Initial Education for Families with Children Diagnosed with Type 1 Diabetes: Consensus from Experts in a Delphi Study

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ABSTRACT
A child’s diagnosis of type 1 diabetes can create major challenges for the family, and early education about the disease is crucial. The aim of this study was to identify and reach expert consensus about the priority of topics for the two initial weeks of education of families with a child diagnosed with type 1 diabetes. Specialist nurses (n = 15) working with children and adolescents with diabetes at Swedish pediatric clinics participated in a Delphi study. We sent these experts three rounds of a web survey and analyzed their answers using qualitative content analysis and descriptive statistics. The results show the experts’ consensus on the most important educational topics for families of a child diagnosed with type 1 diabetes. The highest priority topics were actions for hypo-/hyperglycemia, blood-glucose monitoring, symptoms of hypo-/hyperglycemia and adjustment of insulin. The experts’ top-ranked educational topics were in line with the International Society for Pediatric and Adolescent Diabetes guidelines for educating children with type 1 diabetes and also considered important by children and their families. The topics identified here can help nurses educate children with type 1 diabetes, contribute to further research into type 1 diabetes education, and inform the development of national guidelines.

Introduction
When children are diagnosed with type 1 diabetes, they and their families need comprehensive education to perform the self-care expected of them. During this period, children and adolescents have been found to worry about why they have received the diagnosis, hope for a permanent cure (Roper et al., 2009), fear needles and injecting themselves with insulin (de Cássia Sparapani et al., 2015; Ekra et al., 2015), and feel different to other young people (Freeborn et al., 2013).

Parents of children recently diagnosed with type 1 diabetes described feelings of chaos, powerlessness (Wennick & Hallström, 2006), and worry – particularly about the child’s eating and blood-glucose level, and found it difficult to give up control and adapt to a strict routine (Marshall et al., 2009; Rechenberg et al., 2017; Sparud-Lundin et al., 2013).

Children recalled feeling exposed and unsafe in the unfamiliar environment during their first hospital stay (Ekra et al., 2015), and families relied upon health-care professionals, strove to create good relations with them, and appreciated a personal approach directed mainly to the child (Ekra et al., 2015; Howe et al., 2012). Being allowed to participate helped...
children feel empowered and more in control of the disease (Coyne, 2006). Both parents and children appreciated meeting highly competent health-care professionals and receiving guidance and a plan for the child’s coming treatment (Howe et al., 2012). By gradually transferring responsibility to parents, health care professionals made the parents feel safe (Wennick & Hallström, 2006).

For this transition to succeed, education is crucial and a core part of the care given to the child and the family (Phelan et al., 2018). This education begins straight at diagnosis and aims at making families more confident and self-reliant about managing the disease at home. It should include all family members and is delivered partly by the diabetes team including a specialist nurse in pediatric diabetes care, partly by the staff nurse caring for the child during the hospital stay (Jönsson et al., 2010; Konrad et al., 2016; Pennafort et al., 2014; Phelan et al., 2018). A thorough education has been associated to improved glycemic control in children and improved family functioning (Feldman et al., 2018).

Initially, the family should be educated about the basic pathophysiology of the disease, how to monitor blood glucose, inject insulin, and make dietary changes (Jönsson et al., 2010; Pennafort et al., 2014). However, in a stressful hospital environment, nurses perceived having too little time to make the children involved at managing their disease themselves or to attend to psychosocial needs in the family (Pennafort et al., 2014). Both the families and the nurses experienced that the time in hospital barely was enough to address the most urgent topics about the treatment before being discharged (Jönsson et al., 2010, 2012; Lawton et al., 2015).

Even though international guidelines from International Society for Pediatric and Adolescent Diabetes (ISPAD) for diabetes education in children and adolescents suggest topics to be included at diagnosis and for continuing education (Phelan et al., 2018), staff nurses still report that education is not optimal and that priorities are difficult (Pennafort et al., 2014). Further, these guidelines do not state precedence for the different topics, which should be useful in a stressful clinical setting. Also, little is known about the priorities for education from the perspective of clinical diabetes nurses. To further improve the nursing care of families with a child diagnosed with type 1 diabetes, more guidance on where clinical diabetes nurses should start their initial education is needed.

