

Health literacy of mothers in managing emergency situations of their children with diabetes***Letramento em saúde de mães no gerenciamento de situações de urgência dos filhos com diabetes****La alfabetización en salud de las madres en el manejo de situaciones de emergencia de hijos con diabetes**Ana Carolina Andrade Biaggi Leite¹Kéllen Campos Castro Moreira²Rebecca Ortiz La Banca³Karen Bernardi da Graça⁴Rhyquelle Rhibna Neris⁵Karine Vilela Nascimento⁶Lucila Castanheira Nascimento⁷**Received: 20/03/2020****Approved: 15/10/2020****Published: 05/11/2020**

This is a qualitative and descriptive study, carried out between 2018 and 2019, in an outpatient clinic and pediatric wards of a public university hospital in the interior of the state of São Paulo, aiming to identify how Health Literacy helps mothers in the management of emergency situations of their children with type 1 diabetes mellitus. Individual semi-structured interviews were conducted with 10 mothers aged between 25 and 44 years (mean=34.1 years; SD±6.5). The number of emergency situations experienced: more than 10 (n=1); between 5 and 10 (n=3); and less than 5 (n=6). The respondents' children and adolescents were aged between 8 and 17 years (mean=12.2 years; SD±3.4) and time since diagnosis of T1D was between 3 months and 11 years (mean=4.1 years; SD ± 3.5). Four themes emerged: "Getting information related to diabetes care"; "Understanding information about diabetes"; "Assessing emergency situations: recognizing and interpreting signs and symptoms of hypoglycemia and hyperglycemia"; and "Applying knowledge: conduct of mothers in an emergency situation". The skills on access and understanding were insufficient, but the mothers constantly evaluated their children and referral to hospitals during emergencies was frequent, in the applying knowledge competence. It is concluded that mothers' literacy is dynamic, since competences are used according to their experiences in urgent situations, so health professionals must consider this dynamism and the need to provide support and promote mothers' health literacy.

Descriptors: Health literacy; Diabetes mellitus, Type 1; Pediatric nursing; Mothers; Emergencies.

Este é um estudo qualitativo e descritivo, realizado entre 2018 a 2019, num ambulatório e enfermarias pediátricas de um hospital público universitário no interior do estado de São Paulo, com o objetivo de identificar como a utilização do Letramento em Saúde auxilia mães no gerenciamento das situações de urgência de seus filhos com diabetes mellitus tipo 1. Foram realizadas entrevistas semiestruturadas individuais com 10 mães com idades entre 25 e 44 anos (média=34,1 anos; DP±6,5). O número de situações de urgência vivenciadas: mais de 10 (n=1); entre 5 e 10 (n=3); e menos que 5 (n=6). As crianças e adolescentes filhos das pesquisadas possuíam idades entre 8 e 17 anos (média=12,2 anos; DP±3,4) e tempo de diagnóstico de DM1 entre 3 meses e 11 anos (média=4,1 anos; DP±3,5). Emergiram quatro temas: "Acessando as informações relacionadas ao cuidado do diabetes"; "Compreendendo as informações sobre o diabetes"; "Avaliando as situações de urgências: reconhecendo e interpretando os sinais e sintomas de hipoglicemia e hiperglicemia"; e "Aplicando os conhecimentos: conduta das mães diante de uma situação de urgência". As competências sobre acesso e compreensão apresentaram-se insuficientes, mas as mães avaliavam constantemente seus filhos e foi frequente o encaminhamento para o hospital durante as urgências, na competência aplicação de conhecimentos. Conclui-se que o letramento das mães é dinâmico, visto que as competências são utilizadas de acordo com suas vivências em situações de urgência, de modo que os profissionais de saúde devem considerar esse dinamismo e a necessidade de fornecerem apoio e promoverem o letramento em saúde das mães.

Descritores: Letramento em saúde; Diabetes mellitus tipo 1; Enfermagem pediátrica; Mães; Emergências.

