Learning needs of children and adolescents with type 1 diabetes

ORIGINAL

Denizielle de Jesus Moreira Moura[1], Ariane Alves Barros[2], Luciana Catunda Gomes de Menezes[3], Ana Cileia Pinto Teixeira Henriques[4], Lúcia de Fátima Silva[5], Maria Vilani Cavalcante Guedes[6].

Abstract

Objective: To identify the learning needs of children and adolescents with T1D related to their disease and treatment.

Methods: It was a descriptive study. Data collection occurred through interviews with 19 participants and secondary data were extracted from blogs. Data analysis was based on the thematic content analysis technique proposed by Bardin.

Results: The most talked-about topics on the blogs concerned needles and injections, namely: insulin therapy, insulin pump, and blood glucose monitoring. When asked what they wanted to know about diabetes, most children showed interest in knowing the appropriate food and reported difficulties in insulin therapy. It was verified that there are many doubts and difficulties permeating the daily lives of children with type 1 diabetes and their families, in which the main ones are related to drug treatment.

1 Nurse. Professor at the Faculdade Metropolitana da Grande Fortaleza (FAMETRO). PhD in Clinical Care in Nursing and Health, Universidade Estadual do Ceará, UECE, Fortaleza (CE), Brasil.
2 Nurse. Master's degree in Clinical Care in Nursing and Health, Universidade Estadual do Ceará, UECE, Fortaleza (CE), Brasil.
3 Nurse. Master's degree in Clinical Care in Nursing and Health, Universidade Estadual do Ceará, UECE, Fortaleza (CE), Brasil.
4 Nurse. Master's degree in Public Health, Faculty of Medicine, Universidade Federal do Ceará.
5 Nurse. PhD in Nursing. Assistant professor at the Universidade Estadual do Ceará, UECE, Fortaleza (CE), Brasil.
6 Nurse. PhD in Nursing. Assistant professor at the Universidade Estadual do Ceará, UECE, Fortaleza (CE), Brasil.

Contact information:

Denizielle de Jesus Moreira Moura.

✉ deniziellemoreira@gmail.com

Keywords

Learning. Diabetes Mellitus, Type 1. Child.

Introduction

Nursing has been consolidated as a profession and science oriented to human care. There are many efforts in building a clinical care through scientific theories, humanism, ethics, aesthetics, spirituality, and health education, providing people with treatment, cure, rehabilitation, comfort, and well-being.

From the perspective of care needs, chronic diseases stand out, especially Diabetes Mellitus (DM). Among the classifications of diabetes, we highlight type 1 diabetes (T1D), which appears in 5% to 10% of cases. Its incidence shows significant geographic variation, presenting rates of 38.4 in Finland, 7.6 in Brazil, and 0.5 in Korea per 100.000 people younger than 15 years, for example[1-2].

T1D is a chronic disease that requires life-long treatment. Thus, from the time of diagnosis, children must receive information to construct knowledge on their health-disease process. Knowledge empowerment is a valuable ally for the child to reach the independence and autonomy necessary for self-care.

Health education focus on providing emancipatory care, in other words, training people to perform self-care. In order to support the health education planning according to the needs and learning ability of each child, it is essential to know their cognitive development and their learning needs.

Knowing the cognitive development, their apprehension of reality, how they organize daily life, and how they see themselves in a world full of limitations, subsidizes the planning of care strategies consistent with the child's learning needs and ability.

In meaningful learning, prior knowledge acts as ideational and organizational matrix for the incorporation, understanding, and retention of new knowledge when these are "anchored" in specifically relevant knowledge[3].

In this context, the following question arose: What are the learning needs of children and adolescents with T1D concerning their disease and treatment?

As regards the practical application, this study contributes to the planning of care strategies involving educational assistance activities, guided by the learning needs and difficulties of the target audience. Action planning based on the identification of learning needs tends to be more effective, since it respects the uniqueness of the individual.

This study aimed to identify the learning needs of children and adolescents with T1D related to their disease and treatment, which has been fully achieved. Its results reflect the statements obtained with people from several Brazilian cities (based on blogs analysis), along with in situ identification of the target audience.

Methods

This was a descriptive study with qualitative approach.