**Aim**

The aim of this study was to identify and reach expert consensus about the priority of topics for the two initial weeks of education of families with a child diagnosed with type 1 diabetes.

**Materials and methods**

The Delphi technique can find and structure consensus from experts in a specific field by asking for their opinion through several rounds of questionnaires. In each round, the experts are fed back the results from the previous round, so they can gain a perspective on their own responses in relation to the collective response and from that change their scorings (Hasson & Keeney, 2011; Hasson et al., 2000). In this study, the experts answered three rounds of questionnaires.
**Expert panel**

Our expert panel consisted of diabetes nurses working with children and adolescents in Sweden. They were recruited through an e-mail sent to all members in the The Swedish Association for Diabetes Specialist Nurses working with children and adolescents \( n = 37 \), and through letters to 16 departments of pediatrics at Swedish hospitals. An invitation was also sent in the largest Facebook group for Swedish nurses (“Sjuksköterskan”). To be included, experts should show an interest in the actual topic, which we deemed they had if they participated in the study. Nurses working only with adults or young adults were excluded.

Our panel consisted of 15 experts. Other Delphi studies have used expert panels ranging from 12 to 50 experts (Hasson et al., 2000; McPherson et al., 2018).

The experts were 13 women and two males, and had an experience from the field ranging from one to 30 years (mean 11.4 years, SD 9.4). As for educational background, eight had a master’s degree in children’s nursing plus a diabetes nursing degree, one the diabetes nursing degree only, two the master’s degree in children’s nursing only, and four were registered nurses without a specialist degree. They came from five regional councils, representing both rural and metropolitan areas. All 15 experts participated in Round 1, and one dropped out from Round 2.

**Data collection**

The experts answered web surveys to speed up the process between the rounds (McPherson et al., 2018). To this study the online service SurveyMonkey was used. The questionnaires for all three rounds were piloted on a smaller number of nurses.

**Delphi round 1**

The purpose of Round 1 was to collect a broad set of topics as a foundation for the next rounds (Hasson et al., 2000). The experts answered an open-ended question after reading the hypothetical case, designed by the authors to capture a typical situation at diabetes diagnosis (Box 1).

**Box 1.**

Kim, nine years, is diagnosed with type 1 diabetes. Recently Kim noticed increased diuresis, thirst, and weight loss. When Kim and the mother Karin visit their GP, a blood sample reveals a blood glucose of 25 mmol/L. Kim and the family are admitted to the paediatric ward and insulin treatment starts. Karl, the father, and two siblings also attend the ward. You are responsible for Kim and the family for the first two weeks. What topics are necessary to include in your education of the family?

In this round, we also collected demographic data about the experts.

The answers from Round 1 were analyzed with qualitative content analysis (Graneheim & Lundman, 2004). The 1st and 3rd author jointly split the text into meaning units, which were condensed and coded, and the 4th author scrutinized this analysis. There were 125 codes that we grouped into 28 categories, named topics.
**Delphi round 2**

In Round 2 we asked the experts to consider their answers from the Round 1 when looking at the complete set of topics (Keeney et al., 2006), presented as an unordered list in the web survey. The experts were then asked to score all the topics on a 5-point Likert scale from 1 ‘not important at all’ to 5 ‘very important.’

After this, we calculated consensus for each topic, defined as the percentage of experts scoring 4 or 5 on each topic (Hsu & Sandford, 2007).

**Delphi round 3**

In Round 3 we again presented the topics and their corresponding consensus levels to the experts and asked them to rank the topics from 1, the most important topic, to 25, the least important. Due to limitations in the survey system, three topics were then unranked. The final ranking of the topics was then calculated as the mean value of the ranks in reverse (Hasson et al., 2000).

**Ethical considerations**

The study follows the Swedish law for ethical vetting (SFS, 2003:460) and was approved by the local university ethical board at Umeå University. Nurses in the expert groups were invited via e-mail to members in a network for the profession. They were informed regarding the aim of the study and participant confidentiality. Participants explicitly gave their informed consent on the first screen page of the questionnaire in Round 1.

**Results**

**Round 1**

The experts answered an open question and the topics identified varied between everyday life with diabetes and informing friends and relatives, to the role of insulin and dextrose treatment (Table 1).