Este es un estudio cualitativo y descriptivo, realizado entre 2018 y 2019, en un ambulatorio y salas de pediatría de un hospital público universitario, en el interior del estado de São Paulo, con el objetivo de identificar cómo el uso de la Alfabetización en Salud ayuda a las madres en el manejo de las situaciones de emergencia de sus hijos con diabetes mellitus tipo 1. Se realizaron entrevistas individuales semiestructuradas a 10 madres entre 25 y 44 años (media=34,1 años; SD±6,5). El número de situaciones de emergencia experimentadas: más de 10 (n=1); entre 5 y 10 (n=3); y menos de 5 (n=6). Los niños y adolescentes hijos de las encuestadas tenían edades entre 8 y 17 años (media=12,2 años; SD±3,4) y el tiempo de diagnóstico de DM1 entre 3 meses y 11 años (media=4,1 años; SD±3,5). Han emergido cuatro temas: "Accediendo a las informaciones relacionadas con el cuidado de la diabetes"; "Comprendiendo las informaciones acerca de la diabetes"; "Evaluando las situaciones de emergencia: reconociendo e interpretando los signos y síntomas de la hipoglucemia y la hiperglucemia"; y "Aplicando los conocimientos: la conducta de las madres en una situación de emergencia". Las competencias acerca del acceso y de la comprensión fueron insuficientes, pero las madres evaluaban constantemente a sus hijos y se hacían frecuentes remisiones al hospital durante las emergencias en la competencia de aplicación de conocimientos. Se llega a la conclusión de que la alfabetización de las madres es dinámica, ya que las competencias se utilizan de acuerdo con sus experiencias en situaciones de emergencia, por lo que los profesionales de la salud deben tener en cuenta ese dinamismo y la necesidad de prestar apoyo y promover la alfabetización en salud de las madres.

Descriptores: Alfabetización en salud; Diabetes mellitus tipo 1; Enfermería pediátrica; Madres; Urgencias médicas.

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INTRODUCTION

Type 1 diabetes (T1D) is the most prevalent endocrine-metabolic disorder in childhood and adolescence. In Brazil, the estimated number of children and adolescents with T1D is 88,300, with 9,600 new cases per year, making it the country with the third highest number of children with T1D in the world, less than only the USA and India¹.

It is characterized by an increase in the level of glucose in the blood, resulting from a functional failure of the immune system, which destroys beta-pancreatic cells and prevents the production of insulin and, consequently, hinders the use of glucose as an energy source by the body². The treatment of children with T1D is based on the replacement of the exogenous insulin hormone, by subcutaneous application and self-management through glycemic, nutritional monitoring, physical exercise and health education in diabetes to avoid acute and chronic complications^{2,3}.

The changes resulting from diagnosis and treatment have an impact on the daily life of the whole family. Visits to the health unit become recurrent, it is necessary to apply insulin daily and change diet, with meal times, as well as instituting other care related to T1D in the school context, which together can be overwhelming, including in the financial aspect⁴⁻⁶.

Emotional and psychosocial factors also interfere with the management of children with T1D⁶⁻⁸. The diagnosis of T1D in a child has a significant impact on the parents' experience of caring for them. After diagnosis, many families adopt hypervigilant behavior in care that involves feeding and glycemic monitoring of children and adolescents, this being a role played mainly by the mother⁹. This attitude is taken by families to prevent future health complications and urgent situations.

Metabolic ketoacidosis is the most common cause of emergencies and deaths in children and adolescents with T1D¹⁰. The initial recognition of symptoms and the timely search for treatment prevent the occurrence of metabolic ketoacidosis. However, scientific evidence points to reflections of the functional level of Health Literacy (HL) in the recognition of urgent signs and symptoms, as well as in the quick decision making in seeking health care¹¹⁻¹³.

Individuals with higher levels of HL have better control of chronic diseases such as diabetes. On the other hand, people with low levels of HL have increased morbidity, low adherence to medications, limited levels in shared decision making, frequent hospitalizations, greater use of health services and higher cost in the treatment of the disease^{11,12}.

Alfabetização para a Saúde (Health Alphabetization - HA) is a non-comprehensive translation for Health Literacy in Brazilian Portuguese. In Brazil, sometimes the terminologies Health Alphabetization or Health Literacy (HL) are used, which expresses a concept that goes beyond reading and writing skills alone, emphasizing the resulting dynamic, progressive and reflective aspect of knowledge¹⁴.

Thus, HL consists of the ability to access, understand, evaluate and apply information in favor of healthier lifestyles and quality of life, and implies the continuous development of skills and competences¹⁴. The theoretical model consists of four competencies: access, understanding, evaluation and application of health information. These skills are related to three domains: health care, disease prevention and health promotion^{13,14}.

