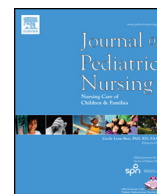




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## A fun way to learn about diabetes: Using therapeutic play in a Brazilian camp

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### ABSTRACT

**Purpose:** Understanding disease mechanisms inside the body is crucial to engage youth with type 1 diabetes (T1D) in self-care behaviors. This study describes how Instructional Therapeutic Play (ITP) group sessions held by nurses in a Brazilian camp can enhance youth's understanding about T1D.

**Design and methods:** Youth with T1D participated in video recorded ITP group sessions guided by the Sensitive Creative Method. First, participants were asked to create an artistic production based upon the query "What happens in the body of a young person who has diabetes?". They described their drawings and shared information, providing opportunities to discuss T1D pathophysiology. Second, campers were told a story about a child who had T1D onset using a rag doll and illustrative figures. Participants were asked to create a second artistic production based upon the same initial query. Finally, campers had another presentation of the drawings, discussion, and sharing through the question "How did the story told help you understand your diabetes?" Transcriptions of ITP sessions were submitted to thematic analysis.

**Results:** Twenty participants (9–17yo) were assigned to age/gender matched groups. Four themes were built: Designing insulin production; Experiencing the glycemic vigilance in diabetes management; The ITP session as a safe space to share challenges with nurses and peers; and Unraveling the myths of diabetes with the ITP session.

**Conclusion:** Therapeutic play sessions enhanced youth's knowledge and unraveled myths of T1D pathophysiology.

**Practice implications:** ITP sessions can be developed by nurses in order to deliver age-appropriate diabetes education to pediatric patients.

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### Introduction

Global estimates stated over 1,106,000 people under 19 years old have being diagnosed with Type 1 Diabetes (T1D) (Cho et al., 2018). Regardless technology advances in diabetes treatment, only few youths with T1D achieve optimal glycemic control (Foster et al., 2019). Diabetes education is key to promote self-care behaviors, enhance glycemic management and prevent chronic complications (Phelan et al., 2018). Therefore, education focused on diabetes self-management should

begin in childhood allowing young people to actively participate in their treatment (Beck et al., 2017; Strand, Brostrom, & Haugstvedt, 2019).

Although guidelines present plural benefits of educational strategies for youth with T1D and their families, there is no single strategy able to engage people with diabetes in long-term maintenance of self-care (American Diabetes Association, 2019). Several factors are responsible for acquisition and perpetuation of self-care behaviors related to managing a chronic disease such as T1D. Among these factors, understanding the diabetes pathophysiology plays an important role. When a person can understand the physiological mechanisms that justify their disease treatment, their acceptance is eased (Moskovitz, S, Frydman, Allen, & Tonyushkina, 2018).

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Diabetes educators must select age-appropriate language and resources to educate pediatric patients (Dickinson et al., 2017). One pediatric approach for diabetes education is Therapeutic Play. The Instructional Therapeutic Play (ITP) is commonly used in health care settings by pediatric nurses to communicate with children (La Banca et al., 2019; Vessey & Mahon, 1990).

In 2015, a diabetes camp in Brazil implemented ITP sessions as one of the nursing strategies for diabetes education. Previous research has shown the benefits of participating in diabetes camps for youth and their families (Barone, Vivolo, & Madden, 2016; Beesley, Riddell, & Fraser-Thomas, 2018; Bultas, Schmuke, Moran, & Taylor, 2016; Venancio, La Banca, & Ribeiro, 2017). However, to our knowledge this is the first diabetes camp to use therapeutic play in diabetes education.

This study describes how Instructional Therapeutic Play group sessions held by nurses in a Brazilian camp can enhance youth's understanding about T1D.

## Methods

### Camp context

The camp for youth with T1D was funded by a partnership between a recreational camp, a public university, and a non-governmental organization (NGO) in 1953. This camp is held every summer in southeast of Brazil, lasts six days and hosts about 80 campers from eight to 14 years old diagnosed with T1D. Nursing staff is comprised of undergraduate nursing students and registered nurses experienced in diabetes education. The health care team also includes endocrinologists, psychologists, dietitians, physical trainers, and dentists.

