

Sensitizing children with diabetes to self-care: Contributions to educational practice

Sensibilizando a criança com diabetes para o cuidado de si: Contribuição à prática educativa
Sensibilizando al niño con diabetes para el cuidado de sí: Contribuciones a la práctica educativa

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ABSTRACT

Objective: To analyze the applicability of Body Knowledge dynamics in sensitizing children, through the expression of their experiences, to the practice of self-care. **Methods:** This descriptive and analytical study was conducted in May and June 2013 with six diabetic school-aged children attending the outpatient clinic of a referral hospital in Fortaleza, CE, Brazil. **Results:** The dynamics promoted a relaxed environment conducive to the expression of feelings and the reporting of basic care provided for diabetes. Sensitization was permeated with reflections upon the onset of the disease and current time. Thus, the children shared with their peers the need for care actions and learning concerning metabolic control. **Conclusion:** The application of Body Knowledge dynamics favored the development of educational activities with the participation of children, which promoted learning regarding self-care.

Keywords: *Diabetes Mellitus*, Type 1; Child Care; Health Education; Nursing.

RESUMO

Objetivo: Analisar a aplicabilidade da dinâmica Corpo Saber na sensibilização da criança para o cuidado de si por meio de suas experiências. **Métodos:** Estudo descritivo e analítico desenvolvido em maio e junho de 2013, com seis crianças diabéticas em idade escolar, atendidas no ambulatório de um hospital de referência em Fortaleza/CE. **Resultados:** A dinâmica promoveu um ambiente de descontração favorável à expressão de sentimentos e demonstração dos cuidados básicos ao conviver com o diabetes. A sensibilização foi permeada de reflexões sobre o início da doença e o momento atual vivido. Assim, compartilharam com os pares as necessidades de cuidados e aprendizagens no controle metabólico. **Conclusão:** A aplicação da dinâmica Corpo Saber favoreceu o desenvolvimento de atividades educativas com a participação das crianças em momentos de aprendizagem sobre o cuidado de si.

Palavras-chave: *Diabetes Mellitus* Tipo 1; Cuidado da Criança; Educação em Saúde; Enfermagem.

RESUMEN

Objetivo: Analizar la aplicabilidad de la dinámica Cuerpo Saber en la sensibilización del niño para el cuidado de sí mediante sus experiencias. **Métodos:** Estudio descriptivo y analítico desarrollado en mayo y junio del 2013, con seis niños diabéticos en edad escolar, atendidas en el ambulatorio de un hospital de referencia en Fortaleza-CE. **Resultados:** La dinámica promovió un ambiente de relajamiento favorable a la expresión de sentimientos y demostración de los cuidados básicos al convivir con la diabetes. La sensibilización fue permeada de reflexiones sobre el inicio de la enfermedad y el momento actual vivido. Así, compartieron con las parejas las necesidades de cuidados y aprendizajes en el control metabólico. **Conclusión:** La aplicación de la dinámica Cuerpo Saber favoreció el desarrollo de actividades educativas con la participación de los niños en momentos de aprendizaje sobre el cuidado de sí.

Palabras clave: *Diabetes Mellitus* Tipo 1; Cuidado del Niño; Educación en Salud; Enfermería.

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INTRODUCTION

Type 1 *Diabetes mellitus* (DM1) is a chronic, autoimmune disease of a multifactor nature that affects distinct age groups, though it is more frequently diagnosed in children, adolescents and young adults. Among the last age group, DM1 corresponds to about 5% to 10% of cases; however, its incidence has significantly increased among children under five years of age. It requires ongoing medical care, mediated by health education regarding self-management to prevent the risk of acute and chronic complications^{1,2}.

When DM1 occurs during childhood, it has important repercussions on the family routine and child growth and development. Chronic diseases affecting children may trigger diverse family conflicts in the face of the diagnosis, such as, the need to abandon one's job, which may lead to financial hardships; decreased or interrupted leisure; overburdening of the primary caregiver; or family disruption with negative repercussions for the entire family³.

