

Children with Type 1 Diabetes Mellitus and their friends: the influence of this interaction in the management of the disease¹

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Friends' support is a key element in the management of Type 1 Diabetes Mellitus. This study describes the influence of friends on the lives of children with Diabetes Mellitus and its implications for managing the disease. Empirical data were collected through semi-structured interviews, supported with the use of puppets, with 19 children aged between seven and 12 years old. The qualitative analysis of the testimonies allowed understanding the phenomenon from two perspectives: the attitude of friends towards the child, positively or negatively affecting the disease's management, and the attitude of the child toward friends. The knowledge of those involved and the interaction between the children with DM1 and their friends impacts the management of the disease. Understanding the implications of these interactions contributes to the delivery of qualified nursing care to this population.

Descriptors: Child; Diabetes Mellitus, Type 1; Friends.

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A criança com Diabetes Mellitus Tipo 1 e seus amigos: a influência dessa interação no manejo da doença

O apoio dos amigos constitui-se em um dos elementos essenciais no manejo do Diabetes Mellitus Tipo 1. Este estudo objetivou descrever a influência dos amigos na vida da criança com Diabetes Mellitus e suas repercussões no manejo da doença. Os dados empíricos foram coletados por meio de entrevista semiestruturada, aliada à utilização de fantoches, com 19 crianças entre sete e 12 anos. A análise qualitativa dos depoimentos permitiu a apreensão do fenômeno por meio de duas perspectivas: a atitude dos amigos perante a criança, interferindo de forma positiva ou negativa no manejo da doença e a atitude da criança perante seus amigos. O conhecimento dos envolvidos e a interação entre a criança e seus amigos interferem no manejo da doença. Compreender as repercussões dessas interações contribui para o oferecimento de cuidado de enfermagem de qualidade a esse grupo.

Descritores: Criança; Diabetes Mellitus Tipo 1; Amigos.

El niño con Diabetes Mellitus Tipo 1 y sus amigos: la influencia de esta interacción en el manejo de la enfermedad

El apoyo de los amigos constituye uno de los elementos esenciales en el manejo de la Diabetes Mellitus Tipo 1. Este estudio objetivó describir la influencia de los amigos en la vida del niño con Diabetes Mellitus y sus repercusiones en el manejo de la enfermedad. Los datos empíricos fueron recolectados por medio de entrevista semiestruturada, aliada a la utilización de muñecos, con 19 niños entre siete y 12 años de edad. El análisis cualitativo de las declaraciones permitió la comprensión del fenómeno por medio de dos perspectivas: la actitud de los amigos delante del niño (interfiriendo de forma positiva o negativa en el manejo de la enfermedad) y la actitud del niño delante de sus amigos. El conocimiento de los envueltos y la interacción entre el niño y sus amigos interfieren en el manejo de la enfermedad. Comprender las repercusiones de esas interacciones contribuye para el ofrecimiento de un cuidado de enfermería de calidad a ese grupo.

Descriptorios: Niño; Diabetes Mellitus Tipo 1; Amigos.

Introduction

The incidence of type 1 diabetes mellitus (DM1), one of the chronic diseases that mostly affect the population of children and youth, has increased worldwide⁽¹⁾. A multi-center study⁽²⁾, coordinated by the World Health Organization (WHO), reported an increase of the disease from 1990 to 1999 among children up to 14 years of age⁽²⁾. In Brazil, despite the few studies addressing the profile of the disease in this age range, an incidence of 8 for each 100,000 children has been observed for the same age range and period⁽²⁾. Given the magnitude of DM1 among children and adolescents in Brazil and in the world, researchers assert the need to appropriately manage it to achieve success in the treatment and to prevent complications in the short and long terms⁽³⁻⁴⁾.

The term 'self-management' was first defined in the 1960s and refers to the participatory action of patients in their own treatment, aiming to minimize the physical consequences of the disease in the individual's global health in order to help them cope with the disease's psychological effects⁽³⁾. It involves activities such as dealing with the symptoms, treating the condition, coping with physical and psychological consequences related to the routine of a chronic disease, and changes in lifestyle⁽³⁾. Hence, we understand that self-care activities such as administering insulin, monitoring blood glucose, planning a diet and exercising are included in self-management activities⁽⁵⁾.