In addition, young leaders with diabetes integrate with the camp staff in all activities. Young leaders with diabetes are youth with T1D older than 16 years who provide recreation activities and serve as role-models to campers in managing their own diabetes.

### Study procedures

This descriptive qualitative research study was approved by the Research Ethics Committee of a Brazilian university. No study procedures were performed before ethical approval. Eighty parents/guardians received an electronic invitation by e-mail, along with the assent and consent forms in December 2017 prior to camp experience. The assent and consent forms asked for permission to engage the youth in ITP video recorded sessions during the camp, and to use their images for study related purposes. Only one parent returned the signed forms electronically, while the investigators made the assent/consent forms available in paper on the first day of the camp for those who were willing to participate in the research. In addition, the two main investigators were available at the camp for answering questions regarding the study procedures.

Data collection occurred in January 2018 on the second day of the diabetes camp. Campers are sorted according to their age and sex during the diabetes camp and assigned to groups of six to seven children/adolescents. These groups sleep in the same cabin and are assigned to camp activities together. The ITP sessions were included as one of the camp activities, and youth had the option to participate in it with their cabin peers or to play with the camp counselors instead.

The ITP sessions were planned to last up to 45 min and were offered to all campers at the same time. Therefore, each camper could participate in only one session – the ITP session held within his/her cabin. All ITP sessions followed the principles of the Creative Sensitive Method (Soratto et al., 2014), described in Chart 1.

The story told by nurses in ITP sessions was written in age-appropriate language, describing the T1D onset in a young boy. Nurses used rag dolls that matched gender of each group to tell the story. The dolls were donated by the NGO to all campers (Fig. 1). Each group received cardboards and markers for artistic production.

## Chart 1

Steps from the Creative Sensitive Method that guided the Instructional Therapeutic Play group sessions.

1. Organization of the participants in a circle
2. Brief presentation of group members
3. Explanation of research activity and its objectives
4. Participants were asked to create an artistic production (individual or group drawing) based upon the query "What happens in the body of a young person who has diabetes?"
5. Participants described their drawings and this sharing of information provided the opportunity to discuss the T1D pathophysiology
6. Tell a story of a young boy who had a sudden diabetes onset using a rag doll and illustrative figures
7. Participants were asked to create a second artistic production (or complete the first drawings) based upon the same initial query
8. Participants had a final presentation of the drawings, discussion, and sharing through the question "How did the history told during the ITP session help you understand your diabetes?"
9. Synthesis and validation of data produced in the ITP session

### Data analysis

Twelve ITP sessions were held in the camp. Three of them were used in this research, as they were coordinated by the research team. One session took place on the porch and two sessions occurred inside the camp cabins. All sessions happened concurrently and lasted about 60 min each. The Study utilized the CONSolidated criteria for Reporting Qualitative research (COREQ) checklist (Tong, Sainsbury, & Craig, 2007).

Two authors experienced in qualitative research used Braun and Clarke's process of thematic analysis to analyze the ITP sessions (Braun & Clarke, 2006). First, the investigators independently coded all session transcripts. Then together the investigators reviewed the codes and associated excerpts, sorting codes into categories based on how they were related and linked to one another. The investigators assigned themes to the code groupings and associated excerpts, looking for a "coherent pattern" (Braun & Clarke, 2006).

## Results

Nineteen campers and one young leader in diabetes (70% female,  $12.3 \pm 2.2$  years of age) participated in the ITP sessions. Youth were divided into three groups, named the Blue group (seven 11-year-old girls), Red group (seven girls aged 14 and one 17-year-old young leader in diabetes) and Purple group (six boys aged nine to 11). Even after being encouraged by the research team, some campers were resistant to actively participate in the first part of the ITP session. One participant from the blue group and most of the teenagers in the red group hesitated to collaborate in artistic production and group discussions. The girl in the blue group asked to stay in the room where the ITP session



Fig. 1. Rag doll and nurse in the Instructional Therapeutic Play session.

was taking place and watched the session quietly. The adolescents from the red group had help from the young leader and completed the ITP session. The researchers found the red group to be particularly challenging to engage in the proposed activity.