Due to its relevance, the number of studies that address HL in the experience of chronic diseases, such as T1D, has been increasing^{11,12,14}. However, there is a lack of qualitative scientific evidence on child health that addresses the HL interface and the experience of mothers in urgent situations for their children with T1D. Thus, this study aimed to identify how the use of Health Literacy helps mothers to manage emergency situations of their children with type 1 diabetes.

METHOD

This is a descriptive study, with qualitative analysis of data, conducted under the theoretical framework of Health Literacy¹⁴. HL is defined as the knowledge, motivation and skills that people have to access, understand, evaluate and apply health information in the context of health care, prevention and promotion. This theoretical model indicates that HL has four competencies: access, understanding, evaluation and application of health information¹⁴.

These skills were used to guide data analysis and identify how mothers use HL to manage urgent situations for their children with T1D. The guidelines of the consolidated criteria for reporting qualitative research (COREQ) checklist were used to report the information of this research¹⁵. It was used as a research question: *How the use of Health Literacy helps mothers in managing the urgent situations of their children with T1D.*

The mothers of children and adolescents with T1D participated in the study. Mothers with children under 18 years of age who were undergoing treatment for T1D for more than two months were included. Mothers who were not the primary caregivers of their children and had not experienced emergency situations related to T1D were excluded from the study.

Data collection took place between August of 2018 and September of 2019 in the waiting room of a pediatric outpatient clinic and in the pediatric wards of a public university hospital, both located in the interior of the state of São Paulo.

Potential mothers were approached, and they received explanations about the investigation and an invitation to participate. In order to provide comfort and ensure confidentiality, they were sent to a private place with less circulation of people, without the presence of their children. This is where the interviews, which were audio-recorded, took place.

A semi-structured interview was conducted with each participant, guided by the following questions: *"Tell me how was the first time you experienced an emergency situation with your child due to diabetes?"*, *"Tell me how were other emergency situations you experienced with them due to diabetes?"* and *"What has changed between the first experience and the others?"*. Other questions were asked according to the progress of the interview and the need to deepen the data. The minimum and maximum time for the interviews was 15 and 46 minutes, respectively, with an average of 25 minutes, always respecting the availability of interviewees.

Individual interviews were conducted by a trained undergraduate student and accompanied by a nurse and PhD student with experience in collecting qualitative data. Both were supervised by a researcher experienced in the theme and methodological approach of the research. The researchers had no previous link with the study participants and were not involved in the care of their children. A convenience sample was used, and the recruitment of mothers was interrupted when the data collected was sufficient to answer the research question¹⁶.

The interviews were transcribed in full and analyzed using deductive content analysis^{17,18}. The QDA Miner Liter[®] software was used to assist in the organization and analysis of qualitative data. The deductive content analysis was conducted according to the following steps^{17,18}: (I) familiarization of the data, through repetitive reading of the transcribed interviews; (II) identification of initial codes, according to content related to the theoretical framework of Health Literacy¹⁴; and (III) Construction of results. These steps were taken by two authors and validated by two others, both experienced researchers in the subject and in this type of analysis.

The project was approved by the Human Research Ethics Committees of the proposing and co-participating institutions (under filling No. 2,819,293). All participants were previously informed about the study proposal, guarantee of anonymity and about the right to withdraw from the study at any time, without prior justification. After accepting the invitation, they signed the Free and Informed Consent Form. In the presentation of results of this research, the names of the participants were replaced by other fictitious ones, in order to preserve anonymity.

RESULTS

This study included 10 mothers, aged between 25 and 44 years (mean = 34.1 years; SD \pm 6.5). The number of emergency situations experienced: more than 10 (n = 1); between 5 and 10 (n = 3); and less than 5 (n = 6). The level of education presented by the mothers was: incomplete elementary school (n = 2); complete elementary school (n = 2); incomplete high school (n = 1); complete high school (n = 4); and complete higher education (n = 1).

The children of the respondents were aged between 8 and 17 years (mean = 12.2 years; SD \pm 3.4) and time since diagnosis of T1D was between 3 months and 11 years (mean = 4.1 years; SD \pm 3.5).

Through the analysis of interviews, four themes related to the HL competences of mothers of children and adolescents with T1D were constructed: (1) "Getting information related to diabetes care"; (2) "Understanding information about diabetes"; (3) "Assessing emergency situations: recognizing and interpreting signs and symptoms of hypoglycemia and hyperglycemia"; and (4) "Applying knowledge: conduct of mothers in an emergency situation".

