Health literacy of children with diabetes on self-monitoring of capillary blood glucose

Letramento em saúde de crianças com diabetes sobre a automonitorização da glicemia capilar

Alfabetización sanitaria de niños con diabetes sobre el autocontrol de la glucemia capilar

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Abstract

Objective: To identify the domains of health literacy of children with diabetes evidenced in a therapeutic play session on self-monitoring of capillary blood glucose.
Methods: Qualitative study describing instructional therapeutic play sessions conducted at a diabetes camp in Sapucaí Mirim, Minas Gerais, Brazil. Children 8 to 12 years old, with no neurological disease or cognitive impairment, diagnosed with type 1 diabetes were included. The therapeutic play session included: demonstration of the self-monitoring of capillary blood glucose procedure on a doll, thematic storytelling and teach back from participants. During the session, participants were encouraged to report their previous experiences with self-monitoring, to demonstrate the technique and to reflect about its importance. All sessions were recorded and transcribed for thematic analysis, conducted in three phases: preparation of data, organization of categories, and communication of findings. Thematic content analysis investigated the domains of health literacy in light of Sørensen›s theoretical model.
Results: Two school-aged boys revealed how they understand and apply information about self-monitoring. The children showed that they did not know what glucose is and had difficulty explaining its relationship with diabetes. They also demonstrated that they were unaware of the need to record their blood glucose levels, the appropriate puncture sites, and how sharp objects should be disposed of.
Conclusion: The therapeutic play sessions revealed how children understand and apply information about self-monitoring of capillary blood glucose through a playful activity that is interesting for children with diabetes.

Keywords

Health literacy; Type 1 diabetes mellitus; Self-monitoring of blood glucose; Child; Games and toys; Pediatric nursing

Resumo

Objetivo: Identificar os domínios do letramento em saúde de crianças com diabetes evidenciados em uma sessão de brinquedo terapêutico sobre a automonitorização da glicemia capilar.
Métodos: Estudo qualitativo descritivo conduzido em um acampamento para crianças e adolescentes com diabetes na cidade de Sapucaí Mirim, Minas Gerais, Brasil. Foram incluídas crianças de 8 a 12 anos, sem distúrbios neurológicos ou dificuldades cognitivas, com diagnostico de diabetes tipo 1. A sessão de brinquedo terapêutico instrucional incluiu demonstração do procedimento em um boneco, uso de materiais usados no teste de glicemia capilar, narração de uma história temática e validação dos conceitos pelas crianças. Durante a sessão, os participantes foram incentivados a relatar sua experiência prévia com o automonitoramento, demonstrar a técnica e refletir sobre sua importância. As sessões foram filmadas e transcritas para análise temática de conteúdo, conduzida em três fases: preparação dos dados, organização em categorias e comunicação dos achados. Os domínios do letramento em saúde foram analisados segundo o modelo teórico de Sørensen.
Resultados: Dois meninos em idade escolar revelaram como compreendem e aplicam as informações sobre a automonitorização. As crianças mostraram não saber o que é glicose e apresentaram dificuldades para explicar sua relação com o diabetes. Demonstraram também desconhecer a necessidade do registro da glicemia, os locais adequados de punção e como devem ser descartados os perfurocortantes.
Conclusão: As sessões de brinquedo terapêutico revelaram como as crianças compreendem e aplicam as informações sobre o automonitoramento da glicemia capilar por meio de uma atividade lúdica interessante para a criança com diabetes.

Descritores

Alfabetização em saúde; Diabetes *mellitus* tipo 1; Automonitorização da glicemia; Criança; Jogos e brinquedos; Enfermagem pediátrica

Resumen

Objetivo: Identificar los dominios de alfabetización en salud de niños con diabetes evidenciados en una sesión de juego terapéutico sobre automonitoreo de glucemia capilar.

Descriptores

Alfabetización en salud; Diabetes mellitus tipo 1; Autocontrol de la glucemia; Niño; Juegos y juguetes; Enfermería pediátrica

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Métodos: Estudio cualitativo que describe sesiones de juego terapéutico instructivo realizadas en un campamento de diabetes. El análisis de contenido temático investigó los dominios de la alfabetización en salud a la luz del modelo teórico de Sørensen.
Resultados: Dos niños en edad escolar revelaron cómo entienden y aplican la información sobre el automonitoreo. Los niños demostraron que no sabían qué era la glucosa y tenían dificultades para explicar su relación con la diabetes. También demostraron una falta de conocimiento sobre la necesidad de registrar los niveles de glucosa en sangre, los sitios de punción adecuados y cómo deben desecharse los objetos punzantes.
Conclusión: Las sesiones de juego terapéutico revelaron cómo los niños comprenden y aplican la información sobre el automonitoreo de la glucemia capilar a través de una actividad lúdica interesante para los niños con diabetes.