Thematic analysis of the ITP sessions produced four themes: Designing insulin production; Experiencing the glycemic vigilance in diabetes management; The ITP session as a safe space to share challenges with nurses and peers; and Unraveling the myths of diabetes with the ITP session. The four themes are shown hereinafter in which participants' speeches are represented by a fictitious name and researchers quotes by letter R.

#### *Designing insulin production*

After nurses organized each group in a circle, participants started the drawings and discussion of the topic "What happens in the body of a young person who has T1D?" Simultaneously, they talked with each other and with the researchers, showing that they understood T1D is related to lacking insulin and need for replacement through injections.

R: What now? What happened inside the boy's body? [...] ARTUR: "When the body stops producing insulin, it can no longer spread it to other organs. Then comes the insulin injection, which is manufactured in pharmaceutical industries." (Purple group)

HELENA: Our pancreas doesn't work anymore, so it doesn't make insulin, so we have to apply insulin to get it into our cells. My doctor explained that it was like a trolley. We applied [the injection] and the cart went to the cells. (Blue group)

Despite recognizing T1D is related to deficient insulin production, participants had difficulty on defining how and where inside the body they would draw the pancreas, as well as the mechanism of insulin secretion.

CAMILA: "I think it [the pancreas] looks like a little gun like that. Except it's all gutsy actually. It doesn't have to be straight [the line of the drawing], because the pancreas has all these little things [bounces her hand like waves]." (Red group)

MIGUEL: "The cells noticed this part here [in the pancreas], and thought it was a disease too. And then they attacked there and destroyed the insulin-producing part" R: And where is that part? MIGUEL: "I put it here [points to the belly of the body drawing], because I don't know where exactly it is." (Purple group)

In the three sessions analyzed, two groups explained the reason for the interruption of insulin production by the pancreas and included this into their drawings. Although participants knew the interruption was due to a reaction from the body itself, they did not know why it happened.

YASMIN: "I drew a pancreas and wrote that it is not working. Because the cells that kill have confused the pancreas. I don't know why, but they kill themselves" REBECA: "My pancreas no longer produces insulin". HELENA: "Mine has stopped." LORENA: "Mine too." (Blue group)

LAURA: "Are you going to make those cells there [in the drawing]? That destroy the pancreas. CAMILA: "The beta cells" (Red Group)

#### *Experiencing the glycemic vigilance in diabetes management*

When participants presented their drawings, it was noticeable that the relationship between taking insulin and glycemic control is a complex topic for children. Although participants showed they understood

what the pancreas is and their need of daily insulin injections, the physiological explanation of what happens to glucose inside their bodies was unclear.

GABRIEL: "We have an organ called the pancreas that produces insulin. When you have no insulin, your blood sugar goes to the pancreas and our insulin goes up too much. So we send it insulin to stay regular. The best way to lower insulin is to drink water and exercise a lot." (Purple group)

ARTUR: "When your pancreas stops working, you have changes, which is when your sugar melts faster and your glucose rises." (Purple group)

REBECA: "When we eat the food, it goes to the pancreas or the body. I don't know. Then we take our insulin, then the food crumbles because the sugar has already been resolved." (Blue group)

Understanding what happens inside the body of those who have T1D is linked to the memories of their diabetes onset. During the explanation of their drawings, participants in the Purple group reported their discovery of diabetes diagnosis. Youth related their knowledge of the T1D pathophysiology to their self-care tasks, such as insulin administration, glucose monitoring, carbohydrate counting, and practicing physical activity.

DAVI: "I'll talk about the symptoms you feel when you are at risk for diabetes [says when presenting his drawing]. The symptoms you feel are drinking a lot of water, going to the bathroom a lot. [...] the doctor was suspecting I had diabetes. I was drinking a lot of water and going to the bathroom, so he said I was going to be hospitalized. Then he had to buy all the blood glucose stuff, the pen. Then I left the hospital." (Purple group)

BERNARDO: "I put arrows [in the drawing] to show where you apply insulin to our body. It can be on the arms, belly, thigh or buttocks. When we get diabetes, we have to use a medicine called insulin, we can use a pen." (Purple group)

GABRIEL: "So diabetes is a disease that the pancreas stops producing insulin and so we have the pump [referring to the insulin pump]. It helps inject insulin to end our high diabetes, our blood sugar. It's like a machine that helps us to live." (Purple group)

The Red Group, comprising adolescents older than 14 years, described T1D pathophysiology based on chronic complications, as a consequence of inadequate self-care. The adolescents hesitated to expose their knowledge, either through drawing or verbalizing their opinion or experiences to the group.