Getting information related to diabetes care

After diagnosing their children's T1D and inserting a new care routine, mothers felt the need to expand their information. Access to information about T1D is a constant process:

Because it is a disease that has no cure, which is forever, and can progress more and more. (Gabriela, 28 years old, incomplete high school education. Mother of a boy of 8 years, 4 years of diagnosis)

Before the diagnostic confirmation, some mothers stated that they were unaware that diabetes could affect children and adolescents, as exemplified:

I did not understand that diabetes happened in children. My son was ten years old, for me this disease happened only later on. (Helena, 38 years old, complete high school education. Mother of a 17 year old boy, 7 years of diagnosis)

Consequently, the possibility of these mothers linking signs and symptoms with the diagnosis of T1D was more distant:

She was losing weight fast, it was my mother who saw it, she thought she was very thin, with very deep eyes. We thought it was an urine tract infection, because she drank a lot of water and went to the bathroom. (Emília, 30 years old, complete high school education. Mother of a 12-year-old girl, 6 years of diagnosis)

However, some mothers assumed the possibility of their children being diagnosed with T1D, as they had previously accessed this type of information, and they knew that this diagnosis is not restricted to the adult population:

At night I couldn't win the diaper changes. I started to realize that my son was peeing a lot and was asking for too much water. I got suspicious. I took him to the pediatrician and said: "I suspect he may have diabetes". (Camila, 37 years old, incomplete elementary school education. Mother of a 12 year old boy, 11 years of diagnosis)

After consolidating the diagnosis, the mothers had doubts about the pathophysiology of the disease, as they did not know what had triggered it and associated T1D with the risk factors of Type 2 Diabetes (T2D), such as eating habits, as shown in the above:

I imagined that he had diabetes because he ate too much candy. It was what I always heard. But the first time the doctor did his "dextro" [capillary blood glucose test], he said: "Mother, be calm, it's not your fault, he didn't eat too much candy". (Gabriela, 28, incomplete high school education. Mother of an 8-year-old boy, 4 years of diagnosis)

At times, the access was lonely:

All of this I had to learn on my own. I am a nursing technician, but I had never applied insulin. (Alice, 25 years old, complete high school education. Nursing technician. Mother of a 9 year old girl, 8 months of diagnosis)

Other times, the process of accessing information involved other people, such as health professionals:

The health professionals were very polite, answered all my doubts. (Diana, 32 years old, complete high school education. Mother of a 12 year old girl, 11 months of diagnosis)

The context of hospitalization favored mothers' contact with health professionals and provided access to information:

Now, during treatment at the hospital, both nurses and [nursing] technicians answered all my doubts. (Gabriela, 28, incomplete high school education. Mother of an 8-year-old boy, 4 years of diagnosis)

When the information accessed with health professionals was not sufficient or the language used by them was not adequate to answer the mothers' doubts, they would resort to books, the internet (YouTube®), other parents of children with T1D, relatives and friends. The

most cited relatives and friends were those who had previous experience with diabetes, such as an aunt diagnosed with T2D:

The doctor gave me a book, and I didn't understand much. So I went to YouTube® (laughs). I would go to YouTube® and search. Other times, I called my aunt, who has T2D, and asked her. (Alice, 25, complete high school education. Mother of a 9-year-old girl, 8 months of diagnosis)

The mothers identified the most favorable context for accessing information, especially in urgent situations. For them, health professionals who are specialists in T1D and worked in the hospital where their children were being cared for were the ones who best guided them and met their needs. Thus, once this source of access to information was identified, mothers gathered skills and experiences to assess information from other contexts, such as emergency care in health services in primary care:

Primary care professionals are not used to it, and when there is some guidance that the endocrinologists pass on to me, I pass it on to them, especially to nursing technicians, who do not know what to do when blood glucose is high or low. (Diana, 32 years old, complete high school education. Mother of a 12 year old girl, 11 months of diagnosis)

Understanding information about diabetes

Mothers showed understanding of information about their children's diabetes and, consequently, are able to identify signs and symptoms of hypoglycemia and hyperglycemia:

When she has hypoglycemia, she feels sick. Her stomach starts to turn, she starts to feel sick. When her diabetes is already high, hyperglycemia, she is very sleepy, she goes straight to sleep. (Diana, 32 years old, complete high school education. Mother of a 12 year old girl, 11 months of diagnosis)