DM1 often develops in children who still do not have the cognitive skills or emotional maturity to plan and make decisions concerning the adjustments required in their therapeutic regime⁽⁶⁾; such skills develop around 12 years of age⁽⁷⁾. Therefore, the self-management of DM1 in children should consider, among other issues, their developmental stage⁽⁸⁾, the particularities of which may interfere in the disease's management.

Valuing the role of the family and the experience of the child, in addition to identifying their support and social networks and the work of the health team, are essential elements in the management of the disease during childhood⁽⁹⁾. Lack of support and also the involvement of family members and friends may either positively or negatively influence the education and development of self-care⁽¹⁰⁾. The support of friends facilitates the experiences of children with DM1 in living with the disease⁽¹¹⁾, which contributes to the development of self-management. This study was conceived based on the assumption that friends are central elements in a child's socialization, whether s/he is healthy or has a chronic disease, and on the fact that there are few studies addressing the role of friends among children in the management of the disease. Its objective is to describe the influence of friends in the lives of children with DM1, indicating the repercussions on the management of the disease. This study is part of a larger research project designed to understand, from the perspective of children with DM1, the elements that impact the management of the disease.

Method

This is an exploratory study with qualitative analysis of data. Based on the authors' ethics and in compliance with ethical guidelines of the Resolution of the National Council of Health 196/96⁽¹²⁾ that regulates research with human subjects in Brazil, the project was submitted to and approved by the Ethics Research Committee at the *Hospital das Clínicas*, University of São Paulo at Ribeirão Preto, Medical School (Process HCRP nº 1223/2008). The study was conducted in the Endocrinology and Childhood Diabetes Outpatient Clinic at this hospital, a referral center for the treatment and follow-up of children with DM1. Among the activities performed in this unit, there are group meetings aimed to listen to caregivers, children and adolescents, encourage the exchange of experiences concerning the disease among the participants, and clarify potential doubts concerning the pathology and treatment. The study's participants were recruited from this group.

After the main researcher gradually became familiar with the diabetes group, the children and their parents were then contacted and informed concerning the study and its objectives, potential risks and benefits, and their consent either to participate in the study or refusal to participate was respected. In presenting the opportunity, authorization to record the interviews were asked of the participants who were ensured that their testimonies and the information provided would be confidential and their names would be replaced by cartoon characters chosen by the children themselves. Both parents and children signed free and informed consent forms and kept one copy. The inclusion criteria were: children aged between seven and 12 years old; having experience with the disease for at least one year; whose parents or legal guardians consented to their participation. Children older than seven years old have verbal communication skills and are able to understand and orally express their feelings given their developmental stage, which facilitates dialogue⁽¹³⁾. A minimum time since the disease diagnosis was disclosed was set, seeking to explore the experiences of children with the disease.

A semi-structured interview was used as the main data collection technique. Aiming to obtain candid testimonies and based on the assumption that this is a difficult task given the various issues inherent to the children's development itself⁽¹⁴⁾, and also aware that children prefer activities that involve toys and dynamics appropriate to their age⁽¹⁵⁻¹⁶⁾, we opted for using puppets within a scenario constructed by the children themselves as a resource to facilitate communication and the interaction between the participants and interviewer. The scenario and the puppets were constructed during focal groups so that children became familiar with their toys for the individual interviews. The scenario functioned as the "stage" for the interview. At the end, a total of seven focal groups were held with the children. All the material used was provided by the main researcher who also coordinated the activities.

Two pilot tests were conducted to certify the relevance of the guiding questions and the technique used. Monitoring of the steps developed for data collection was performed in regular meetings with the authors and researchers in the field; experts on data collection techniques were chosen for this investigation, conferring rigor onto the data collection process. Examples of questions guiding the interview were: "Tell me about what has helped you to control the disease; what has helped you most at school? What has made it difficult? How do you think people have helped (or

hindered) you control your disease at school?" The reports were obtained between August 2008 and August 2009 in a private room at the outpatient clinic itself. The children could opt for the presence of their parents during the interview; however, given the familiarity and bond established between the interviewer and children during the construction of the scenario and puppets, all the children dispensed with the parents' presence. On the day of the individual interview, the researcher prepared the environment and ambience. Included in the scenario were the puppet manufactured by the child him or herself and another four puppets that could be added to the conversation and broaden the possibilities of dialogue.