Introduction

Type 1 diabetes mellitus (T1D) is a chronic condition that affects children and adolescents.[1] In Brazil, the third country in terms of number of cases, an average of 88,300 young people live with the disease.[2]Adequate T1D management is a challenge for the pediatric population, given the lack of adequate skills and knowledge, which can contribute to non-adherence to treatment as well as a significant increase in long-term complications.[3]

This difficulty, however, can be alleviated by developing diabetes education actions in order to promote people's autonomy, improve clinical results and prevent complications. Educating children about diabetes self-care helps them maintain a good quality of life, build social support networks, develop good family relationships and establish trusting relationships with healthcare professionals and their caregivers.[4] Furthermore, strategies and techniques based on behavioral theories, which consider children's development and preferences, can favor T1D management.[5,6]

In search of a better understanding of how health education strategies can help people with chronic diseases, the construct of health literacy (HL) has been widely documented.[7,8] HL consists of the ability to obtain, process, and interpret basic health information to make appropriate decisions and is influenced by personal, situational, societal, and environmental factors.[9] Therefore, HL impacts individual lives with regard to their use of healthcare services, their health behaviors, active participation in society as well as socioeconomic sustainability.[10] It is recommended that the promotion of HL begins in childhood, since during this period, cognitive, physical, and emotional capacities are still developing.[11]

When managing a chronic condition such as diabetes, HL has also been the subject of research over the last 10 years, especially with regard to the associations between the degree of HL and the clinical and psychosocial outcomes of the disease.[12,13] HL assessment, in turn, is also part of the nursing process and is included in the diagnosis "Readiness for Improved Health Literacy", included in the NANDA International, Inc. (NANDA-I) Classification.[14] However, there are no clear guidelines in literature regarding HL assessment in children with T1D.

One of the communication strategies in pediatric nursing that can benefit nurses in assessing children's HL is Instructional Therapeutic Play (ITP), recognized by the Federal Nursing Council as part of the nursing process for assisting children.[15] Specifically, ITP aims to prepare children to undergo some procedures,[16] such as capillary blood glucose testing.

Considering the importance of promoting HL in childhood and the potential of ITP in nurses' communication with children with T1D, in addition to the need to outline guidelines for nursing assessment of HL, this article aimed to identify the HL domains of children with diabetes evidenced in an ITP session on blood glucose self-monitoring.

Methods

This is a descriptive qualitative study, whose design and analysis followed the COnsolidated criteria for REporting Qualitative research (COREQ) guidelines.

The invitation to participate in the study, with the provision of consent and assent forms, took place at a meeting prior to the camp, when the coordination team clarified any questions parents and caregivers may have about the season. When boarding for the camp, the main researcher collected the signed forms and made them available to other caregivers and interested children. Among the signed forms, those relevant to school-aged children were selected, and information on the time of T1D diagnosis and the last

hemoglobin A1c (HbA1c) value was sought in campers' health records.

Two ITP sessions were held as part of a therapeutic play educational program implemented at a summer camp aimed at the recreation and education of children and adolescents with T1D in 2014 in the city of Sapucaí Mirim, Minas Gerais, Brazil.[17] This private camp welcomes around 80 young people aged 8 to 15 for six days in January for the diabetes session. The young people go to the camp unaccompanied by their parents and remain under the supervision of a volunteer multidisciplinary team, made up of endocrinologists, nurses, nutritionists, psychologists, physical educators and dentists.

All children participating in the camp, aged 8 to 12 years, without neurological disorders or cognitive difficulties that could prevent their participation in the educational activities with ITP, were invited. The exclusion criterion in the educational program was the use of an insulin pump, since the other meetings of the program included the conventional insulin injection technique only.

The ITP session held at the first meeting of the program addressed the blood glucose self-monitoring. The general objective outlined for participants was to understand the basic aspects of blood glucose monitoring. The specific objectives were: to understand and perform the correct technique for testing capillary blood glucose; to understand the importance of rotating the blood glucose monitoring sites; to understand the importance of recording blood glucose values and being able to interpret them appropriately; and to understand the appropriate disposal of the materials used.