Given this context, we highlight the importance of preparing the health staff dealing with diabetic children so that they appreciate their patients as individuals undergoing the growing and developing process, as individuals with inherent characteristics who require their basic needs to be met, such as nutrition, socialization and affectivity⁴. Children with diabetes require social support and specific care from both their families and healthcare workers. Therefore, the families of these patients need to be included in the treatment early on so that they can monitor and encourage their children to adhere to the treatment. Healthcare professionals can facilitate this when the families share their experiences, easing their learning process of therapeutic interventions and how to keep the health of those dear to them.

Health education is crucial for diabetes management. From this perspective, it is essential that health educators know the context, worldview and expectations of each subject so that they can prioritize the needs of patients and implement therapeutic requirements. Pre-existing knowledge should be taken into account, even when dealing with children, because disregarding a child's experiences and expectations may lead to undesired consequences, such as non-adherence to treatment, poor self-care, the adoption of harmful beliefs and habits, detachment from the multidisciplinary team, and a belief that others are responsible for their care⁵.

Indeed, considerations and reflections upon the care and health education provided to children with diabetes emerged when we verified that nurses, both in the hospital and outpatient settings, face difficulties addressing children in a way that both patient and family can understand, decide and act upon the health condition, adhering to the therapeutic project shared with the team⁶.

The following questions guided this study: what is the experience of children living with diabetes? Does the Body Knowledge approach sensitize the child to practice self-care?

We saw the possibility of learning about this context by establishing with children a situation mediated by creative and sensitive dynamics in order to contribute to reflections and theoretical conjectures regarding the topic, which is necessary in academia, and support clinical care provided to children with diabetes aiming to value their experiences and sensitize them to self-care based on care practice and education. This study's objective, then, was to analyze the applicability of Body Knowledge dynamics to sensitize children through expression of their experiences, to practice self-care.

METHODS

This qualitative study is based on the Creative Sensitive Method (CSM), which in turn is composed of the triad of group discussion, creativity and sensitivity dynamics, and participant observation. When implementing the study, we opted to use the creativity and sensitivity dynamics as an axis of this method, which encourages people to step out of egocentricity and experience affection and other feelings when addressing topics of common interest. Hence, the introduction, production, analysis, discussion and validation of data took place within Creativity and Sensitivity Dynamics (CSD)^{7,8}.

The study was conducted in the Endocrinology Outpatient Clinic of a tertiary referral hospital in May and June 2013 in Fortaleza, CE, Brazil with six school-aged children. The inclusion of participants was based on the following criteria: being seven to 11 years old and attending the service regularly. Two meetings of approximately 90 minutes were held with a total of six participants in each meeting, though Body Knowledge dynamics was implemented in a single meeting. A different dynamics addressing eating and not reported in this study was implemented in the second meeting. Note that the children and their families had difficulties commuting to the hospital area due to its geographical distance.

In conformity to ethical principles provided by Resolution of National Council of Health, N^o 196, October 10, 1996, which regulates research with human subjects⁹, the study was submitted to and approved by the Institutional Review Board at the State University of Ceará. This study is part of a larger study addressing juvenile diabetes that was approved in 2012, protocol N^o 181.489.

Written authorization was requested from the head of the Pediatric and Endocrinology Service, the study setting. Additionally, the participants' legal guardians signed free and informed consent forms and children also gave their consent through a Consent Form that stipulates voluntarily accepting care or participating in studies¹⁰. We also requested both parents' and children's authorization to record and photograph the meetings, as well as using any data collected. Confidentiality of the participants' identity was maintained; instead of their actual names, biblical names were used according to an agreement with their legal guardian of them. But for the purpose of the publication they were named by the first letter of those names; for girls, M1 and S, for boys, J1, J2, M2 and M3.