The scenario was composed of a mobile and colorful fabric panel that simulated a place with open windows that permitted the participants to communicate from one side to the other side of the fabric and through figures previously drawn during the focal groups. The figures were used to characterize the panel and represented the child's significant objects and people who, in the child's opinion, either helped or hindered her/him in managing the disease. Together with these figures, other figures called "standard kit" were added. These were developed by the researchers and contained all the children's previous drawings. Since each drawing was individual, when observed by another child, their meaning could not be understood. This "kit" ensured that all children would recognize the drawings exposed there. Children were invited to sit near these elements and after constructing their ecomap, they were asked to choose a place from their daily routine in which they would like to initiate the conversation and characterize it adding figures to the panel. Then, as if it were a visit, the interviewer (with her own puppet) would take a look at the child and the environment through the communication window and then initiate the interview. At this point, the child was encouraged to tell about her/his everyday life and identify the elements that impacted the management of the disease at that specific place and in each place visited during the interview - the child could choose places that were significant in her/his routine and visit them as wished. When the child manifested no interest in visiting any other place, the interview was ended.

A total of 19 children were interviewed: 13 girls and six boys who were on average 9.8 years old with an average time since diagnosis of 3.3 years. The process of analysis began as the interviews were fully transcribed and occurred in stages according to the content analysis guidelines⁽¹⁷⁾. The last stage, data integration, enabled

the identification of how categories related with each other, recurrent issues in all the analyzed data, and finally, the study's conclusions⁽¹⁷⁾. In this stage, the constant presence of friends in the lives of children with DM1, which influences the management of the disease—the focus of this study—was observed. Nicknames chosen by the children were used in the presentation of the excerpts selected to illustrate the results and followed the standardization: parentheses (...) indicate excerpts of the same report, and information within brackets [...] refers to observations that contextualize the reports or express the participants' non-verbal behavior.

Results and Discussion

Friends were mentioned in all the meaningful places from the routine of children. They were recalled in the reports of situations at school, during play dates at friends' homes, in leisure activities, during meals, at the times insulin is administered, and were also recalled due to the support they provide and concern they manifested with the children's clinical state, as well as exhibiting prejudice. Therefore, interpreted data are presented from two perspectives represented by three categories: the attitude of friends toward the child with DM1, positively or negatively impacting the management of the disease, and the attitude of children with diabetes mellitus toward friends.

The management of DM1 influenced by the positive attitudes of friends

Children believe that friends help in the management of the disease, which would be even more difficult without their support and affection. Blossom (10 years old) told us about a situation in which the disease developed out of control and culminated in her hospitalization. It was a difficult situation she experienced in which she could count on her best friend to provide support. She told us: *[referring to the previous hospitalization due to the lack of control of type 1 diabetes mellitus] (...) my best friend, she gets very worried. There was a time she even cried. (...) She sent me a letter telling me to get well. She said she'd go there [home] as soon as I left there [hospital]* (Blossom). Camilla Wave (9 years old) spontaneously included her best friend in the conversation and introduced herself to us. Using a puppet that represented her friend, she told us how her friend reacted to the diagnosis and her understanding concerning food restrictions, showing her camaraderie: *[child with two puppets: one represented herself and the*

other her best friend:] You know what I wanted? I wanted to introduce you a friend that always helps me to care for my diabetes. Ah! There she is. [Using the puppet that represented her friend, she altered her voice as if her best friend introduced herself]. (...) My name is Maria. [At this point, the interviewer says to the puppet that represented the friend:] Camilla Wave told me that you help her to care for her diabetes, is it true? [The child, representing the friend, said:] It is very true. I helped her with her diet, that she has to bring crackers, has to drink two glasses of milk a day, I tell everything to her (...) Ah! I found that it was a good thing [referring to the diabetes diagnosis], because then I'll take care for her till death (Camilla Wave).