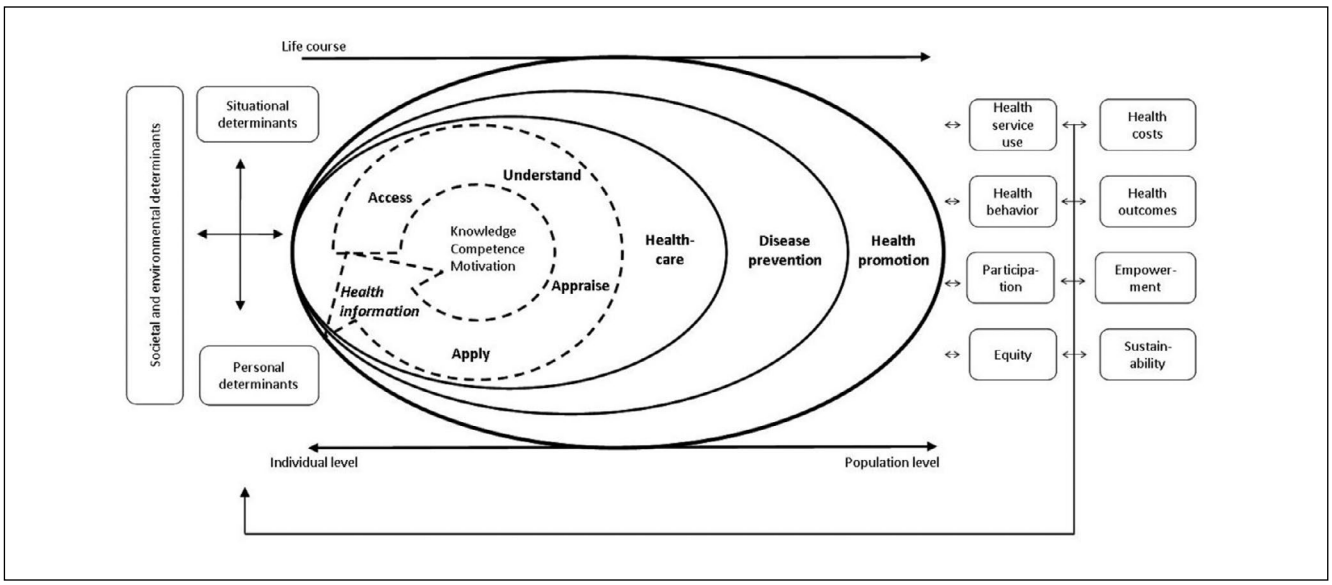
A cloth doll, a glucometer with reagent strips, disposable lancets, cotton, a 70% alcohol canister, a blood glucose diary and a ballpoint pen were used for the ITP session. The choice of materials followed the recommendations in literature for preparing therapeutic procedures.[15]

The session was planned and carried out by a nurse, the principal investigator, and followed these steps: 1. Inviting a child to participate in the ITP, respecting their refusal; 2. Providing information about the approximate duration of the ITP and the need to return the toys at the end of the session; 3. Asking the child to report how often they perform the blood glucose test at home; 4. Asking the child to demonstrate, using the doll, how they test their blood glucose at home; 5. Telling the child a story, available in Chart 1, about a young person who has diabetes and needs to perform the capillary blood glucose test by themselves; 6. Asking the child to demonstrate the capillary blood glucose test using the doll again, validating the concepts.

