

# Care demands of children with type 1 Diabetes Mellitus

*As demandas de cuidado das crianças com Diabetes Mellitus tipo 1*

*La demanda de cuidado de los niños con diabetes mellitus tipo 1*

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## ABSTRACT

**Objective:** To know the experience of families in caring for children with Diabetes Mellitus Type 1. **Methods:** Descriptive and exploratory study with a qualitative approach. For the production of empirical material, it was developed open interview with thirteen relatives. The analysis took place according to the process of inductive thematic content analysis. It was used the framework of family-centered care as a driver of the analysis. **Results:** It were categorized in two themes: the family role facing the demand for modified usual care; and insulin therapy in the family's daily lives. **Conclusions and implications for the practice:** The experience of time with the disease coupled with support structures, commitment and perseverance from the families potentiate the management of chronic disease in childhood. It is suggested the reorganization of health services seeking to develop a care based on the concept of care centered on the family.

**Keywords:** Pediatric Nursing; Family; Type 1 Diabetes Mellitus.

## RESUMO

**Objetivo:** Conhecer a experiência de famílias no cuidado às crianças com Diabetes Mellitus tipo 1. **Métodos:** Estudo descritivo e exploratório com abordagem qualitativa. Para a produção do material empírico desenvolveu-se entrevista aberta com 13 familiares. A análise ocorreu segundo o processo de análise de conteúdo do tipo temática indutiva. Utilizou-se o referencial do Cuidado Centrado na Família como condutor da análise. **Resultados:** Foram categorizados em dois temas: a família diante da demanda de cuidado habitual modificado e a insulinoterapia no cotidiano das famílias. **Conclusões e implicações para a prática:** Conclui-se que o tempo de vivência com a doença aliado às estruturas de apoio, empenho e perseverança das famílias potencializam o manejo da doença crônica na infância. Sugere-se a reorganização dos serviços de saúde buscando o desenvolvimento de um cuidado pautado na concepção de cuidado centrado na família.

**Palavras-chave:** Enfermagem Pediátrica; Família; Diabetes Mellitus Tipo 1.

## RESUMEN

**Objetivo:** Conocer la experiencia de las familias en el cuidado de los niños con diabetes mellitus tipo 1. **Métodos:** Estudio descriptivo y exploratorio con enfoque cualitativo. Para la producción de material empírico fueron desarrolladas entrevistas abiertas con trece familias. El análisis se llevó a cabo de acuerdo con el proceso de análisis de contenido/temático inductivo. Se utilizó el marco de la atención centrada en la familia como referencial de análisis. **Resultados:** Fueron producidos dos temas: la familia mediante la demanda de cuidado habitual modificado y la terapia de insulina en las vidas diarias de la familia. **Conclusiones e implicaciones para la práctica:** Se concluyó que la experiencia del tiempo con la enfermedad junto con las estructuras de apoyo, las familias de compromiso y la perseverancia potenció el manejo de la enfermedad crónica en la infancia. Se sugiere la reorganización de los servicios de salud que buscan desarrollar una atención basada en el concepto de atención centrada en la familia.

**Palabras clave:** Enfermería pediátrica; la familia; Diabetes mellitus tipo 1.

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## INTRODUCTION

Type 1 Diabetes Mellitus (DM1) is a metabolic disease characterized by the absolute deficiency of insulin secretion due to the autoimmune destruction of pancreatic beta cells, and is responsible for 5 to 10% of diabetes cases; worldwide, the DM1 is one of the most prevalent diseases in childhood and adolescence.<sup>1</sup> In Brazil, the incidence rate is 7.6 per 100,000 inhabitants under the age of 15 years, with an estimate that there are around 25,200 children and adolescents with DM1 in the country.<sup>2</sup>

It is a disease of difficult control, prone to several complications both acute and chronic. Thus, after confirming the diagnosis, it is necessary to incorporate a rigid and permanent treatment in order to balance the supply and demand of insulin, that is, adequate diet, controlled practice of physical activity and insulin therapy.<sup>3</sup>

In this perspective, children and adolescents with DM1 fall into the classification of children and adolescents with special healthcare needs, because they are clinically fragile, requiring healthcare beyond that offered to people of the same age.<sup>4,5</sup> According to the classification of care demands, children and adolescents with DM1 present a demand for medication care in view of the need for continuous insulin therapy, as well as the demand for regular care modified as they require adjustments in diet, regular physical activities and continuous monitoring of blood glucose.<sup>6</sup>