R: Do you think you need a head [in the drawing]? ISABELA: "I think yes, because it has the complications that diabetes can give. Like blindness." BEATRIZ: "There are a lot of people with diabetes whose kidney stops." LAURA: "When you start to discover diabetes, you often get ants in the toilet because of the sugar." ISABELA: "Yeah, and if you don't take care of it, you can go to hemodialysis or you will have to get a transplant." (Red Group)

Examples of children and adolescents' drawings during the sessions are shown below in Fig. 2.

#### *The ITP session as a safe space to share challenges with nurses and peers*

During the ITP session, children from the blue group felt comfortable sharing their personal experiences while the nurse was telling the story. One of the topics shared in this group was how school can be both a challenging and a supportive place for a child with T1D.

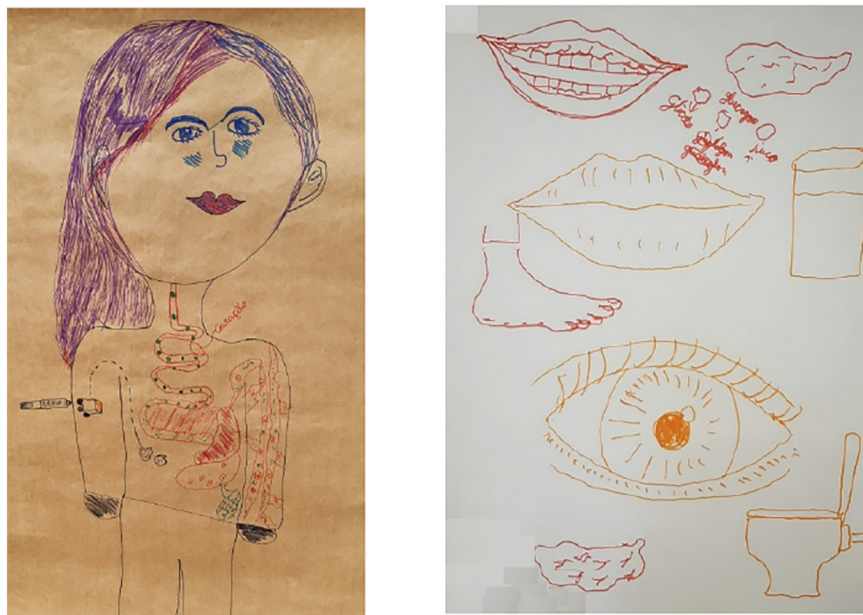


Fig. 2. Examples of children's drawings during the Instructional Therapeutic Play sessions.

The role of the school in the lives of these children is fundamental, given that they spend most of their time in school activities. Participants reported situations where they got upset and missed classroom activities. One of these situations was leaving the classroom to perform blood glucose testing and administer insulin. Furthermore, they reported that sharing their diagnosis with school mates allows peer acceptance.

R: And at school, is the diabetes care normal? REBECA: "No, because we have to leave the classroom to take insulin and to test [the blood sugars]." LORENA: "Yeah! There are people who stare at us. There are people who prefer to leave the classroom. There is also a teacher who tells you to leave the classroom. This is absurd for me!" (Blue group)

HELENA: "When I found out I had diabetes, a girl from my school who also has [diabetes] gave a talk, saying that there are people who say that it is contagious. Then she gave that talk and it was very cool." (Blue Group)

The story told by the nurses helped the children from the blue group to share situations in which other people were responsible for their diabetes care. According to the children's perspectives, sometimes their caregivers do not understand the mechanisms of T1D and how glycemic control occurs, exposing children to complications such as hypoglycemia, or blaming children for their diagnosis.