Chart 1. Instructional Therapeutic Play Session Story

This is Juju. He is 10 years old and has type 1 diabetes. When he found out he had diabetes, a nurse explained what glucose was. Do you know what glucose is? Glucose, or blood sugar, is found in many foods we eat and it is what gives us energy to play! It is not just sweets that have sugar. Pasta, bread, fruits and vegetables also turn into glucose, and the stomach breaks them down into little pieces and releases these molecules into the blood. People with diabetes have difficulty controlling their blood sugar. Sometimes it is too much, sometimes it can be too little. And how do we know this? A nurse showed Juju a device called a glucometer. To know how much sugar is in your blood, you need to test your blood with this device. Before taking the test, it is important that your hands are clean. You can clean them with soap and water or with a cotton ball and alcohol, whichever you prefer, always remembering that your fingers must be dry before the test.
To do the test, we need a device (glucometer), lancet (to prick your finger), and test strips (which will take the blood to the device and tell you how much sugar you have). The first step is to put the test strip in the device and check if it is working. With your hands clean, prick your finger with the lancet. The ideal place to prick your finger is on the side of your fingertip, because that is where we do not have our fingerprints and also where we have fewer nerves. After prickling, we put the blood drop on the test strip. Then, we put the strip in the device and a number will appear on the screen. Ideal blood glucose levels are individual. The expected blood glucose level for Juju may be different from that expected for another child. The important thing to know is that when it is less than or equal to 70, our blood sugar is too low. And when it is greater than or equal to 180, it is too high! Are we done? No. You still need to record the value, the time and any other important information about the value in your blood glucose diary. Capillary blood glucose should be measured at the times agreed with your doctor and whenever you feel it is necessary. You can never have too much control! That is why we should always go to appointments and do routine tests, because, in addition to blood glucose, we need to know how our metabolism is functioning and whether the insulin we take is working properly!

ITP sessions were filmed for later inductive thematic analysis[18] according to the following phases: 1) Preparation phase, which consists of collecting data suitable for content analysis, making sense of the data and selecting the units of analysis; 2) Organization phase, which includes coding and category creation, in addition to abstraction; 3) Results communication phase, in which results are described by the content of the categories that describe the HL domains identified in ITP session. In this regard, there was repeated reading of the transcripts of ITP sessions; listing of ideas



Source: Sørensen *et al*.[9]

Figure 1. Conceptual model of health literacy

about the data; classification of the data into main topics; review; naming and construction of results.

The results were interpreted according to the conceptual model of Sørensen *et al*.,[9] illustrated in Figure 1. According to this model, from the moment a person accesses information, they use their HL to understand that health information. The model then indicates that a person will assess the information, which means that they must have the ability to judge, filter, interpret and weigh health information. The last stage concerns the ability to apply the information considered relevant in health decision-making. To verify thevalidity and reliability of the analysis, the criteria suggested by ELO *et al*. for qualitative content analysis studies were used.[19]

Ethical precepts were ensured in compliance with Resolution 466/12 of the Brazilian National Health Council (In Portuguese, *Conselho Nacional de Saúde* - CNS). The study was approved by the Research Ethics Committee of a university under Opinion 72.608/2012 (Certificate of Presentation of Ethical Appreciation 05296712.2.0000.5505). To ensure the anonymity of selected subjects, fictitious names were assigned to participants.

Results

Two boys participated in ITP sessions: Chico Bento (C), 10 years old, diagnosed with T1D 4 years ago and with HbA1c of 8.2%; and Franjinha (F), 11 years old, diagnosed with T1D 6 months ago and with HbA1c of 7.1%. Each ITP session lasted approximately 20 minutes. Considering the four stages explained in the conceptual model, ITP sessions highlighted how children understand and apply the information received about blood glucose self-monitoring. Data analysis resulted in the creation of two categories: understanding information about blood glucose monitoring; and applying information about blood glucose monitoring. Both are presented below, with C and F representing children's discourse and R representing the researcher's discourse.

Understanding information about capillary blood glucose

At the beginning of ITP sessions, before explaining the origin of diabetes and the need for daily blood glucose testing, the investigator asked participants if they know what T1D is. Both children had difficulty describing what blood glucose and diabetes are, which may indicate a lack of understanding of the disease.

> *R: Do you know what blood sugar is? C: Blood sugar [Answers looking intently]. R: Yes. A nurse told him that diabetes was blood sugar. But do you know what diabetes is? C: Diabetes [pause] I don't know how to explain it, like that.*

R: But first I'm going to tell you a story, okay? With this doll you're showing me. This one here is Juju, he's 10 years old and has type 1 diabetes. When he found out he had diabetes, a nurse explained that sugar... that diabetes was blood sugar. Do you know what diabetes is? F: Yes, it is that [pause] when the pancreas has type 1 and type 2. Type 1 is when the body's cells [pause] the pancreas, but [pause] in my case it was like this, where the body's cells is not [pause], it thinks that the pancreas is not part of the body, so it goes there and attacks. Then type 2 [pause] produces insulin, but it does not produce enough.

The children also demonstrated partial knowledge of reference values for glucose monitoring results, but did not know how to interpret them completely. Chico Bento reported knowing the normoglycemia values and justified his knowledge based on the explanations provided by his mother.