Data collection took place in two phases. Initially, secondary data extracted from blogs about T1D were collected. In order to get a larger perspective of the learning needs of the study population, we searched the keyword "health education on diabetes mellitus type 1" on Google and restricted the selection to blogs.

The initial search found 7,130 results. Blogs with interaction through posts and in Brazilian Portuguese were included. Websites (news related, with scientific or commercial purposes), journal articles, and those that were not specifically about DM were excluded, resulting in 38 blogs. Among those remaining, 14 were excluded for they approached exclusively T2D, totaling 24 blogs.

Later, we verified that 17 from those 24 blogs were specifically about T1D, but written by the patients themselves in adulthood. For this reason, they were also excluded, since the posts addressed primarily adult patients. Thus, at the end of the survey, the selection comprised 7 blogs, which were written by the mother, father, or caregiver of children

with T1D or by the patient in adolescence.

Two researchers conducted independent secondary data collection in January 2015 with subsequent consensus meeting to finalize the sample. Data collection occurred through a checklist that enabled the identification of topics and number of posts.

Later, in January and February 2015, interviews in focus groups in a specialized center for the treatment of hypertension and diabetes were held. At the end, there were five groups totaling 19 participants. The inclusion criteria in the study was being diagnosed with the disease for at least one year. It was a convenience sample, i.e., participants present at the time of data collection and who met the inclusion criteria were selected. The number of participants was determined by saturation criteria and they were designated as "Child" followed by an Arabic numeral.

Seeking to facilitate the interaction between researcher and participants and thus obtain more reliable answers, we used a theatre play to ask the guiding questions of the interview. Interviews took place in a private room, lasted thirty-five minutes on average, were audio recorded, and transcribed for analysis.

The play began by presenting the participants, with jokes related to the names that were being identified and, subsequently, the following questions were made: What do you want to know about diabetes? What do you consider important to learn so you can take care of yourselves? What are your difficulties in the treatment?

Data analysis was based on the thematic content analysis proposed by Bardin and the categorization criterion was the logical-semantic (thematic categories[4]).

All the ethical principles in accordance to the law 466/12 of the National Health Council[5] were followed. The participants and their guardians signed the Free and Informed Agreement Term and the Free and Informed Consent Form, respectively. Research Ethics Committee of the Universidade Estadual do Ceará approved the project under protocol number 681631, CAAE 31318514.8.0000.5534 on June 9, 2014.

Results

This work is part of a thesis entitled "Construction, validation and implementation of a booklet on insulin therapy for children with T1D"[6]. The booklet was created by analyzing the learning needs of the target audience, focus of this manuscript.

In order to get a broader perspective of the learning needs of the target audience, blog posts were analyzed, in addition to interviews with children with T1D.

The blog survey and selection of virtual content on T1D occurred by recognizing that the internet has turned into an important tool in communication. The interaction in virtual environments has become very common among people of all ages, facilitating access to information and breaking barriers of space, time, language, and culture.

Content analysis of the seven blogs composing the sample allowed the identification of the most common doubts, questions, and comments. Furthermore, it enabled the identification of learning needs and topics of interest among internet users. **Table 1** describes the topics of 582 posts identified in the survey.

In these virtual environments, people deal with everyday matters related to type 1 diabetes. Patients and family members exchange information and experiences on disease care, treatment, coping mechanisms, among others.

Analysis of the topics presented in **Table 1** motivates reflection on the impact of insulin therapy on the daily lives of children. Reports of parents/caregivers revealed concern due to the child's suffering with insulin injections. Fortunately, these reports describe suffering at the beginning of the-

Table 1. Description of the topics identified in blogs about diabetes mellitus type 1. Fortaleza-CE, 2014.

TOPIC	F	%
Insulin therapy	156	26.8
Insulin pump	115	19.8
Glucose monitoring	60	10.4
Lifestyle changes	59	10.2
Hyper- or hypoglycemia	32	5.5
Mothers of children with T1D	28	4.8
Blue November	19	3.2
Time of diagnosis	18	3.1
Lack of inputs	18	3.1
DM and pregnancy	16	2.7
DM and family	16	2.7
DM and school	13	2.2
Food	13	2.2
Motivation	11	1.9
Health education	8	1.4
TOTAL	**582**	**100.0**

Source: Prepared by the authors

rapy, but with the support of family, friends and professionals, children tend to acquire mechanisms to confront this situation.