The closest friend, always mentioned as the best friend, proved to be essential for children in this study, both to face daily difficulties and to deal with interurrences. Blossom (10 years old) referred to a day of leisure, telling us that friends act in solidarity with her at meal times and when she has to stop playing to perform care actions concerning her diabetes mellitus. *They [friends] help me like: they eat only when I eat. (...) They even know the time I have to take insulin: Blossom is going to take insulin. So, they stop playing. Then, I go and take insulin! (Blossom).* Bubbles (8 years old) also expresses the companionship of her friends at school: *When it is high [referring to the capillary glucose] they [friends] ask me to play. When it's low, they give me something to eat. Otherwise, they ask the teacher whether I can eat this or that (Bubbles).* The companionship of friends, who promote fun and relaxation, make the children feel accepted, even with their condition, which favors successful management of the disease⁽¹⁸⁻¹⁹⁾.

Studies⁽¹⁹⁻²⁰⁾ reinforce the importance of friends at school knowing and understanding the disease and encourage the existence of a friend or best friend at school, who are called 'diabetic buddies' by these studies' authors, which is also valid for those friends outside of the school context⁽¹⁹⁻²⁰⁾. Clover's report shows there was a change of attitude of a friend at school when she was informed about the care required in relation to food: this friend established a relationship of camaraderie: *(...) a friend of mine, she didn't know [referring to the diagnosis]. So she asked me what I could not eat, whether it was sugar or salt. I said: Sugar. She said: So, then I cannot give anything sweet to you? Then I said: Yes. She said: So, I won't eat candies whenever you come here! [referring to the school] (Clover).* The existence of a friend was identified in this study and plays an important role in helping the child with diabetes mellitus in various situations such as during meals, exercising, capillary glucose tests, and in the

event of interurrences. Children with DM1 should be encouraged by the health team to tell their friends about their diagnosis, explaining that children with DM1 will feel safer with such support, and that they can count on friends.

The importance of understanding the disease and the care required for managing DM1 should also be made known to the parents of the friends of children with DM1 because their homes are frequented by children during leisure times and these events are a matter of concern for the parents of friends and the parents of children with the disease; both become concerned with potential interurrences during play dates. This concern may lead parents to prevent children from visiting the house of friends, such as to spend the day with friends, depriving them of times of great pleasure during childhood. Exploring this aspect, Blossom (10 years old) told us about a play date at a friend's home. *(...) I was at a friend's house, and her mother gets scared to death, you know? Dangerous. She's afraid of what I can do and what I can't. So she asks: Blossom, can you eat this? [child answers] Yes. So, they are very nice to me also. They help me a lot. Being able to go to other people's houses. My mother wouldn't allow me before; she used to be afraid to (Blossom).* It is the role of health professionals to give opportunities to transmit such information and encourage new ways of doing so, such as during school meetings or through educational booklets, promoting positive attitudes to help children appropriately manage their disease. An interesting strategy would be to develop a simplified manual with information concerning food options and care to be adopted during interurrences in relation to the glucose level. This little manual could be carried by the child and presented to teachers and parents of friends as recommended by the Juvenile Diabetes Association that proposes a model to be printed and which is already freely available online⁽²¹⁾.

The management of DM1 is influenced by the negative attitudes of friends

Many negative attitudes of friends occur due to a lack of knowledge concerning the diagnosis. Sometimes, even when they have knowledge, friends' attitudes are influenced by misunderstanding of how the disease functions and what care is required by the disease. The diet plan, one of the pillars of self-care, is essential for successful management of DM1⁽⁴⁾ and is one of the most negatively impacted aspects when there is a lack of knowledge. The reports show that this fact may result in behaviors not always desirable for children with DM1, especially when they involve children offering candy to them.

The difficulties in dealing with the desire to consume sugary food items are expressed in the following excerpts: *Sometimes, they [classmates] won't help me. They forget I have diabetes. (...) They give me candies, sweet stuff and I give them back* (Woody Woodpecker).

Candy available at school, brought from home by friends or bought by them at the cafeteria, are also difficulties posed to self-management during school break. The report of Buffy (8 years old) exemplifies the fact that, even though friends know her diagnosis, their actions make it difficult to manage their disease: *Sometimes, they (girlfriends) help, sometimes they hinder [care with diabetes]. Sometimes, they help by not buying candies; sometimes they don't help me because they buy them [candies]. Sometimes, I have a candy [referring to what she does when her friends buy candies and offer to her] (...) (Buffy).* The supply and selling of fruit-based foods, salads, natural juices and sandwiches by school cafeterias, instead of candies, sweets and soft drinks, would certainly minimize such discomfort for children with DM1 and would encourage healthier eating habits for all children.