The participants also recognized the need to change habits to control a chronic disease such as T1D, in search of a more quality life:

The difference is the food, it is eating at the right time, to not get sick. Being aware of eating right, at the right times and the right foods, to have quality of life. (Fernanda, 38 years old, complete higher education education. Mother of a 8 year old girl, 3 months of diagnosis)

Understanding what behaviors should be adopted in imminent urgent situations was another aspect highlighted, so that they could take responsibility for the care:

We have to do what needs to be done: give him sugar and wait for the reaction. Because if we manage to give him sugar before he goes into a coma, we don't have to take him to the doctor. So, first, you have to run with sugar. Now, if I had glucagon at home, I would just apply it. Glucagon makes the reaction faster. I try to help with sugar and then, if necessary, take him to the doctor. We have to be very careful, because we cannot give him water, he can choke. (Camila, 37 years old, incomplete elementary school education. Mother of a 12-year-old boy, 11 years of diagnosis)

Recognizing themselves as references of care in the family, mothers considered themselves the primary caregivers of their children, which imposed on them the need to be always up to date on the best behaviors. However, they believed that this knowledge should be shared with other family members, including the child or adolescent with T1D, as they were afraid that they would not be close to their children at all times to manage any emergency situations:

At home I give instructions, but nobody else knows how to do it like I do, nobody does it. Like in a situation of hypoglycemia: if he is with someone, nobody knows how to do it. So I'm afraid, a fear. My husband does not know how to deal with the symptoms, if he has a seizure, hyperglycemia, hypoglycemia, he will call me, if I am not at home. (Gabriela, 28 years old, incomplete high school education. Mother of an 8 year old boy, 4 years of diagnosis)

The mothers want to transmit this knowledge to their children and teach them how to practice self-care, so that they also remain vigilant in relation to urgent situations:

At first I didn't understand anything. She was sick, I didn't know what she had, and then I started to learn. Now she says she is hungry, she already takes the device [glucometer] and sees it. She takes care of herself, she helps a lot. (Juliana, 44 years old, incomplete elementary school education. Mother of a 17 year old girl, 7 years of diagnosis)
I know how to explain, but those who have diabetes have to help a lot too. (Camila, 37 years old, incomplete elementary school education. Mother of a 9 year old boy, 5 years of diagnosis)

When experiencing the care of their children, mothers were learning and understanding more about T1D:

When we find out, we try to study more. Over time, we learn how to deal with situations. (Emília, 30 years old, complete high school education. Mother of a 12 year old girl, 6 years of diagnosis)

The learning and understanding of some information often occurred during the situations themselves, which shows the continuity and dynamics of this process:

As they say, we never learned everything, we are always learning. From experience, diet stuff are interesting, but they raise glucose in the same way that non-diet stuff. (Camila, 37 years old, incomplete elementary school education. Mother of a 12 year old boy, 11 years of diagnosis)

Although they were able to access information about T1D, this did not guarantee that they fully understood the content of everything they accessed. There were situations in which they only understood some information during the performance of care, in the face of failure, exposing their children to a possible emergency situation:

The doctor asked me to apply the three insulins every half hour. For example, I applied NPH, then I waited a little and applied Humalog. Then waited and applied the other. But I went and applied all at once. At once, each with their own syringe, but at once. I finished applying one and had the other ready. Then I think it peaked at once and fell [referring to blood glucose]. (Alice, 25 years old, complete high school education. Mother of a 9 year old girl, 8 months of diagnosis)

Assessing emergency situations: recognizing and interpreting signs and symptoms of hypoglycemia and hyperglycemia

When mothers accessed and understood information about T1D, they were able to assess urgent situations. Recognizing and interpreting signs that indicated these situations. However, it depended on the ability of each one of them to use skills and abilities, which are usually acquired and improved during the care process.