Insulin pump was also highlighted among internet users. It was recognized as an instrument that provides better quality of life, as it avoids daily injections.

Another issue verified frequently was the blood glucose monitoring. Posts identified indicate the importance of monitoring and maintaining blood glucose levels in appropriate values, which relate directly to the food adopted, as well as to insulin therapy, since the blood glucose value may require adjustments of insulin dosage.

It was observed that the three most talked-about topics on the blogs were related to needles and injections. In general, the posts were related to fear and pain of multiple insulin injections or glucose

monitoring at the beginning of treatment. Nevertheless, they also emphasized the adaptation to those procedures and recognition of their importance for controlling blood glucose.

After analyzing the virtual content, interviews were conducted in five focus groups, totaling a participation of 19 children (four, three, four, three, and five children in each group). Interviews aimed at questioning children about the difficulties in DM management and their learning needs. To obtain more reliable answers, we entered the children's imagination, conducting interviews through theatre play.

Dialogue was established through a theatre play in which the characters (nurse and child with T1D) interacted with the participants.

The play was written and performed by the author along with an undergraduate nursing student. It began by presenting the "actors" and the "audience". After moments of interaction, asking the participants' name, they made the following questions: What do you want to know about diabetes? What do you consider important to learn so you can take care of yourselves? What are your biggest difficulties in the treatment?

The meetings were recorded on video and audio, and the speeches were fully transcribed. Analysis of this content enabled the identification of units of meaning and context, which motivated the creation of the thematic categories presented in **Table 2**.

There are many doubts and difficulties permeating the daily lives of children with T1D and their families. When asked what they wanted to know about diabetes, most children showed interest in knowing the appropriate food. Among the answers to this question, we highlight:

> *I want to know what I can eat. My mom told me there are things that make me feel sick.*
>
> (Child 14)

Table 2. Description of thematic categories that emerged from the interviews in focus groups with children with T1D. Fortaleza-CE, 2015.

Question	Thematic category	Frequency of answers
1. What do you want to know about diabetes?	- Appropriate food - Insulin therapy - Why do I have diabetes?	11 7 1
2. What do you consider important to learn so you can take care of yourselves?	- Insulin self-administration - What I can eat - Glucose monitoring	10 6 3
3. What are your difficulties in the treatment?	- Daily insulin injections - Not eating what I like - Hypo- or hyperglycemia	10 5 4

Source: Prepared by the authors

> *I am still learning what I can eat. I know it is not good to eat street food, but sometimes I wonder if I can eat some food or not.*
>
> (Child 5)

> *It is good to know the food, so we do not end up eating the wrong things.*
>
> (Child 9)

Insulin therapy was mentioned in a smaller proportion by participants who reported being initiating self-administration or in the learning process for self-administration. The following statements demonstrate the unfinished knowledge and the interest in learning more about the subject: *"I am learning to inject insulin. I am not sure yet. I am afraid to do it wrong"* (Child 9). *"My mother said it is good to inject it myself. I want to learn it"* (Child 2).

Although food is a topic of great interest, insulin therapy was considered the main learning need, given its prevalence in subsequent questions.

Insulin therapy stood out because of the interest of participants who were learning self-administration as well as the other participants who raised difficulties related to pain, fear, transportation, and hyperglycemia after application.

Answers to the second question reveal the importance of knowing how to self-administer insulin, as shown in the reports:

> *The doctor showed me how to use insulin because I have to use it in the afternoon when I am at school.*
>
> (Child 2)

> *I do not like being pricked all day. This is very annoying.*
>
> (Child 8)

Food and blood glucose monitoring were also mentioned as knowledge required for self-care by six and three participants, respectively. "

> *You need to learn to prick your finger to monitor glucose. When your level is 100 it is good. If it is too high I feel sick.*
>
> (Child 3)

When asked about the difficulties in treatment, once again daily insulin injections predominated, followed by dietary restrictions and inability to eat the favorite foods, as described:

I receive a lot of pricks. Some days it makes me angry.

(Child 3)

I always liked chocolate. Before I used to eat it, but I cannot anymore.