As already mentioned, having knowledge and understanding the disease is also important for the friends' parents. The parents of friends may know the child's diagnosis but not know the care required by the disease and they may even have the desire to treat children with diabetes mellitus the same way they treat their children, disregarding the impact of such actions on these children's lives. The testimony of Hanna (12 years old) makes clear the desire of the mother of a friend, in a leisure situation, of treating her the same way she treats other children. This mother insists that Hanna accept the same food offered to the other children, which Hanna does not accept; other children with DM1 may not have had the same response. Hanna reports she explained to the friend's mother about the effects of food on her glucose control and that such a food could be replaced by diet food, which would not arouse her desire to eat it. She told us: *(...) it happens when we are playing there, her mother [referring to the friend's mother] took a piece of cake to her and the other friend who were playing. Then, she almost shoved the piece of cake into my mouth. I said: You can't do that! Ask my mother if I can eat it, because if I eat it behind her back, she'll get mad at me. My glucose would get too high. She [friend's mother] always thinks I'll get a craving. I've already explained to her that there is the diet version of everything she eats* (Hanna).

The integration of the child with DM1 into her/his group of friends and the understanding of her/his peers concerning the disease and required care are extremely valid issues if one wants to achieve appropriate management of the disease. Many children with DM1 believe that the care they should take in relation

to the treatment interferes in their social activities, making them feel different from their friends, that they spend time with such care and have to interrupt their activities⁽²²⁾. The report of Ronaldinho (12 years old) expresses this issue. In this case the child was at school, but these are facts that can occur in any place where there is socialization with friends. He told us: *Friends [referring to friends at school] are mostly annoying. They offer candy even though they know I have diabetes. When I refuse, they stop playing. I've already tried to explain about diabetes, but it didn't work* (Ronaldinho).

In addition to the issues already presented, there is another difficulty indicated by the children that interferes in the management of the disease, which was bullying related to DM1. The reports indicate the existence of bullying at school, though we cannot ignore its existence outside of school, either. When children talk about their relationships with their peers, they express the prejudice they suffer for the fact that they have diabetes mellitus through the way children name them or treat them, which are causes of great sorrow: *Sometimes I get sad because boys call me 'diabetic'* (Bubbles). One study⁽²³⁾ shows that depression related to bullying can contribute to poor treatment adherence, harming self-care and consequently contributing to the onset of complications in the long term. The development of educational programs involving visits by nurses to schools and also to homes, encouraging the discussion and transmission of information, and the search for solutions among health professionals, parents, students and teachers in order to heed the difficulties children face, are important strategies to appropriately manage the disease⁽²⁴⁾. Such initiative is viable given the Health Program at School⁽²⁵⁾ launched at the federal level, which recommends collaboration between health professionals working within the Family Health Strategy and the city educational network. It is also important that health professionals investigate the existence of situations related to bullying⁽²³⁾ when in contact with children with DM1 and also verify what information concerning the disease the child has already shared with friends as well as the need to provide help and explore other issues.

The management of DM1 influenced by the child's attitude toward friends

The analysis of data provided evidence that the attitude of children with DM1 toward their friends can impact the management of the disease. The reports show actions related to *lack of knowledge, fear, and shame* of children in the face of their friends. The

children have some difficulty telling their friends about their disease. They report embarrassment in explaining the disease as mentioned by Maxpen (12 years old), Mystic force (8 years old) and Goku (8 years old). We take the example of Maxpen: during the interview he was able to explain to the interviewer various aspects concerning diabetes mellitus. However, during his report, he used a puppet to represent a friend who did not understand diabetes mellitus and the care required during interurrences. When asked why his friends did not understand diabetes mellitus, Maxpen reported he could not explain the disease to them the way he did to the interviewer saying: *Ah! But it is different talking about what it is [diabetes] to him [friend] (Maxpen).*