Given these care requirements, families, especially the mothers, need to incorporate technical and scientific knowledge to support this specific care, such as food composition, preparation and administration of medications, signs and symptoms of hypoglycemia, among others.<sup>3</sup> Thus, studies have shown that the mothers of children with DM1 feel incompetent on the diagnosis and unprepared to deal with the complex situation of the disease, expressing feelings of anxiety, stress and social isolation.<sup>3,7</sup>

Based on these assumptions, the importance of a multiprofessional approach in the care of children with DM1 and their family is emphasized, since understanding and evaluating their experience in the process of a disease like diabetes constitutes the foundation for health interventions, that is, family-centered care enhances home care.<sup>7</sup>

Given these perspectives, the development of this study is motivated by the need to respond how families experience the demands of care required by a child with DM1. Thus, the present study aims to know the experience of families in the care of children with Type 1 Diabetes Mellitus.

## METHODS

This is a descriptive and exploratory study, with qualitative data analysis, carried out in a municipality located in the northeastern region of the state of São Paulo. The theoretical concept of Family Centered Care was used.

It is a concept that starts from the family as an essential source of support, in which the main focus of attention is not the disease, but the individual and its family.<sup>8,9</sup> It is based on the premise that the family is a source of strength and support and that the effectiveness of care is achieved when health services activate the family's ability to meet the needs of the child. It is necessary to involve the family in the planning of care from the effective sharing of information and participation and collaboration among those involved in decision-making.<sup>10,11</sup>

The study population consisted of thirteen family members of children with DM1 being monitored at a clinic of Child Endocrinology. This clinic provides multidisciplinary care for about 150 children and adolescents.

The eligibility criteria were: to be a family member of the child with DM1; be over 18 years old and reside in the research municipality. Initially, were identified thirteen families that had the potential to meet the eligibility criteria, however, four of them were excluded from the study because the registered address was not updated and, therefore, they were not located. So, participated in the study thirteen family members, who belonged to nine distinct families. Exclusion criteria were: family members of children with DM1 with experience with the disease less than three months.

The production of the empirical material occurred in the period from July to October 2013. For this purpose, it was made contact with the families selected and a home visit was scheduled according to the availability of the participant. An organized instrument with socio-economic data of the family was used, such as number of children, educational level, occupation, family income and marital status, as well as with clinical data of the child or adolescent, for example, time of diagnosis, therapeutic treatment and complications of the disease.

An open interview was developed with the following guiding question: Tell me about your experience of taking care of (name of child or adolescent) with respect to diabetes. It should be noted that the data collection was conducted by a post-graduate nurse and a graduate student in nursing. The duration of the interviews was approximately 40 minutes.

The analysis of the data covered the steps recommended by the content analysis technique of thematic inductive type:<sup>12</sup> pre-analysis (reading of the empirical material seeking to map the meanings attributed by the subjects to the questions asked); analysis of the expressed and latent senses (identification of the sense nucleus); elaboration of the themes (synthesis of the empirical material) and final analysis (discussion of the themes). In the end, the empirical material was categorized into two themes: the family role facing the demand for modified usual care; and insulin therapy in the family's daily lives.

Considering the involvement of human beings in research, the study followed the ethical assumptions of Resolution 466/12 of the National Commission of Ethics in Research of the National Health Council. The project was submitted to the Research Ethics Committee and approved under the protocol number

13602313.0.0000.5393, on April 16<sup>th</sup> of 2013. We emphasize that, to preserve anonymity, the families members were identified by the degree and kinship and the family name and chronological order of interviews.

## RESULTS AND DISCUSSION

To address the experiences of families in the care of children with Type 1 Diabetes Mellitus it is relevant to briefly present a characterization of the participants, starting from the perspective of enrichment made possible by considering the social context of these families.