**Round 2**

Fourteen (93%) of the experts participated in Round 2, where they scored the 28 topics on a 5-point Likert scale, from not important at all to very important (Table 1).

The topics with the highest priority were actions for hypo-/hyperglycemia, symptoms of hypo-/hyperglycemia, adjustment of insulin, and blood-glucose monitoring. These topics all reached 100% consensus. Continuous glucose monitoring (CGM; 50%), maintaining an ordinary diet (50%), diabetes register (29%) and diabetes association (14%) were graded as least important.
Table 1. Topics identified in round 1 and scores from round 2.

| Topics                                               | Mean* | SD    | Median | Range | Consensus b |
|------------------------------------------------------|-------|-------|--------|-------|-------------|
| Actions for hypo-/hyperglycaemia                      | 5.00  | 0.00  | 5.0    | 5     | 100%        |
| Symptoms of hypo-/hyperglycaemia                      | 4.93  | 0.26  | 5.0    | 4–5   | 100%        |
| Adjustment of insulin                                 | 4.86  | 0.35  | 5.0    | 4–5   | 100%        |
| Blood-glucose monitoring                              | 4.86  | 0.35  | 5.0    | 4–5   | 100%        |
| Injection techniques                                  | 4.64  | 0.48  | 5.0    | 4–5   | 100%        |
| Contacting the diabetes team                         | 4.64  | 0.48  | 5.0    | 4–5   | 100%        |
| Diabetes in school                                    | 4.36  | 0.48  | 4.0    | 4–5   | 100%        |
| Correction factors                                    | 4.64  | 0.61  | 5.0    | 3–5   | 93%         |
| Carbohydrate counting                                | 4.57  | 0.62  | 5.0    | 3–5   | 93%         |
| The insulin pen                                       | 4.50  | 0.63  | 5.0    | 3–5   | 93%         |
| The role of insulin                                   | 4.50  | 0.63  | 5.0    | 3–5   | 93%         |
| The diabetes disease                                  | 4.50  | 0.63  | 5.0    | 3–5   | 93%         |
| Everyday life with diabetes                          | 4.43  | 0.62  | 4.0    | 3–5   | 93%         |
| Ketone monitoring                                     | 4.29  | 0.70  | 4.0    | 3–5   | 86%         |
| Insulin storage                                       | 4.21  | 0.67  | 4.0    | 3–5   | 86%         |
| Dextrose treatment                                    | 4.50  | 0.82  | 5.0    | 3–5   | 79%         |
| Actions at high ketone levels                         | 4.36  | 0.81  | 5.0    | 3–5   | 79%         |
| Informing friends and relatives                       | 4.29  | 0.80  | 4.5    | 3–5   | 79%         |
| Diabetes during illness                               | 4.00  | 0.65  | 4.0    | 3–5   | 79%         |
| Meal-time routine                                     | 3.86  | 0.99  | 4.0    | 2–5   | 71%         |
| Physical activities                                   | 3.79  | 0.86  | 4.0    | 2–5   | 64%         |
| Metabolic control                                     | 3.79  | 1.01  | 4.0    | 2–5   | 64%         |
| Diet                                                  | 3.79  | 0.77  | 4.0    | 3–5   | 57%         |
| Technological tools                                   | 3.64  | 0.81  | 4.0    | 2–5   | 57%         |
| Continuous glucose monitoring (CGM)                   | 3.50  | 0.91  | 3.5    | 2–5   | 50%         |
| Maintaining ordinary diet                             | 3.43  | 0.82  | 3.5    | 2–5   | 50%         |
| Diabetes register                                     | 2.86  | 0.99  | 3.0    | 1–4   | 29%         |
| Diabetes association                                  | 2.71  | 0.88  | 3.0    | 1–4   | 14%         |

*Scores: 1 = not important at all to 5 = most important. b The percentage of experts scoring 4 or 5 on each topic.

Round 3

Fourteen (100%) of the experts from Round 2 answered the questionnaires in Round 3, ranking the 28 topics from 1 to 25. The highest ranked topics in Round 3 were actions for hypo-/hyperglycemia, blood-glucose monitoring, symptoms of hypo-/hyperglycemia and adjustment of insulin (Table 2, Box 2). The lowest ranked topics were continuous glucose monitoring, maintaining an ordinary diet, diabetes register, and diabetes association.

