). Secondly, clear teaching and learning pathways will be created that act as a common language, facilitating greater mobility of HCPs between countries to enhance professional experience and expertise. Thirdly, greater quality assurance will help

to increase standards amongst the diabetes workforce and equally, raise the profile of diabetes educators collectively. Finally, and most importantly, the goal of achieving significant improvements in the short- and long-term health outcomes of all CYP with diabetes will be more attainable.

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Tables

Table (i) Research participants

DATA COLLECTION / SWEET COUNTRIES	SURVEY	FG/INT HCPs	FG/INT NLDLs	FG/INT AELs	FG/INT CYP/FAMILIES	WORKSHOPS	
						CYP/FAMILIES	HCPs
CZECH REPUBLIC	5	1	1	1	1	3	2
GERMANY	2	7	1	2	7	0	0
GREECE	3	3	2	2	8	16	5
PORTUGAL	0	1	1	0	1	5	10
SLOVENIA	1	1	1	1	1	19	28
UNITED KINGDOM	12	4	3	4	7	5	9
CUMULATIVE TOTAL	23	17	9	10	25	48	54
TOTAL PARTICIPANTS	186						

Key

FG: Focus Groups

INT: Interviews

HCPs: Healthcare Professionals

NLDLs: National and Local Diabetes Leads

AELs: Academic and Education Leads

CYP: Children and Young People

Table (ii) CDE Curriculum Template

	CDE Curriculum Template							
Learning area	**1**		**2**			**3**		
	Healthcare process – exploration and assessment of the health status of the child/young person		Guidance, consultancy, coaching and education			Interdisciplinary work in the diabetes team		
Module number	1.1	1.2	2.1	2.2	2.3	3.1	3.2	
Module content	Diabetes basics and therapy schemes	Assessment of the child/young person's situation	Planning, designing and reflection of case scenarios using bio-psych-social processes	Planning, organization, implementation and evaluation of educational programs	Consultancy and education in practice	The role of the diabetes educator as part of the care team	Quality assurance, case management and evidence-based practice	
AQR Level	**4**	**4**	**5**	**5**	**5**	**5**	**4**	
ECVET transfer	possible	possible	possible	possible	possible	possible	Not possible	

Course structure												
Weeks of presence	**Stage 1**			**Stage 2**			**Stage 3**		**Stage 4**		**Stage 5**	
Learning week	1	2	3	4	5	6	7	8	9	10	11	12
Modules												
1.1			Exam						Exam			
1.2					Homework: History taking							
2.1								Homework: Case study				

2.2									Homework: Educational video			
2.3												Oral exam
3.1											Lecture	
3.2												

Learning outside the class				
Modules	**Stage 1 and 2**	**Stage 2 and 3**	**Stage 3 and 4**	**Stage 4 and 5**
1.1	Revision: Theory	Revision: Theory	Preparation: Theory exam	
1.2	Preparation: History taking	Deadline for the homework (history taking)		
2.1	Preparation: Case study	Preparation: Case study	Deadline for the homework (case study)	
2.2	Preparation: Educational video	Preparation: Educational video	Deadline for the homework (educational video)	
2.3	Visits, consultancy and education	Visits, consultancy and education	Visits, consultancy and education	Preparation: Oral exam and case study
3.1		Preparation of the lecture	Preparation of the lecture	Lecture
3.2	Revisions			

Key

AQR: Annual Quality Review

ECVET: European Credit System for Vocational Education and Training