HELENA: "My friend spent the weekend with her grandparents and they didn't eat carbohydrates. Then [her blood glucose] was very low for a long time. She went to the hospital and nearly died." (Blue Group)

REBECA: "There are people who keep saying that we have diabetes because we ate too much candy." HELENA: "But people don't know that there are two types of diabetes. Sometimes it is annoying to keep explaining. A friend of mine said "This is what happens when you eat many sweets, see? You go to the hospital." (Blue group)

#### Unraveling the myths of diabetes with the ITP session

In the last step of the ITP session, campers shared what they learned by making new drawings or completing the first ones. At this time,

children and adolescents verbalized a better understanding of organ shapes and their functions, as well as the metabolic role of insulin.

P: Where is the pancreas located? GABRIEL: "It is under the stomach." (Purple group)

REBECA: "I thought food went to pancreas, then we took insulin, and insulin went to the pancreas. Then the food would crumble in the pancreas." R: "And now, do you understand?" REBECA: "Yes. Insulin goes to the cell, which gets [the glucose] absorbed." (Blue group)  
In addition to understanding the body location of organs, the story told at the ITP session allowed children to learn new concepts about glucose metabolism, from its absorption in the digestive system to its excretion by the renal system in cases of hyperglycemia.

HELENA: "I draw the cart that will take [insulin] to the cells. Then the cells will get insulin and the blood sugar will drop." LORENA: "Will they go over here?" REBECA: "Here, the food goes through the gut. It will fall apart and go to the blood." (Blue Group)

P: And then this excess sugar has to be eliminated, it has to come out somehow. GABRIEL: "That's why we take insulin." ARTUR: "Not only insulin, but ..." GABRIEL: "Exercising, [drinking] water. What does water have to do with it?" DAVI: "It cleans." ARTUR: "It dissolves, it dissolves the sugar." (Purple group)

Although they learned concepts about the pathophysiology of T1D in the ITP session, some topics were shown to be difficult for young people to understand, such as what a cell is and where it is located.

HELENA: "I was going to draw her taking her insulin and make some little cars like that. It's because it's from the pancreas, right, the cells? Where do I design it?" (Blue group)

The story told at the ITP session allowed children to share what they knew about T1D complications as well.

R: "They had a neighbor who had diabetes and could not see well" GABRIEL: "Because he didn't take care of his diabetes. My mother always says that those who do not take care of diabetes just eat, get high [blood glucose]. You can go blind or feel very bad." BERNARDO:

"My grandfather lost both legs, he didn't take care of his diabetes." (Purple group)

R: "Do you know what can happen if your blood sugar stays high for a long time?" HELENA "The kidney may stop working." (Blue group) Finally, the interaction between the researchers and participants helped clarify youth doubts on the T1D pathophysiology, such as how glucose is excreted.

MIGUEL: "What about our sweat, is it sugary too? Because when we are high, we get... I get electric! Then we run, play, even though we want to pee. And the sweat? Does sweat have anything to do with it?" R: It does. When we practice some physical activity, we get ...?" MIGUEL: "Sweaty." R: Sweaty, but why? Because our cells are eating faster, that glucose." ARTUR: "And we are burning it." R: "And we are burning it, understand?" ARTUR: "When it is not eliminated [glucose] through pee, it can be eliminated through sweat." (Purple Group)

## Discussion

The use of ITP at a diabetes camp is an example of intervention delivered by nurses to teach complex subjects to the pediatric population, such as T1D pathophysiology. In this research, youth reported to know that the bodies of people with T1D do not produce insulin. However, they had doubts about the shape and location of the pancreas, as well as the relationship between glucose and insulin. These doubts can be explained by the distinct cognitive development of each participant, since the knowledge about T1D is based on the understanding of the concepts of the disease since its diagnosis (Cabrera et al., 2013; Markowitz, Garvey, & Laffel, 2015).

The process of building new knowledge regarding diabetes pathophysiology was evident when comparing the beginning and the end of the ITP session. In the beginning, participants mention that something occurs in pancreatic beta cells. However, at the end of the session, they still have difficulty explaining the autoimmune reaction. It is important to highlight the three ITP sessions analyzed comprised different age-group participants. Therefore, developmental differences in how children learn about diabetes were expected. According to Piaget's cognitive theory, the mental schemes about these concepts have been assimilated, but still need educational reinforcement for their cognitive accommodation (Piaget, 1962).