The Body Knowledge dynamics was used to meet this study's purposes so that representation of body and care were obtained, which enabled understanding the experiences of children with DM1, while representations of the disease were provided through drawings of bodies showing the symptoms of the disease, where they are located, and how they are manifested, in addition to dimensions that involve healthcare. The questions used in the dynamics were guided by the children's experiences with diabetes (what changes in the body) and care required to keep glucose within ideal parameters. Based on the children's explanations in response to questions presented with language appropriate to facilitate comprehension, we provided material (paper, pen, cropped figures) for the children to use to draw their bodies and express their experiences. Three researchers supported the children during this stage.

A sequence of steps is recommended to properly conduct the creative-sensitive dynamics. First, the environment was organized and we welcomed the participants, aiming to provide a comfortable and quiet environment. Then, the researchers introduced themselves and allowed each participant to do the same, after which the study's proposal, the dynamic procedures, and ethical aspects were presented to the children and their respective guardians, ensuring their names would be kept confidential. The third step referred to the consent terms, signed by both children and legal guardians, and the dynamics and its objectives were then explained. In the fourth step, each participant showed the material they produced (drawings) and talked about their individual experience to the group, which enabled discussions among the participants. The fifth step included collective analysis and validation of data because, at this point, individual experiences generated knowledge that was common to the entire group and that emerged from the dialogue. This phase corresponds to the organization and preliminary analysis of data because it culminates in a synthesis of what was discussed, systematizing information that was collected according to its spatial, creative and sensitive conformation^{7,8}.

Data produced in the creative and sensitive dynamics were organized and analyzed through critical and reflexive reading. The themes were coded based on the core meanings. Hence, the categories were organized, classified and formulated in order to understand the meanings of experiences expressed by the participants, obtaining cues and insights that favor the development of educational activities and care delivered to this population.

RESULTS AND DISCUSSION

Data emerged from the implementation of Body Knowledge Dynamics, that is, when children collectively developed data. The analysis, discussion and interpretation of information are presented in the three themes, which represent the meanings concerning the children's experiences and sensitization through artistic production and dialogues.

Recognizing the disease's clinical manifestations from the children's perspectives

To grasp the experiences of children with diabetes and sensitize them to self-care, we paid attention to what they had to say, with sensitivity to the context they experienced. The first theme shows the perceptions of M1, J1 and J2 concerning the disease, highlighting changes that occurred in their bodies.

[...] I felt nothing. My mother was the one who found out. I urinated a lot. My mother realized I had diabetes because I drank lots of water and peed a lot; [...] I drank a lot of water, then I peed a lot, then I started losing weight.

Having a diagnosis of type 1 diabetes causes a lot of inconvenience to the child and family and presents them with an unfamiliar and challenging situation. Gradually, they acquire knowledge of the disease and how to control it and, depending on social support and the care provided, they can have a more balanced life, ensuring the growth and development of these patients.

It is very important to assess their prior knowledge and discuss this with both child and family in order to demystify preconceptions and advise them of the best way to provide care and manage the disease. The use of creative strategies in the communication between professional and child facilitates the expression of feelings and experiences with important meanings for clinical care.

School-aged children with chronic conditions are capable of playing roles and taking responsibility along with their families and avoiding acute complications, provided they receive instructions about necessary care and which health resources are available, and are valued in regard to their individual perspectives. Including the child in the management of his/her care in order to prepare them for different functions favors children's decision-making so that they collaborate with their family and healthcare workers¹⁰.

From this perspective, nurses can use educational tools when dealing with diabetic children to support and teach them care actions that are crucial in the management of the disease and to improving their well-being.

The six participating children (S, J1, J2, M1, M2 e M3) and their imagination manifest clinical situations of the disease acknowledging signs and symptoms:

[...] When my diabetes is too low, I shake and my mouth gets white. I pee a lot. My legs hurt. My legs hurt when my diabetes is high. When my diabetes is low, I feel hungry. When my diabetes is low, I feel really hungry and I get sleepy. When my diabetes is high, I don't feel anything. [...] I get pale and my lips get really white when it's low and when my diabetes is really high, I feel dizzy. I feel my legs shaking. I can't get up. I drew my flesh shaking when diabetes is high. I don't feel anything.