The mothers' assessment capacity is related to several factors. First, their previous life experiences, which are linked to the information they accessed, to what was actually understood and to situations previously experienced:

I already knew how to control better in the second emergency. I already knew what had to be done. (Helena, 38 years old, complete high school education. Mother of a 17 year old boy, 7 years of diagnosis)

We have to be alert, if she feels any pain, we already run with her [to the health service]. (Emília, 30 years old, complete high school education. Mother of a 12 year old girl, 6 years of diagnosis)

The assessment was also influenced by the individual characteristics of the children, such as: clinical condition, type of current treatment, age, stage of development and involvement in self-care. These specificities determined different contexts of urgencies to be assessed:

My son started complaining a lot about pain in his belly, he said he felt like throwing up and didn't want to eat. He was like that, very soft. He was feeling really bad and his mouth smelled of ketone. I did the "dextro" [capillary blood glucose test] at home, it was around three hundred. (Gabriela, 28 years old, incomplete high school education. Mother of a boy of 8 years, 4 years of diagnosis)

Mothers assessed the signs and symptoms with the help of their children, when they were in a developmental phase in which they were able to report what they felt:

My daughter arrived saying she was not well and went to bed. I was in the room, she sent a message, because sometimes she doesn't have a reaction to get up or call, shout, something. I arrived at the room and she was already crying, saying she was not well. (Ingrid, 42 years old, complete elementary school education. Mother of a 16 year old girl, 2 years of diagnosis)

Over time, after experiencing care, they demonstrated to know how to correctly recognize and interpret signs and symptoms of T1D. It is noteworthy that this assessment took into account the individuality of their children:

When it is high [blood glucose] she becomes a little more nervous, and when it is low, she becomes soft. She starts to say: "I don't feel well". She eats something and goes back to normal. (Fernanda, 38 years old, complete higher education. Mother of an 8 year old girl, 3 months of diagnosis)

When he complains of hunger, when he is very soft, I know it is hypoglycemia. He had a white mouth and said "mom, I'm hungry". So I already know that it is a hypoglycemia. Now when he is very agitated, very nervous, I know his blood sugar is high. Even if it's not time of the dextro, I do it, because I know it is high. (Gabriela, 28 years old, incomplete high school education. Mother of a 8 year old boy, 4 years of diagnosis)

During the evaluation, some mothers felt insecure and were unable to differentiate the signs and symptoms of situations of hypoglycemia or hyperglycemia:

When it is low I know, now when it is very high it is more difficult. (Ingrid, 42 years old, complete elementary school education. Mother of a 16 year old girl, 2 years of diagnosis)

Other mothers needed clearer data, such as the capillary blood glucose level, to assess signs and symptoms that preceded the emergency situation:

I still can't tell what the symptom is. I prefer, so as not to be in doubt, to prick and look [refers to the capillary blood glucose test] if it is low or if it is high. When I'm in doubt, I already do that. (Alice, 25 years old, complete high school education. Mother of a 9 year old girl, 8 months of diagnosis)

Applying knowledge: conduct of mothers in an emergency situation

Once the information regarding their children's T1D was accessed, understood and evaluated, mothers were able to apply this knowledge in urgent situations. Usually, they tried to control their children's blood glucose with food or insulin, and monitored the effectiveness or lack of it in these behaviors based on the capillary blood glucose test. If they were unable to manage the situation, they sought care at the health services:

I correct it with insulin if it is high [blood glucose], I give water. If it is low, I have to put honey in her mouth, gums and give her water too. (Fernanda, 38 years old, complete higher education. Mother of an 8 year old girl, 3 months of diagnosis)

She warns before that she is not well, or that she starts to feel numb, something like that. It measures diabetes, if it is too high, I give insulin. If it doesn't get better, we run with her to the hospital. (Ingrid, 42 years old, complete elementary school education. Mother of a 16 year old girl, 2 years of diagnosis)

I had given her juice to drink, but it didn't raise her blood sugar. I waited for half an hour and measured again [capillary blood glucose]. It had risen a little bit, it didn't go up a lot, and she was still sick, throwing up. So I called her father, and we took her to the hospital. (Emília, 30 years old, complete high school education. Mother of a 12-year-old girl, 6 years of diagnosis)

Some mothers, when they identified the emergency situation, preferred to go to the health service immediately. The most cited health service was the referral hospital, where their children received treatment:

She was vomiting, had a headache, started to vomit black. She was at home with a headache and started to vomit. So I took her to the hospital. (Bruna, 27 years old, complete elementary school education. Mother of an 11 year old girl, 3 years of diagnosis)

I don't even do anything at home. I already pick her up and take her to the hospital. (Diana, 32 years old, complete high school education. Mother of a 12 year old girl, 11 months of diagnosis)

Faced with urgent situations, the participants changed the habits of the whole family, including food, to avoid possible emergencies:

The diet is lowcarb [laughs]. So, for the family, it was good, everyone has already entered the diet. (Fernanda, 38 years old, complete higher education. Mother of an 8 year old girl, with 3 months of diagnosis)