Other children also showed a lack of knowledge or insufficient skills for transmitting information concerning the disease to friends. In the following report, Camilla Wave (9 years old), visiting a friend during the interview, used a puppet to represent him. During the dialogue, the friend told us that he could not learn about diabetes mellitus for personal reasons, and Camilla Wave reports difficulties in helping him. *[Using a puppet that represented her friend, she altered her voice:] No! [Referring to the desire to learn about diabetes]. I'll confess something to you: I'm very lazy. [Using the puppet that represented Camilla Wave, referring to what she would do if she ever needed her friend's help] Ai ai ai! Nothing! I don't know. [When she was asked about what she needed to teach her friend, she said:] But I don't know either [about diabetes], how can I teach him? [friend] If I don't know it myself! Ai ai ai, I'm lost! [Referring to what she would ever do if in an event of interurrence that she needed to teach him] (...) Camilla Wave). Oftentimes, rather than dealing with difficulties, children opt not to tell their friends about their disease, not valuing the support they could receive. When Woody Woodpecker (8 years old) explained about his decision of not telling his friends about the aspects with which they could help him, he told us: *It is because I don't like to talk about it [diabetes]. I don't like to tell them. No [answering to whether he thinks it is important his friends to learn about diabetes]. No, because they don't help me. (Woody Woodpecker). Buffy (8 years old) reports problems related to when her friends offer her candy: she has difficulty explaining the implications of eating sugar for the appropriate control of diabetes mellitus to her school friends. When Buffy was asked whether she ever tried to explain these difficulties to her friends, she said: No. Hum (thinking). Because I don't understand much [referring to diabetes] (Buffy).**

Many children become ashamed or afraid of revealing the diagnosis to their friends. Having someone

to help in such situations makes this task less painful. An example is Maxpen (12 years old) who told us about the support he received from the school coordinator to inform his friends about his diagnosis: *(...) the coordinator told them [referring to the diagnosis]. I didn't [tell them about diagnosis] because I was ashamed (Maxpen). Givana (8 years old) recalled during the interview the reaction of her cousins after she disclosed her diagnosis and revealed she had not tell her school friends for fear they would have the same reaction. She recalled: *I told them that I had a problem called diabetes and that I'd have to take injections. Then, they [referring to her cousins] got scared and run away. (...) [When she was asked whether her school friends knew about her diagnosis, she said:] No, no, no. Because I'm afraid they'll react the same way my cousins did and run away from me (Givana). Transmitting information concerning diabetes mellitus to friends is very important and should be done in a manner appropriate to the child's age; it may be transmitted by the parents, teachers, nurses, or by the children themselves. The reports show that the children would like their friends to be informed about diabetes mellitus and that they understood the care required to control the disease. When Maxpen was asked about this issue, he said: *That would be nice (Maxpen). Teaching children with DM1 how to effectively communicate with their friends about the disease can be useful and consequently improve self-care⁽²²⁾. Working issues such as understanding the disease, difficulties expressing oneself, fear of being seen as "different" and being ashamed of the diagnosis as well as the supply of appropriate information to school friends and peers from other places the children frequent, can contribute to strengthening friendships and promoting a greater understanding of their health condition, collaborating in the successful management of the disease. The support of a close friend during medical follow-up and educational programs frequently facilitate one's understanding concerning the disease and encourages the exchange of information with other children within the DMI patient's circle of friendship.***

Final considerations

This study's results show the importance of considering, during consultations, the experiences of children with DM1 with their friends in all the significant places in their daily routine, such as school, friends' homes, and leisure places. In this study, the interactions of children with DM1 and with friends, which influence the management of the disease, were presented from

perspectives that revealed both positive and negative attitudes of friends toward the child with DM1 and attitudes of children with DM1 toward their friends. Positive attitudes were revealed through demonstrations of the companionship of friends in the face of diverse situations faced by children with DM1, including interferences. The negative attitudes were related to diet and prejudice. Children with DM1 revealed a lack of knowledge concerning the disease, which contributes to the manifestations of negative feelings, including shame at revealing the diagnosis to friends for fear of their responses. Nurses and other health professionals should be attentive to the potential forms of interaction between children with DM1 and their friends, valuing opportunities to evaluate the knowledge and understanding of all those involved concerning the disease. The nursing care provided to this population should include the collection of information about how these interactions occur, helping to identify elements that either weaken or strengthen the management of DM1, therefore contributing to qualified and individualized nursing care delivery.

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