R: Do you know your blood glucose levels? What is normal and what is not? C: My mother always tells me when it is normal, that it is 77 to 100. So, 77 and below is [pause] hypoglycemia. And high, hyperglycemia, when it is 200, 300. That is how my mother explains things to me.

Franjinha, when asked what a blood glucose level below 70 mg/dL and above 180 mg/dL means, demonstrated that he knew the concept, despite having some difficulty with some terms.

R: What is important to know? That when it is lower than [pause]? 70, we are [pause]. F: You have to [pause] is [pause] in glycemia. R: Hypoglycemia. F: Hypoglycemia. R: And if it is higher than 180, it is high. F: Yeah, and [pause] and [pause] is [pause] hyper [pause]. Wow, what was it like? Hyperglycemia.

Finally, the children demonstrated that they knew how to perform the capillary blood glucose test, although they did not always perform it correctly and did not understand the reasons for some practices. During ITP sessions, both participants were asked to demonstrate on the doll how they performed blood glucose tests at home. Chico Bento demonstrated that he knew the correct place on the finger for puncture as well as the reasons why the side is the most suitable region.

R: Is that it? Okay. Okay. And when you're doing the test, do you take any care with your finger, any place that you always prick? What is it like? C: It's in the corners, because it hurts less, and here is [pause] the fingerprint. There it hurts a lot. There on the side it hurts less, it's better, I think. [He says showing the correct puncture site on his fingers].

Franjinha demonstrated that he understood that sometimes the blood glucose value is altered due to not waiting for the alcohol to dry. He also recognized the importance of rotating the fingers and the correct puncture site, but he did not know why it was performed on the sides of the fingertips.

F: Then, I put [the drop of blood on the device], and it measures it. Sometimes my [blood sugar] would go up. R: Was [the finger] still wet? F: Yes, it was wet. R: I understand. And where do you prick the finger? F: Here in the corner [points to the side of the left thumb]. R: Do you switch fingers? F: Yes, I prick here. Sometimes I prick here, or here, here [while speaking, points to the sides of the fingertips of the left hand]. R: Do you know why we prick the side? F: It's because here [pause], I don't know. But, [pause] they said, it's to be pricked on the side. I don't know why. R: You don't know why? On our finger, the part where there are more nerves, which hurts the most, is the middle. And here in the middle we have a fingerprint, right, which is what identifies people. F: Oh yeah, because then the [pause] fingerprint can disappear.

Applying information about blood glucose monitoring

During ITP sessions, the children showed on the doll not only what they understand about blood glucose self-monitoring, but also how they apply the pertinent information in their daily lives. The use of health information about blood glucose monitoring was related to recording the values for later discussion with the doctor and daily decision-making. Chico Bento said he recorded everything on the computer to print and take to appointments.

C: I make a list, then I write down the day, the time, and my glucose. Then I write down what I ate. Then I write down how much insulin I took to mark everything. I find it easier, because if something happens, everything is marked down. Then nothing will happen. [R: [...] As soon as the result comes out, we'll write it down, somewhere. Do you write down the result at home? F: I do. R: Where do you write it down? F: On a piece of paper the doctor gives us. R: Do you have a notebook? F: Yes.

As for the interpretation of blood glucose levels for decision-making in T1D treatment, the participant also mentioned using a glucometer for verification. When asked about the need to perform blood glucose tests, he reported a situation related to sports practice and how he manages high values.

C:[...] When it [blood glucose] is high, and if glucose is over 260, you wait. You have to drink water to do sports, because otherwise it [blood glucose] can go up more and you can get sick. That's what I understand. R: [...] So, sometimes it can be very high, it can be too much, or it can be too little. And how do we know that? C: You have to check the glucose. (Chico Bento)

The interpretation of values in everyday life was also evident when one of the participants expressed the need to understand the relationship between blood glucose monitoring and nutrition for the proper T1D management.

C: Then you see the result, you see if you're going to correct it, or if you're not going to correct it, if everything is normal, if you're going to count your carbohydrates, if you're going to eat. I eat every 3 hours. So, I think it's important because you're always monitoring. Otherwise, you don't control it, you don't know what's happening to you.