Everything changes. Food changes, behavior changes, care changes, we start to have more attention. Sometimes, we nag her a bit, because we are afraid that she will do something and get hurt. Because healing wounds is difficult for her. (Emília, 30 years old, complete high school education. Mother of a 12-year-old girl, 6 years of diagnosis)

These changes were linked to challenges. One participant reported difficulty adjusting the family's diet because her other daughter had a different lifestyle from the one that diagnosed with T1D. Another mother said that the school adapted food to her son's needs over time and, when there were children's parties, she prepared and sent a piece of diet cake, so that he could eat some sweets like the other children:

We didn't succeed and she couldn't adapt. The sister goes out, goes to the clubs, and she wants to go along, so it doesn't help. (Ingrid, 42 years old, complete elementary school education. Mother of a 16 year old girl, 2 years of diagnosis)

In the beginning, the school did not provide an adequate snack. I had to send it. Today, at school, I thank God very much, because they provide what he needs. At parties, I was afraid that he would feel like it, so I made a cake for him myself, and put it on the napkin. (Camila, 37 years old, incomplete elementary school education. Mother of a 12 year old boy, 11 years old diagnosed)

DISCUSSION

This research revealed how mothers of children with T1D access, understand, evaluate and apply information related to their child's diabetes management, especially in urgent situations. Given the chronic nature of T1D, management must be implemented from the moment of diagnosis and extend over the course of life⁵. Therefore, the health team that assists families of young people with diabetes needs to be attentive to the development of mothers' HL, in all stages of the disease.

Participating mothers obtained information about pathophysiology and care of T1D through the guidance received from health professionals, in books and through internet search.

However, they reported not understanding the origin and pathophysiology of this disease. It is common for parents to confuse T1D with type 2 diabetes mellitus, often related to complications such as nephropathy or amputations in adults, or to associate the occurrence of their children's T1D with hereditary causes. For this reason, many feel guilty about the child's diagnosis and fear for the child's future, which can lead to other psychological problems such as anxiety and depression^{19,20}.

The quality of the information provided at the time of diagnosis and during treatment of T1D is extremely important for mothers, as they are factors that can impact the management of the child's disease, as mentioned in not trusting the care provided to the child in primary care or in emergency services. Thus, in addition to access to quality information, they need to understand the content of what was explained to them, considering that, in this investigation, there was no relationship between understanding of the information and the mothers' education level.

The insecurity reported by mothers reveals a gap in the training of health professionals working in these areas that deserves to be highlighted. A multicenter study identified barriers encountered by health professionals in managing diabetes, such as few resources offered at the institution or not having received training in the area²¹. Thus, health services that care for children with T1D in urgent situations must ensure that professionals are properly trained, since they will be responsible not only for assisting children with T1D but also for the health education of parents, clients of the service.

Access to quality information, offered through effective health communication (with appropriate language, dialogue, respect, participation, multiple knowledge and different professionals) has the potential to improve mothers' understanding of urgent situations. Therefore, it is necessary to invest in the training of health professionals, as well as in permanent education actions in the workplace, and to promote individualized health education to the caregivers of children with T1D, especially to mothers.

The identification of the mothers' HL revealed how they understand and evaluate information received on the recognition and treatment of hypoglycemia and hyperglycemia, considered one of the skills for the survival of children with T1D. Survival skills are the first self-care practices taught to parents and are vital for children with T1D.

Ideally, everyone involved in child care should be trained to recognize and intervene at the event of hypoglycemia or hyperglycemia²². However, this is not an easy task, nor is it intuitive. Understanding and correctly evaluating information about signs and symptoms that precede an emergency situation is decisive for an imminent outcome. For this reason, even after providing information on the management of hypoglycemia and hyperglycemia, the health professional must ensure that mothers feel able to act when required.

The mothers reported knowing some signs and symptoms that precede an emergency situation. Sometimes, even though they did not have adequate access to information through health education, they presented empirical knowledge, the result of their individual experiences. Therefore, the understanding of signs and symptoms occurs in the practice experienced, resulting from the constant evaluation of the child, and not only from access and understanding of information. Future studies may test interventions that aim to improve the mothers' HL on the management of urgent situations. Previous experiences in teaching other life support topics show that the use of theoretical-practical classes and realistic simulation can empower mothers to care for children in emergencies^{23,24}.