Box 2.

Top four topics for education at diagnosis
(1) Actions for hypo-/hyperglycaemia
(2) Blood-glucose monitoring
(3) Symptoms of hypo-/hyperglycaemia
(4) Adjustment of insulin

Discussion

This study aimed to identify and reach expert consensus about the priority of topics for the two initial weeks of education of families with a child diagnosed with type 1 diabetes. There was a clear consensus among experts for the priorities. Actions for hypo-/hyperglycemia, blood-glucose monitoring, symptoms of hypo-/hyperglycemia and adjustment of insulin
Table 2. Results from Delphi round 3.

| Topic                                      | Rank | Mean rank score |
|--------------------------------------------|------|-----------------|
| Actions for hypo-/hyperglycemia            | 1    | 23.71           |
| Blood-glucose monitoring                   | 2    | 22.07           |
| Symptoms of hypo-/hyperglycemia            | 3    | 21.93           |
| Adjustment of insulin                      | 4    | 21.79           |
| Injection techniques                       | 5    | 18.64           |
| The role of insulin                        | 6    | 17.43           |
| Carbohydrate counting                      | 7    | 17.36           |
| The diabetes disease                       | 8    | 17.07           |
| Correction factors                         | 9    | 15.64           |
| Ketone monitoring                          | 10   | 15.00           |
| Contacting the diabetes team               | 11   | 14.21           |
| The insulin pen                            | 12   | 14.07           |
| Everyday life with diabetes                | 13   | 14.00           |
| Dextrose treatment                         | 14   | 13.93           |
| Actions at high ketone levels              | 15   | 12.79           |
| Diabetes in school                         | 16   | 11.57           |
| Insulin storage                            | 17   | 11.00           |
| Informing friends and relatives            | 18   | 8.36            |
| Diabetes during illness                    | 19   | 7.57            |
| Diet                                       | 20   | 5.43            |
| Physical activities                        | 21   | 5.29            |
| Meal-time routine                          | 22   | 5.00            |
| Metabolic control                          | 23   | 4.86            |
| Technological tools                        | 24   | 4.07            |
| Continuous glucose monitoring (CGM)        | 25   | 2.42            |
| Maintaining ordinary diet                  |      |                 |
| Diabetes register                          |      |                 |
| Diabetes association                       |      |                 |

had a 100% consensus in Round 2 and got the highest ranks in Round 3. Nurses in pediatric diabetes care could take this in account when planning the education for families at diagnosis.

Overall, the results from this Delphi expert panel study adheres closely to ISPAD’s guidelines for diabetes education (Phelan et al., 2018). Some exceptions, however, can be noted. The experts did not address topics such as risk for siblings, weight control, diabetes diary, and outlooks for the future. However, our expert panel did bring up topics not mentioned in the ISPAD list, such as quality registers, using dextrose tablets against hypoglycemia, and the recommendation to continue with the child’s ordinary diet; findings that still were considered relevant by the expert panel, albeit not highly ranked. Most topics, and the highest ranked topics, are common with those of ISPAD and then can serve as a validation of those guidelines in a Swedish context.

Educating about actions for hypo-/hyperglycemia were ranked as the most urgent topic by experts in this study. According to parents, this was something they missed in their initial education and wished for more knowledge about (Jönsson et al., 2012), which thus corresponds with the experts’ ranking here. Keeping the blood glucose within the normal range is a constant strive for both parents and children (Silva et al., 2016). Of the children in that study, 69% had hyperglycemic episodes, whereas only 7% had hypoglycemias. Worries about mistreated hyperglycemias and an elevated HbA1c eventually is a concern for many parents (Lendahls & Edvardsson, 2018). Thus, placing a high priority on this topic is meaningful for families to reduce worries and future complications.
Blood-glucose monitoring had the second highest priority according to experts. Learning to do capillary blood-glucose sampling is addressed at diagnosis. Nowadays, with devices for CGM or flash glucose monitoring (FGM) being increasingly used, the number of children needing frequent capillary picking decreases. Using CGM is associated to better glycemic control (Dicembrini et al., 2020) and reduced anxiety (Ng et al., 2019). Besides, children experience the capillary testing as a painful discomfort (Greenhalgh et al., 2004). However, families still need to master traditional capillary testing in case the CGM/FGM device fails and to double-check doubtful CGM/FGM values. In our study, education about CGM was one of the lowest priorities, possibly mirroring its introduction at a later stage of the treatment.