(Child 6)

Discussion

This study found that the most talked-about topics on the blogs are related to needles and injections, namely: insulin therapy, insulin pump, and blood glucose monitoring. The main concern of parents and caregivers was due to the child's suffering with insulin injections and blood glucose monitoring.

When asked what they wanted to know about diabetes, most children showed interest in knowing the appropriate food. Nonetheless, insulin therapy was considered the main learning need, given its prevalence in the subsequent questions, which addressed the difficulties and important aspects of the disease.

Authors[7] used strategy similar to the current study to conduct an interview with children. Those authors collected the empirical data of their study through interviews combined with the use of puppets. They reported the intention of obtaining truthful testimonies, and assuming this is a difficult task due to various issues of the child development itself, they chose to use puppets as a resource to facilitate communication and interaction between participant and interviewer.

Type 1 diabetes treatment seeks to achieve a good metabolic control, promote proper growth and development, prevent complications, and maintain quality of life. In this perspective, insulin therapy stands out in the aspects related to self-administration, daily injections, and proper treatment management, in addition to food as the main learning needs identified in this study.

Program widely used in the UK to teach insulin therapy showed benefits in reducing glycated hemoglobin (HbA fell from 8.51 ± 1.41% (mean ± standard deviation) to 8.24 ± 1.29%, with a difference of 0.27, P<0.001); severe hypoglycaemia rate fell from 1.7 to 0.6 episodes per person per year; as well as evidenced reduced psychological stress and improved health perception[8].

In this program, patients learned to adjust insulin according to carbohydrate intake and glucose monitoring at home[8]. This complementarity action of insulin therapy is also supported by other authors, who claim that insulin, diet, and physical activity should be associated[9].

Study evaluating the impact of eating habits in the metabolic control of children and adolescents with T1D found that diets with high protein, low saturated fat, and low glycemic index and glycemic load positively affected the glycemic control of individuals approached[10].

Among people with type 1 diabetes mellitus, intensive glycemic control prevents the development and progression to micro- and macrovascular complications compared with conventional treatment. Targets for glycemic control in children and adolescents with T1D are also more flexible[2].

Identifying the difficulties in treatment and learning needs contributes to the implementation of motivating educational activities that arouse public interest in an active and reflective way, consequently enabling the knowledge acquisition for self-care.

Only through changes in perception factors and information processing there may be a significant learning with consequent possibility of changing attitudes[9].

International Standards for diabetes self-management claim that diabetes education effectively improves clinical outcomes and quality of life. Nevertheless, continuous support is also crucial to maintain the progress achieved by participants during educational activities[10].

From this perspective arises the need for continuous health education activities contextualized to the reality and individual needs. Additionally, patients should be evaluated on the acquired knowledge and techniques developed for the adequacy and effectiveness in treatment adherence.

Learning is recognized as an active process that requires motivation and willingness to learn. The use of active methodologies increases the potential of educational actions stimulating the construction and reshaping of concepts and meanings of factors related to the health-disease process[11].

Playfulness is also necessary in teaching-learning processes, which, in turn, is used as a tool to establish relationships, facilitating communication between health professionals and children, promoting self-awareness, imagination, cooperation, and creativity.

Study that evaluated educational materials produced for children with diabetes identified that only 66.6% were suitable for children. Among the 30 materials analyzed by the authors, 25 described stories of characters with diabetes, either through comics (20 educational materials) or in book format (5 educational materials). In other educational/informational materials evaluated, it was presented through text with illustrations, questions and answers, poem, music, and Cordel literature[12].

Children have a unique nature and present themselves as creatures that feel and think the world in a very particular way. Health education can offer children conditions to learn through games or intentional pedagogical situations.

In this context, it is emphasized that knowledge is essential, but not necessarily a self-care predictor. Study aimed to verify knowledge and attitudes of people with diabetes who participated in an education program for self-care, indicated that participants had knowledge and understanding of the disease, however, had difficulty with changes. Therefore, they did not change their attitudes to adequately cope with the disease[13].

Given the need for lifestyle changes and adoption of healthy habits, health education should be included as a care strategy for patients with type 1 diabetes. Thus, we highlight the challenge of performing this activity attractively, generating significant learning able to promote change.