The group interaction enabled the children to share their experiences about the disease, such as how to recognize signs of glycemic alteration. Hence, they manifested the clinical signs of hypoglycemia and hyperglycemia. They associated paleness, shakiness, and sleepiness with hypoglycemia and urinary frequency and dizziness with hyperglycemia, which shows the importance and the possibility of children learning and being sensitized to think and develop actions that are beneficial to health and to control the disease; rather than feeling different, they can be encouraged to practice self-care.

The children's drawings present the repercussions of the disease and treatment for their bodies, often "sacrificed" by multiple punctures, as illustrated by the presence of syringes with needles, lancets and blood glucose meters, painful experiences marking their routines and are significant in their lives.

The drawings also portray changes in hypoglycemia, manifested by "hunger, sleepiness and pain in the legs"; sensations in their bodies when they experienced hypoglycemia and shakiness were expressed by J1's (Figure 1) and S's drawings (Figure 2).

Figure 1. Body Knowledge Dynamics (J1)



The subject is considered to be influenced by his/her social context, that is, his/her imagination emerges from the group, therefore, his/her thinking - subjectivity - represents the collective¹¹. Hence, the manifestations of the disease were common for some children, while others reported being asymptomatic. Some recognize the following signs and symptoms: polydipsia, polyuria, pollakiuria and weight loss, which were perceived by themselves and family as something

Figure 2. Body Knowledge Dynamics (S)



"I take insulin in my leg, stomach and arm"
 "When my diabetes is low, I feel really hungry."
 "When my diabetes is high, I don't feel anything"
 "When my diabetes is low, I get really sleepy"
 "When the diabetes was found out I urinated a lot and drank lots of water"
 "My legs hurt"

different occurring with the participant's body. Some of these messages are expressed in the drawings, others were reported during the dialogue when the children talked about themselves and the daily care undertaken to manage their diabetes.

Habit modification and dietary restrictions

Considering the understandings that children hold regarding manifestations of diabetes and, especially, habit modification to control the disease, it is necessary to identify the children's perceptions and sensitize them to understand the need to comply with therapeutic guidance their way. In this sense, M1, S and J1 emphasized a crucial time in their lives - dietary changes and restrictions:

[...] Not eating sweets. Not being able to eat chocolate, only when diabetes is good. Not being able to eat fat. Finger food is not allowed either. You can't eat pasta. You can only eat whole bread and vegetables. You cannot eat sweets, chocolate nor even sweet rolls. You can only eat stuff with sweeteners; fruit juice with sweeteners... there's

an aisle dedicated only for diabetic foods. There, you can find chocolate you're allowed to eat...

Some children reported knowledge of dietary restrictions and talked about options that do not harm the diet meant for individuals with DM, such as juice and chocolate with sweeteners. It shows they learned how to self-care and live with the disease, though they may behave differently in real life. An informal talk with the mothers revealed their difficulties in changing their children's habits, compelling them to "make promises" or use "blackmail"; the children are usually unable to resist treats at school when encouraged by their peers.

It is known how difficult it is to impose dietary restrictions among school-aged children, who gain a level of independence when they start attending school. Controlling food is essential to avoiding complications arising from diabetes, but it can elicit contradictory feelings, as the child has a desire for sweets, which is very common during childhood; at the same time, the child needs to resist this desire. This fact was also revealed in another study with children, when they talked about their difficulties in resisting sweets, especially on commemorative occasions, which affects socialization¹².

A study conducted in the United State with the employees, students and parents of a school reported that the school is a challenging environment for diabetic children and adults, because most schools offer foods that are inappropriate for a healthy diet¹³. The same situation is verified in Brazil. Despite some attempts to introduce healthier menus in school cafeterias, many foods that are inappropriate for child nutrition are still offered.