Of the ten children and adolescents whose families participated in the study, five were male and five female. Age ranged from three to 12 years. Regarding the time of diagnosis, it ranged from 2 to 6 years. The most frequent insulin therapy was the association of NPH and Regular. Intercurrences such as hypoglycemia or hyperglycemia have been reported by most. The following table 1 shows the characterization of the thirteen family members participants:

### The family role facing the demand for modified usual care

A modified routine care is understood as a set of practices that are associated with the daily care of any child, that is, care as with the food that is modified and/or adapted to the special health needs of children and adolescents with diabetes. Proper nutrition is one of the pillars of diabetes treatment in any of its forms and without it is difficult to reach an appropriate metabolic

control.<sup>13</sup> In this sense, the following reports reveal the difficulties related to food restriction:

*It's hard, for me until today is difficult, because somethings she can't eat, can't drink, almost everything... so everything has to be sugar-free, it has to be ruled. (Mom - Family 4)*

*Yes, it changed a lot... the candy we bought in the past, we don't buy anymore, normal juice, soda, now it's diet juice. (Father - Family 1)*

On the other hand, the following testimony shows that the modifications in the diet were well accepted by the whole family, especially the habit of consuming healthy foods:

*This part of alimentation was not difficult because we already ate vegetables and all these things, soda, sweet, these things was really for the weekend. (Mother - Family 1)*

In the same direction, the mother of the family number six addressed her search for diets foods to satisfy the daughter's desire to eat sweet, that is, making adjustments in food before the prohibition of consumption of sugary foods:

*There is a lot of dietary stuff, a lot of it, there's even condensed milk, I was seeing the recipe for a diet honey buns with sweetener... I was thinking of doing it for her... (Mother - Family 6)*

**Table 1.** Characterization of family members of children and adolescents with DM1. Ribeirão Preto, 2013.

| Family | Participant | Relationship | Age | Education         | Occupation        | No. of children | Family income*    |
|--------|-------------|--------------|-----|-------------------|-------------------|-----------------|-------------------|
| F1     | P1          | Mother       | 38  | High School       | Maid              | 03              | 1 minimum wage    |
|        | P2          | Father       | 42  | High School       | Salesperson       |                 |                   |
| F2     | P3          | Mother       | 32  | High School       | Housewife         | 02              | 3 minimum wages   |
| F3     | P4          | Grandmother  | 77  | Elementary School | Retired           | 05              | 2 ½ minimum wages |
|        | P5          | Mother       | 43  | Elementary School | Service assistant |                 |                   |
| F4     | P6          | Mother       | 33  | Elementary School | Maid              | 03              | 2 minimum wages   |
| F5     | P7          | Mother       | 34  | High School       | Kitchen-maid      | 04              | 2 minimum wages   |
| F6     | P8          | Mother       | 47  | High School       | Salesperson       | 02              | 6 minimum wages   |
| F7     | P9          | Father       | 31  | Elementary School | Painter           | 01              | 4 minimum wages   |
|        | P10         | Mother       | 52  | Elementary School | Housewife         |                 |                   |
| F8     | P11         | Father       | 40  | Elementary School | No answer         | 03              | 2 ½ minimum wages |
|        | P12         | Mother       | 39  | Elementary School | Maid              |                 |                   |
| F9     | P13         | Mother       | 29  | Higher Education  | Housewife         | 01              | 2 ½ minimum wages |

\* Minimum wage corresponded to R\$ 678.00 in 2013

Although dietary restrictions are necessary, studies reveal the importance of adjustments in incorporating the new diet, taking into account the sociocultural values of the individual as well as socioeconomic factors, expressed by the supply, access and distribution of food.<sup>14</sup> The carbohydrate count has been shown to be allied in food control, since it allows the calculation of the carbohydrate grams that will be ingested at each meal and allow flexibility in the choice of foods.<sup>15</sup> In this perspective, the mother number nine mentioned:

*When she developed the disease, we strictly followed a diet without sugar, everything diet. Then we discovered that not all diet food is worth it because she was getting high cholesterol due to the high fat rates it has in diet food. So, we chose to eat a normal diet, sugar-free, and we start counting carbohydrates. (Mother - Family 9)*

Another demand of modified habitual care is related to blood glucose monitoring. Glycemic monitoring aims to determine the level of glycemic control acquired by the patient, being the best option in the prevention of acute complications (mainly hypoglycemia) and, over time, in the prevention of chronic complications as a result of effective control.<sup>16</sup> In addition to the capillary glycosometer procedure, family members need to incorporate knowledge regarding the signs and symptoms of hypoglycemia and also hyperglycemia:

*The change is on children's humor. When diabetes is decompensated, she gets very nervous, angrily, you can't say anything that she is already fighting and complaining. If it is low she is very sleepy... the changes are in temperament, when is low she loses to the consciousness, you question something then she responds something that doesn't make sense. So, if you measure, you can be sure it will be low. (Mother - Family 9)*

A study that has the purpose to identify the effects of a family-centered intervention based on the glycemic levels of adolescents with DM1, identified a statistically significant association as the intervention made it possible to share responsibilities and, consequently, better adherence to treatment.<sup>7</sup> Thus, in the perspective of family-centered care, it is opportune that the team identifies and reinforces the potential of parents in the management of care and identification of the signs and symptoms of hypoglycemia and hyperglycemia.

From these new knowledges and practices, incorporated in the daily life of these families, we can observe adjustments in the daily routine, among them, the need for continuous attention. In this sense, families find different strategies to guarantee full-time assistance:

*I work, she stays at her grandmother's house during the week and on Saturday and Sunday she comes home...*

*because I can't leave her alone at home, I'm leaving 6:00AM in the morning. Sometimes she loses the conscience and falls, falls down a lot. I cannot imagine her locked alone and then when I get there she's dead. (Mom - Family 3)*

*I even stopped working because of him, he was very lonely. For him not to be alone I left my job, I worked as a secretary in a psychology clinic. (Mother - Family 2)*

These results corroborate with the literature. Studies indicate that diabetes is a chronic disease with complex and intense care demands, so it is common for many mothers to leave their job to dedicate to their child.<sup>3,15</sup> Starting from the perspective of family-centered care, it is possible that the nursing team can help other family members in acquiring care competencies, thus enhancing the flexibility and spontaneity of family life.<sup>3</sup>

Contradictory situations also occur where the mother is dismissed from work because of the difficulty in dedicating:

*After he was born with this problem, my life totally changed, I could not go neither forward nor backward. I was working at night, I had t to quit the service because no one wanted to take care of him... the school calls all the time, calls to pick him up... I've already lost many jobs because of this. (Mother - Family 5)*

The financial overload was also addressed by some family members:

*We are living day after day, buying what is possible, it's all expensive. (Mother - Family 8)*

*Because it is not only the medication, there is the food, he likes candy a lot, you have to buy everything diet and the value is almost triple, everything is much more expensive. (Mother - Family 2)*

Regarding the financial difficulties, the studies indicate that this is a recurring situation in most families, the family budget for the care of a child with diabetes has a great impact, causing changes in the socioeconomic standard and acting negatively on the perception of the disease.<sup>15</sup> Study states that the healthcare costs of an individual with diabetes is three times higher than an individual without the disease.<sup>7</sup>

The testimonies of family members were also composed of negative and positive experiences regarding the school environment:

*It's been three years since he's in this school, so it's complicated because they serve sweet bread with sugar, milk with sugar... I even sent a note saying that he is diabetic, but sometimes there are teachers who do*

*not know. He says that the teacher does not let him drink water, because she says that his classroom is terrible so there is no exception, they put everyone grounded. (Mother - Family 2).*

*Sometimes in school, I tell her not to get snack of classmates, because we don't know what they're eating, but sometimes she sees and eats. (Mother - Family 4)*

*They call, there's a nursing home there, and the teachers are already oriented, so if she sleeps on the desk, forget it, it's not sleep, is hypoglycemia... then the teachers lead her to the nursing home, the nurse measures the glycemic and calls me in no time. And the instant glucose sachet is in her handbag, so in case of hypoglycemia she sucks this sachet, it is very quick, just five minutes. (Mother - Family 9)*

Corroborating with the results, other studies with children with diabetes have shown that they have had countless negative experiences at school, either by the lack of private space for insulin administration or collection of tests or the lack of knowledge of teachers and colleagues about their condition.<sup>15,17,18</sup> On the other hand, when the school is prepared to receive the student with diabetes and acts in communion with the parents, there is a greater adaptability of the child, who feels welcome and is able to follow the normal activities.<sup>18</sup>

### **Insulin therapy in the family's daily lives.**

In addition to the modified usual care, families experience the need for continuous use of insulin for the management of diabetes. With this, there is a need to develop an additional skill for care, that is, the administration of medication subcutaneously. The acquisition of this ability causes diverse feelings between the family members, however the fear and the insecurity prevail in the testimonies:

*At first it was hard, but then... we got used to it. (Mother - Family 4)*

*They gave me the syringe and asked me to train in oranges, so I applied there only a couple of times in the hospital... but we were disoriented... I had to call my husband to come and pay attention because I couldn't. (Mother - Family 8)*

Despite the fears, studies show that when the family assumes an active position in the adaptation of the physical and emotional needs of the chronically ill child, without the disease or the patient becoming the center of the family system, there is a greater adherence to treatment.<sup>19</sup> In this perspective, after the initial impact, the family members seek to normalize the situation and begin to stimulate the self-application of insulin, but with supervision:

*She is messed up, we have to stay alert all the time, if we don't pay attention, she forgets it. We have to check if she is putting the right dose. One time, she applicate the insulin twice at dinnertime. (Mother- Family 9)*

One of the justifications for not delegating fully the responsibility for self-application was due to the need for rotation of the application parts of the body and consequent difficulty of children or adolescents applying in some regions:

*Because he can only apply on the belly and the belly gets sore from so much you apply, then I apply on the arm. He does not apply on the arm, he does not have that control yet, my husband even tried to teach him, but he is insecure, he shakes, he has a stiff arm, so he ends up hurting himself. He will have time to learn yet, in the meanwhile, we are going to help him to apply. (Mother - Family 2)*

Another important point identified in the testimonies of family members refers to the acquisition of insulins and materials of consumption, which are provided free of charge by the Unified Health System. However, in some situations, the available insulin was not effective for the control of the disease, being necessary the prescription of similar insulins. Therefore, adding another financial burden for families until the insulin is judicially released for free.

*He takes five a month, five bottles, it's 500 reais more in the budget you have to have, because each one is 100 reais. He has diabetes since he was 6 and a half years and we always buy. Now we have request insulin with the social worker, a lot of bureaucracy. (Mother - Family 2)*

*It's been four months since we're trying to take insulin for him and we cannot do it; You depend on everything from the government. He was not taking insulin; this one [shows the bottle] we won. (Father - Family 8)*

As to the difficulties experienced in the process of acquiring high-cost insulins from the Public Ministry, we observed that the results of the present study are in line with the considerations made in the study of children dependent on technology.<sup>20</sup> That is, the institutional care network is fragile and disintegrated and successful experiences result from the commitment and perseverance of these mothers, who engaged in a daily struggle with the system in the search for the rights of their children.

Finally, the results corroborate the idea that families behave differently in the face of illness, that is, they are specific experiences that depend on the time of experience with the disease, as well as the available support structures to meet their needs and find the balance.<sup>20</sup>

From this perspective, the relevance of the concept of family-centered care is reinforced, as it is based on the premise that professionals should respect the individuality of children and their families in order to build care based on family involvement.<sup>9-11</sup> It is also added, the notes in the literature which reinforce that the incorporation of family-centered care in daily care leads to greater adherence to treatment and better results as a therapeutic alliance is formed among health professionals, family and child, with respect, trust and empathy.<sup>9,11</sup>

## CONCLUSIONS AND IMPLICATIONS FOR THE PRACTICE

In this study, we aimed to know the experience of the families of children and adolescents with DM1 front the demands of care required and we believe that the themes that emerged from the empirical material reached the objectives initially proposed. We highlight the financial difficulties and negative experiences at school related to modified usual care demand. In addition, part of this experience is fear and insecurity involving the insulin therapy in the daily life of these families, combined with another financial burden for them.

However, the results indicate that the time of living with the disease as well as the support structures available and the commitment and perseverance of the families potentiate the management of chronic disease in childhood.

On these findings, it is suggested the active participation of nursing professionals in order to establish a link with the families and begin an early and continuous process of education in diabetes with the involvement of all members of the family, based on the concept of family-centered care. In addition, it is necessary to reorganize the health services with the objective of guaranteeing comprehensive and integrated care. It is also essential to involve schools in the care process in order to enhance the care and welcoming of these children with DM1 and their families.

Regarding the limitation of the study, the cross-sectional delineation and the participation of thirteen family members should be highlighted. However, such limitations do not invalidate the results of the research; just indicate the need for further studies on the subject.

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