The third priority in this study was given to symptoms of hypo-/hyperglycemia by experts. Families report anxiety and fear for hypoglycaemias, causing parents to make extra blood glucose checks during the nights and these children also had a higher HbA1c (Lawton et al., 2015; Pate et al., 2019). However, parents who had adjusted to the diagnosis and knew how to manage the disease were less fearful of the child’s blood-glucose measurements (Pate et al., 2019).

Adjustment of insulin was the fourth priority according to the experts. Parents often find it difficult to calculate an insulin dose appropriate to the child’s current blood glucose (Jönsson et al., 2012; Lawton et al., 2015). This also creates worries in the families. For most regimes, dosage is also based on counting carbohydrates (Danne et al., 2018).

Total nursing care for children diagnosed with type 1 diabetes and their families should comprise much more than education about these topics, however. A child-centered approach that supports and comforts the child and the family, clear and honest communication, and children’s and parents’ involvement in decision-making are all necessary (Coyne et al., 2016), however, those fall outside this study’s focus on factual topics for education. Phelan et al. (2018) also emphasize that the educator should have appropriate training and adapt to the child’s situation and cognitive development.

This study mainly took the perspective of nursing professionals; future studies could include other professions such as pediatricians and dietitians to broaden the knowledge base. Parents and children should also be asked about their priorities as they will likely have a different perspective.

**Methodological considerations**

One strength of this study was the relatively experienced expert panel, with a mean of 11.2 years of working in diabetes care. Many experts also had a master education in children’s nursing and/or in diabetes nursing. The experts further came from five regions in Sweden, which vouches for a variation in local traditions and policies. The response rate was high through all three rounds, with only one expert dropping out. This altogether supports the validity of the study. However, using nurses only in the expert panel may be seen as a weakness. Including other health-care professionals, such as dietitians and physicians, parents, and children with type I diabetes may have yielded a different result. Still, this study provides guidance to nurses who are probably most involved in the day-to-day education of the families at diagnosis. The size of the expert panel, 15 members, is considered
sufficient, albeit at the lower end (Hasson et al., 2000). Considering that the consensus measure for the top 10 ranked items were between 100% and 93%, and that the panel was recruited country-wide, we argue that this is a reliable result.

We made the experts anonymous to one another, to reduce the risk of certain members setting the tone in the discussion (Hasson et al., 2000).

The initial case posed before the experts was about a nine-year-old child being diagnosed. Using another age group in the vignette might have resulted in different answers. However, the age of nine corresponds well with the current mean age of diagnosis in Sweden (Samuelsson et al., 2013) making it more representative of this population.

Some topics, that is, dextrose treatment and contacting the diabetes team, were raised by only one expert each in Round 1. They were however still considered high priority by the experts in later rounds. This points to the usefulness of the Delphi method, which compiles collective knowledge into something larger. Still, this is not necessarily the only correct answer to a question, but serves as an input to people writing local procedures for diabetes education.

**Conclusion**

This study reports a clear consensus on topics for initial education of families when a child is diagnosed with type 1 diabetes. Actions for hypo-/hyperglycemia, blood-glucose monitoring, symptoms of hypo-/hyperglycemia and adjustment of insulin were the four top topics. These results can help to form local routines for educating children with type 1 diabetes and their families and complement the ISPAD guidelines on education by ranking the topics. Nurses in pediatric diabetes care may use this as an everyday guideline on where to start when educating about the disease.

**Acknowledgments**

We wish to express our sincere gratitude to the experts all around Sweden who invested their time in this study, as well Mrs Ingela Lavin, specialist nurse in children’s diabetes, MSN, at Umeå University Hospital, for her eager work to promote the study nationally.

**Disclosure statement**

No potential conflict of interest was reported by the author(s).

**Funding**

This work was supported through a regional agreement between Umeå University and Region Västerbotten (ALF), grant: VLL-582751.

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