Despite what most campers had learned with the ITP sessions, one participant withdrew from the activity and the red group campers were resistant to participate in it. In this sense, the use of other educational strategies, such as video games (DeShazo, Harris, & Pratt, 2010; Holtz, Murray, & Park, 2018), mobile applications and audiovisual resources (Dobson et al., 2017; Hood et al., 2016), or text messaging (Franklin, Waller, Pagliari, & Greene, 2003) could provide greater interaction between youth who are not willing to play with dolls.

The story told in the ITP session promoted the sharing of personal experiences within the groups such as the challenges encountered in the school setting. Children and adolescents often find it difficult to maintain their diabetes self-care practices at school, which may have consequences with their diabetes management and social life (Freeborn, Dyches, Roper, & Mandelco, 2013; Sparapani et al., 2017). For this reason, promoting a welcoming environment in which children and adolescents can talk about T1D and be cared for, like the therapeutic play sessions, is paramount.

In addition to the school context, challenges with caregivers managing youth's diabetes were also reported. Several studies indicate the impact of T1D on families' management (Feldman et al., 2018; Harrington et al., 2017; Katz, Volkening, Dougher, & Laffel, 2015). Eating behaviors is one of the major challenges, also addressed by participants in the ITP sessions. Parents of children with T1D often have a hard time on

introducing appropriately balanced meals and coordinating with insulin time to avoid hypoglycemia episodes (Streisand & Monaghan, 2014). Future research could explore the use of therapeutic play sessions to understand family nutrition practices according to children's perspectives.

Participants described diabetes care as being closely related to T1D pathophysiology and their constant glycemic vigilance. The consequences of poor glycemic control should be addressed by nurses when educating the pediatric population on self-care. Although one might consider diabetes complications as a complex topic for young children, participants of this study reported their knowledge of self-care practices is related to the fear of complications. Therefore, delivering education in this important issue beginning at an early age could be addressed by diabetes educators through play-based strategies. By educating young people about the complications of T1D, the educator imparts them with knowledge to reduce insecurity about the future (Ritholz, MacNeil, & Weinger, 2017; Sparapani, Jacob, & Nascimento, 2015).

Finally, our results highlight the potential use of ITP for diabetes education through group dynamics. Previous studies have shown the potential benefit of ITP for pediatric diabetes education (La Banca et al., 2019; Pennafort, Queiroz, Gomes, & Rocha, 2018). Moreover, the use of group dynamics based on the Creativity Sensitivity Method in pediatric diabetes is recent and has also shown great potential for data collection with these subjects (Queiroz, Brito, Pennafort, & Bezerra, 2016). Given group dynamics are a valuable resource in diabetes education (Riley & Marshall, 2010), the use of ITP in group sessions can benefit nurses with a planned activity that is less time-consuming, fun, and capable of educating youth while facilitating peer interaction.

Although this teaching strategy was implemented in diabetes camp, ITP sessions can be implemented and developed by nurses in other contexts as a means of delivering age-appropriate diabetes education to pediatric patients. By educating young people with diabetes using age-appropriate strategies, nurses help youth to develop new skills and to participate in their health care process.

## Conclusion

The ITP sessions enhanced children's and adolescents' understanding about what happens inside their body, unraveling myths about T1D pathophysiology. Moreover, the group discussions promoted the trust for the campers to share experiences with nurses and peers allowing youth to learn in a fun way about their diabetes.

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## CRediT authorship contribution statement

**Rebecca Ortiz La Banca:** Conceptualization, Methodology, Investigation, Writing - original draft. **Maria Carolina de Moraes Brandão:** Conceptualization, Methodology, Investigation, Writing - original draft. **Valéria de Cássia Sparapani:** Methodology, Investigation, Writing - original draft. **Neila Santini de Souza:** Methodology, Investigation, Writing - original draft. **Eliane Tatsch Neves:** Conceptualization, Writing - review & editing, Supervision. **Maria Gabriela Secco Cavicchioli:** Investigation, Writing - review & editing. **Regina Aparecida Garcia de Lima:** Investigation, Writing - review & editing. **Lucila Castanheira Nascimento:** Conceptualization, Writing - review & editing, Supervision.

## Declaration of competing interest

The authors declare that there is no conflict of interest.

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