Understanding of children regarding self-care

This theme shows care actions implemented in the daily routines of S, J1, J2, M1, M2 and M3, especially their familiarity with the devices used in glycemic control.

[...] I take shots. I take insulin in my leg, stomach and arm. I also take shots and insulin (...). I take insulin in my leg, arm and tummy. When I get home, my mom will teach me. I do the pinky testing. I know how to do it. It is a little pen with a needle inside. Insulin, I take it. Here is the syringe, the finger device, the tape, the little pen to check whether diabetes is low or high or normal [showing the drawing]. There are times I play a lot running around and playing with dolls. [...] When it's low, I eat lots of fruits and when it's high, I don't eat. I take insulin. Here is a man with an insulin shot on my arm [showing the drawing]. You can take the shot on the leg, on your thigh... I control my diet. I eat less rice... At school, I run everyday. I eat pie... I don't feel anything. I eat a lot when it is low [glycemia].

In this experience with the disease and the needs imposed by it, the children reported the intake of fruits when there are signs of hypoglycemia and not eating when there are signs of hyperglycemia. One child reported the administration of insulin

to improve his/her clinical condition. The reports of these children did not refer to rejection of the administration of insulin and blood glucose monitoring, which are painful experiences, but the drawings of five children represented these aspects.

The regular use of insulin to keep appropriate glycemic level was reported by children. The children also emphasized they are not supposed to eat sweets, pasta or fat, though one child reported eating pies at school and stated it did not make her feel sick. Another child reported physical exercise when playing, such as running and playing with dolls.

Even though the children reported therapeutic procedures to manage their diabetes, some contradictions were observed in practice. During the dynamics, the children addressed the importance of eating fruits when experiencing hypoglycemia, however the report of one mother shows her son frequently asks for sweets. Additionally, this mother reports difficulties in keeping her son's glycemic level in an appropriate range.

School-aged children have difficulty understanding the severity of the disease or even deny they have the disease, a situation that can happen at any age. Heavy investment in the education of family members is necessary because the immediate care to be implemented in the case of a hypoglycemic or hyperglycemic episode, before the child reaches a healthcare unit, is the responsibility of a family caregiver.

Considering the need for immediate action when facing mild hypoglycemic episodes, the Brazilian Society of Diabetes (SBD) recommends the ingestion of 15g of carbohydrate (glucose tablets) or one tablespoon of sugar or 150 ml of orange juice or soda. Healthcare workers need to highlight the importance of following these recommendations because, by taking these actions, hypoglycemia can be rapidly reverted. Hence, mothers should not encourage their children to take sweets or treats when experiencing hypoglycemia².

Healthcare workers, therefore, should have in mind creative strategies to sensitize children regarding the following: to actively practice self-care; to encourage habit modification, respecting individual difficulties; and to help them overcome difficulties in order to facilitate good glycemic control. The principles for educating children in regard to diabetes should be based on: motivation (desire and need to learn about the disease); context (age and maturity); interactivity (interesting and playful activity); significance (importance of the subject); progressiveness (from simple to complex, in stages); reinforcement (goals and problem-solving); and on reassessment, progression and continuing education¹⁴.

We observed that proximity of the team with the child, in this specific case of caregivers and researchers, through creative and pleasant activities, promoted moments of relaxation and facilitated reflection and learning regarding the child's health condition and use of insulin therapy, socializing the experience of each among them.

When providing care to children, playful stimuli favor greater interaction between children and their peers and family members, which is considered a source of energy and vitalization. For the right to play to be ensured, nurses need to involve the family and,

together with both professionals and families, should encourage children to feel safe and overcome disease and treatment, alleviating trauma and loss¹⁵.