Discussion

This study presents the conduction of two ITP sessions in which the HL domains of children with diabetes were observed, specifically regarding how they understand and apply information on self-monitoring of capillary blood glucose, according to the conceptual model of Sørensen *et al*.[9]

HL assessment in children with T1D is a topic that has not been widely discussed in Brazil. Children and adolescents have the full capacity to seek, assess and use health information, especially when it is inserted into their contexts and transmitted in an age-appropriate manner.[20] Therefore, it is recommended that favorable strategies be used to help the pediatric population understand T1D and understand and accept the procedures related to its treatment.[21]

The results presented in this article demonstrate that the children participating in ITP sessions did not understand what diabetes is, nor the reference values for blood glucose monitoring. They reported obtaining prior knowledge through information providedby their parents, who they indicated as the main source of information. In the literature, there is evidence that the social network of families of children with chronic disease can be considered a strategy to improve quality of life both at the beginning and during the course of a disease.[22] The involvement of family members through education, support and transfer of responsibilities aims to develop self-care for T1D, increase children's knowledge and value their experiences.[23]

In addition to knowledge of the disease, children with T1D need to incorporate some self-care practices that include daily blood glucose monitoring. Participants demonstrated that they understood the blood glucose monitoring technique and, in most cases, recognized its importance, although they did not understand the reasons for some actions. As evidenced in the quotes presented, children reported pricking the side of their fingertips because, according to them, this was the way they were taught, without knowing the reason for that action. Blood glucose monitoring is directly related to maintaining blood glucose levels within the normal range, verified by performing tests that allow obtaining useful information for decision-making.[24] Therefore, this self-care behavior should be encouraged by nurses at every opportunity to educate children and families.

Another point to be discussed is children's ability to make decisions and act when faced with a problem, which was evident when one of the participants stated that he could not exercise when his blood glucose was above 260 mg/dL and that he needed to hydrate in

cases of hyperglycemia. Problem-solving has been the focus of interventions in T1D and is associated with better diabetes self-management and better glycemic control.[25] Cognitive and behavioral skills, involving problem identification, creation of strategies for resolution, implementation and assessment of their effectiveness, represent a key component of the diabetes education process,[26] which should be incorporated into nursing appointments for children with T1D.

Based on the analysis of obtained results, it is concluded that HL assessment related to blood glucose self-monitoring in childhood may contribute to reducing undesirable outcomes in adult life, since low HL makes it impossible to understand and acquire healthy habits.[27] Promoting children's HL on blood glucose monitoring through ITP also guarantees a voice to this vulnerable group and children with T1D need to have knowledge about their diabetes.[28] Understanding their disease helps them regain control of their body and assess what is necessary for adequate diabetes management.

Finally, a systematic review showed that the use of therapeutic play interventions in preparation for invasive procedures reduces anxiety and promotes better behavior in children.[29] The use of ITP to teach blood glucose self-monitoring is, therefore, in line with these findings as it was possible to interact with children and address various aspects of the technique without using a formal learning environment. ITP is an intervention described in other studies[17,28,30] that should be systematized in nursing care for children with T1D.

ITP sessions in this study were only sufficient to identify how children understand and apply health information about blood glucose self-monitoring, but not how they access or evaluate it. To assess HL in children and adolescents, it should be considered that this population is in constant cognitive, physical and emotional development.[10] For this reason, HL categories will not always be presented in a distinct manner and may overlap.

Future research needs to explore how ITP sessions can help identify how children access and evaluate information, which was not possible to assess in this study. Longitudinal studies will allow us to explore the effects of HL on the self-care behavior of children with T1D for blood glucose self-monitoring. Furthermore, in order to ensure the use of ITP by nurses in HL assessment, it is essential to ensure adequate training in both ITP technique and interpretation of the HL theoretical model.

The results of ITP sessions can help nurses to make nursing diagnoses related to children's HL and define new educational interventions. ITP sessions explored in this qualitative study exemplify an intervention that facilitates nurse communication with children with T1D and can be implemented as a diabetes education tool in nursing appointments.

Conclusion

ITP sessions facilitated the identification of HL domains regarding the blood glucose self-monitoring technique in children with T1D. Participants in this study demonstrated in ITP sessions how they understand and apply health information relevant to blood glucose monitoring. HL assessment by nurses through a playful strategy, such as ITP, ensured the voice of children with T1D, highlighting them as individuals capable of using health information for the benefit of self-care.

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Contributions

Figueiredo LL, Alvarenga CS, Lucca M, Visser M, Nascimento LC, Borba RI and Barber ROLB declare that they contributed to study design, data collection, analysis and interpretation, article writing, relevant critical review of intellectual content and approval of the final version to be published.

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