Another way to help in coping with the disease and acquisition of knowledge related to their health-disease process is through the interaction of children and adolescents with friends and family. Authors[7] emphasize that this interaction can have a positive or negative contribution: the integration of children with T1D to their group of friends, understanding of their illness, and the treatment care by their peers are extremely valid questions to achieve a proper management disease.

Talking about the disease enables to work fantasies, exchange experiences, share feelings and doubts, and consequently contributes to the acquisition of coping and adaptation mechanisms[13]. The integration of patients with diabetes in a group of equals is one way of helping them.

It is worth highlighting in this study the wide range of reports due to the analysis of selected blogs nationwide. As limitation, the results identified may not represent a share of the population without internet access. Thus, the interview with the target audience aims to present a different strategy for conducting interviews with children through theater, while minimizing the abovementioned limitation.

References

1. Sociedade Brasileira De Diabetes. Diretrizes da Sociedade Brasileira de Diabetes: 2014-2015; [organização José Egidio Paulo de Oliveira, Sérgio Vencio]. – São Paulo: AC Farmacêutica, 2015.
2. BRASIL. Ministério da Saúde. Secretaria de Atenção à Saúde. Departamento de Atenção Básica. Diabetes Mellitus [Internet]. Caderno de Atenção Básica -N°36. Brasília: Ministério da Saúde; 2013. Acesso em: 25/01/2016. Disponível em: http://189.28.128.100/dab/docs/publicacoes/cadernos_ab/abcad16.pdf

3. Moreira MF; Silva MIT. Readability of the educational material written for diabetic patients. Online Braz J. Nurs [online]. 2012, 4(2). Acesso em: 23/07/2015. Available in: www.uff.br/nepae/objn402moreiraetal.htm

4. Bardin L. Análise de Conteúdo. Lisboa, Portugal; Edições 70, LDA, 2009.

5. Brasil. Conselho Nacional de Saúde. Resolução nº 466, de 12 de dezembro de 2012. Diretrizes e Normas Regulamentadoras de Pesquisas Envolvendo Seres Humanos. Diário Oficial União, Brasília, DF, n. 12, 13 de junho de 2013. Seção 71, p. 59.

6. Moura DJM; Guedes, MVC. Construção, validação, implementação e avaliação de uma cartilha educativa sobre insulinoterapia para crianças com diabetes mellitus tipo 1. Fortaleza. Tese (Doutorado em Enfermagem em Cuidados Clínicos). Universidade Estadual do Ceará. 2016.

7. Sparapani VC, et al. A criança com diabetes tipo 1 e seus amigos: a influência dessa interação no manejo da doença. Rev. Latino-am. Enfermagem. 2012, 20(1). Acesso em: 26/09/2014. Disponível: http://eerp.usp.br/rlae.

8. Mansell P. The Dose Adjustment for Normal Eating (DAFNE) education programme. Journal of Diabetes Nursing. 2010, 16(9).

9. Pereira DA; Costa NMSC; Sousa ALL; Jardim PCBV; Zanini CRO. Efeito de intervenção educativa sobre o conhecimento da doença em pacientes com diabetes mellitus. Rev. Latino-Am. Enfermagem (Internet). 2012, 20(3). Acesso em 10/09/2014. Disponível em: http://www.scielo.br/scielo.php?pid=S0104-11692012000300008&script=sci_arttext&tlng=pt

10. Funnell MM, et al. National Standards for Diabetes Self-Management Education. Diabetes Care. 2009, 32(1).

11. Araújo MG; Cassiano AN; Holanda CSM; Moreira PVSQ; Giovannini PE. Health education in the childhood education: active methodologies in approaching of the extensionist action. Rev enferm UFPE on line. 2013, 7(1): 306-13.

12. Gonçalves VM; Pacífico CF; Teixeira PG; Nagami V; Gon MCC. Análise dos materiais educativos sobre diabetes para criança. Perspectivas em Psicologia. 2015, 18(1): 44-56.

13. Pennafort VPS, Silva ANS, Queiroz MVO. The perception of nurses regarding educational practices for children with diabetes in hospital care. Rev. Gaúcha Enferm. 2014, 35 (3): 130-136