Taking necessary care actions, such as eating healthy, monitoring glucose, exercising, and taking medications to avoid complications and hospitalization, are actions that, from the perspective of children and mothers, contribute to good disease control¹⁶.

Nonetheless, daily tasks that are necessary for self-care often upset children, hindering appropriate disease management. Parents report that their children become very annoyed or sad when they have to take insulin¹⁷. Additionally, the pain caused by capillary glycemia monitoring and insulin shots can lead children to avoid care, neglecting important care actions. The fear of insulin self-application has to be faced daily. Even those who use pumps find the process irritating¹⁷.

Many innovations have emerged in recent years to facilitate and alleviate diabetes treatment. Technological advancements enabled greater flexibility and eased the routine of patients and decreased pain. Among these advancements, we highlight a German insulin pen with a spring-loaded mechanism, already available on the Brazilian market, and which is also painless. There are, however, some disadvantages to it, such as its high cost and setup time, which is greater and longer, respectively, compared to common syringes or pens. There is a glucose meter device (Didget from Bayer) that attaches to the handheld game console the Nintendo DS. Children have fun with the game characters that act as if they are regulating blood glucose levels. There is also a teddy bear that shows where insulin is applied and teaches about a healthy diet¹⁸. These resources enable diabetic children to tolerate the disease better and adhere to their treatment with substantial return to their quality of life.

The children reported some essential care procedures, such as "little finger testing" and insulin application, both use needles that puncture the body, which produce the meaning of pain and are represented in their drawings. In this sense, we observed that care regarding insulin therapy and glycemic monitoring is mainly performed by the mothers. Nonetheless, self-care should be encouraged at this point of development, as diabetes is a chronic disease and requires continuous management; children, however, need to be supervised and supported by adults when assuming responsibilities such as administering subcutaneous insulin and monitoring glucose.

Continuous interdisciplinary monitoring is recommended when introducing responsibilities to children, encouraging both children and families to actively participate in daily care so that they can understand issues considered to be difficult when managing the disease, in order to achieve good results regarding glycemic control⁶⁻¹⁹.

From this perspective, the children's artistic productions enabled moments of group reflection and discussion that can sensitize them regarding self-care and, as a consequence, decrease the time they take to acknowledge the disease and

adhere to their treatment, minimizing costs and the suffering of children and families.

One of the study's limitations is the need to include more subjects; however, many children lived in the interior of the state and mothers who authorized the participation of their children did not have favorable socioeconomic conditions. Even though they were interested in letting their children participate and learn, some of them did not attend data collection. The results, however, present good quality and, for this reason, we consider the objectives to have been achieved.

FINAL CONSIDERATIONS

When participating in the creative and sensitive dynamics, the children expressed feelings and knowledge related to diabetes care performed in their daily routines, which favored the identification of aspects that encouraged spontaneous learning regarding self-care, reinforcing healthy habits. There were times when reflections certainly led children to realize that the disease is not an obstacle to a healthy and happy life, though it does elicit moments of sorrow. These group interactions seem to improve self-esteem, knowledge, and skills to manage the disease, which provides these growing and developing individuals with a positive outlook on life.

Based on the results, we verify how difficult it is for children to manage the disease, because children tend to be impulsive. Even though they know the right thing to do, following an appropriate diet seems to be the most difficult task. Their artistic representations show that painful experiences mark their daily routines. In regard to knowledge concerning the disease and treatment, we verify that children were capable to recognize some symptoms and care actions; however, the supervision and support of an adult is crucial.

The group dynamics enabled dialogue and interaction among the subjects, which facilitated the free expression of experiences and events and also enabled maintaining proximity to the children, which allowed them to acquire a better understanding of the disease and therapy. We verify how easily children express themselves through playful activities, which can be applied in their daily routine of care. When nurses encourage playing, children develop strategies that increase their potential and favor creativity and development. We expect that the understanding achieved with this study can contribute to the care provided to children with diabetes and encourage healthcare workers' interactive and humanized behavior.

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