The action when hypoglycemia and hyperglycemia occur prevents the development of coma or seizures and, for this reason, the parents and caregivers of the child with T1D should be vigilant²². Despite not recognizing the differences between signs and symptoms of hypoglycemia and hyperglycemia, mothers described some home treatment practices and occasions when they took their children to the emergency service. There are parameters that

dictate when the treatment of hypoglycemia and hyperglycemia should transpose home care to hospital care^{25,26}.

Fear of hypoglycemia is one of the aspects most reported by parents of children with T1D, often associated with stress, Burnout syndrome and fatigue^{27,28}. Thus, the actions to be taken in cases of hypoglycemia and hyperglycemia is a subject that must be addressed at each consultation and frequently revisited by the health professional, with a view to identifying any signs of stress from the caregiver.

In the responsibility for treatment in urgent situations, mothers are the main caregivers and, thus, live in constant vigil of the child's glycemic values, feeling forced to be "*super-mothers*"²⁹. However, in this study, mothers expressed the desire to share responsibility for identifying the signs and symptoms that precede an emergency situation with the child's father or even with the child himself.

The division of responsibilities in diabetes management involves areas of priority and delegation of tasks, which can occur between parents and children, as long as they are compatible with the child's developmental skills⁵. In the case of prevention of urgent situations, these tasks include ensuring that the child will always have the glucometer and a source of sugar for rapid absorption, or the material for insulin therapy in case of hyperglycemia. Thus, through the division of tasks, the child learns self-care practices, supported by parents or a responsible adult, who will be fundamental in promoting their health in adult life.

Changes in the whole family's lifestyle, such as changes in eating habits and promotion of a healthier life, were reported by the interviewed mothers and reflect how the care of the child goes beyond the mother-child dyad interaction. Thus, child care is not restricted to a level of care or to a single caregiver. The support networks for children with T1D, especially for the management of urgent situations, are the foundation for the promotion of a healthy life and free of complications from diabetes³⁰.

Support networks are presented in micro and macro social spheres, such as family, health professionals, levels of health care, public policies, the school, educators, the community, organizations and associations related to T1D and peers³⁰. Therefore, health professionals should take advantage of situations in which they promote the HL of mothers of children with T1D to assess the sources of family support in the face of an emergency. Based on this assessment, they must ensure resources that ensure healthy growth and living with diabetes.

The skills on "access" and "understanding" of information were insufficient. Mothers learned to interpret the signs and symptoms of T1D in their children during their own experience, with the "assessment" competence being constantly experienced. As for the "application" competence, the child was frequently referred to the referral hospital in emergency situations, with emphasis on the level of health promotion through changes in the habits of the whole family.

CONCLUSION

This study demonstrated that the HL of mothers of children and adolescents with T1D is dynamic, since they access, understand, evaluate and apply the information according to their experiences in urgent situations. Some limitations can be pointed out, such as the mothers' HL, which occurred exclusively through the analysis of qualitative interviews.

The increase in data collection with the support of a quantitative assessment, involving the application of measurement instruments, could add other results that would broaden the understanding of the object of study. In Brazil, there are few validated instruments to measure HL and, to date, specific instruments for parents or caregivers of children with T1D are unknown. In addition, data collection took place in a specialized service in T1D, which means that the families served there do not represent those without access to secondary health care, nor the particularities of other care contexts.

However, as strengths of this investigation, we can mention the innovation of the theme, as it is the first Brazilian study that highlighted aspects of HL of mothers on the management of urgent situations of children with T1D, which gives the health professional the opportunity an example of HL evaluation in this context.

Future studies are necessary to understand mediating and moderating factors of mothers' HL, such as the effect of schooling, age, employment or family situation, as well as research to access regional differences in access, understanding, evaluation and application of information on the management of urgent situations.

In addition, other studies can be carried out with other family members (father, grandparents and healthy siblings) and with children and adolescents diagnosed with T1D, to understand the dynamics of HL in these families.

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CONTRIBUTIONS

Ana Carolina Andrade Biaggi Leite and **Lucila Castanheira Nascimento** contributed to the conception, collection and analysis of data, writing and review. **Kéllen Campos Castro Moreira** and **Rebecca Ortiz La Banca** participated in the design, data analysis, writing and review. **Karen Bernardi da Graça** worked in the design, data collection and review. **Rhyquelle Rhibna Neris** and **Karine Vilela Nascimento** assisted in writing and proofreading.

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