

# THE DIVISION OF THE CARE OF THE CHILD OR ADOLESCENT WITH TYPE I DIABETES WITH THE FAMILY

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**ABSTRACT:** Descriptive study with a qualitative approach, aiming to understand how the family care for children and adolescents with type I diabetes mellitus takes place. Interviews were held with seven family members in April – June 2012. The data obtained through the semistructured interviews were subjected to content analysis of the thematic modality. Two thematic categories emerged, which revealed the transformations which occur in these families' lives, with emphasis placed on those with dietary restrictions and the lack of appropriate support on the part of social networks, friends and other family members. In this way, one can see the need for continuous education, not only for the family members who live with this child/adolescent on a daily basis, but also for all of those professionals involved in the care, as well as members of the extended family.

**DESCRIPTORS:** Diabetes mellitus; Child; Adolescent; Family.

## A CRIANÇA E O ADOLESCENTE COM DIABETES MELLITUS TIPO 1: DESDOBRAR DO CUIDADO FAMILIAR

**RESUMO:** Estudo descritivo de abordagem qualitativa cujo objetivo foi apreender como ocorre o cuidado familiar às crianças e adolescentes com diabetes mellitus tipo 1. Foram entrevistados sete familiares no período de abril a junho de 2012. Os dados obtidos por entrevista semiestruturada foram submetidos à análise de conteúdo, modalidade temática. Emergiram duas categorias temáticas, que revelaram as transformações ocorridas na vida destas famílias, destacando as relacionadas à restrição alimentar e à falta de suporte adequado por parte das redes sociais, amigos e demais familiares. Desta forma, vislumbra-se a necessidade de educação continuada não somente junto aos familiares que convivem diariamente com esta criança/adolescente, mas também a todos os profissionais envolvidos na assistência, bem como aos membros da família extensa.

**DESCRIPTORES:** Diabetes mellitus; Criança; Adolescente; Família.

## EL NIÑO Y EL ADOLESCENTE CON DIABETES MELLITUS TIPO 1: DESPLEGAR DEL CUIDADO FAMILIAR

**RESUMEN:** Estudio descriptivo con abordaje cualitativo cuyo objetivo fue reflexionar acerca de cómo ocurre el cuidado familiar de niños y adolescentes con diabetes mellitus tipo 1. Siete familiares fueron entrevistados en el periodo de abril a junio de 2012. Los datos fueron obtenidos por entrevista semiestructurada y sometidos al análisis de contenido, modalidad temática. De ellos, resultaron dos categorías temáticas, las cuales mostraron las transformaciones que ocurrieron en la vida de las familias analizadas, destacando aquellas asociadas a la restricción alimentar y a la falta de apoyo adecuado por redes sociales, amigos y otros familiares. Así se vislumbra la necesidad de educación continuada no solamente con los familiares que conviven diariamente con este niño/adolescente, pero con todos los profesionales que hacen parte de la asistencia y con los miembros de la familia ampliada.

**DESCRIPTORES:** Diabetes mellitus; Niño; Adolescente; Familia.

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## ● INTRODUCTION

Diabetes mellitus, type I, (T1D), known as juvenile diabetes and/or insulin-dependent diabetes, is responsible for approximately 10% of cases of diabetes in Brazil. In this type of diabetes, the destruction of the Beta cell of the pancreas takes place, due to an autoimmune process or other degenerative diseases associated with T1D, compromising the total capacity for production of insulin, which is necessary to lower the glycemic levels and thus to prevent ketoacidosis, coma and death<sup>(1)</sup>.

In spite of the seriousness of T1D, there are no preventive measures for avoiding its appearance, and for this reason its incidence has grown over the years. In the United Kingdom, for example, T1D is the third most-common chronic illness in childhood, and its incidence has doubled in the last 20 years; each year, 13.5 new cases appear in each 100,000 children<sup>(2)</sup>.

The disease's impact on society is notorious, due to the growing number of people who are affected, the premature deaths, the presence of incapacitation and complications which result from the illness, and the high costs involved in its control and treatment<sup>(3)</sup>.

One study undertaken in Scotland showed there to be a close relationship between the family structure and the glycemic control throughout childhood, it being the case that psychosocial and educational influences perform a fundamental role in determining the results of the management of T1D in children. Adolescence also has an important role in this management, due to the rapid physical changes of puberty, which can trigger relative resistance to the effects of insulin and simultaneous changes in development, as well as raising the level of stress as a result of pressure from friends<sup>(2)</sup>.

In Brazil, one study observed that the child/adolescent with T1D, upon noticing the parents' difficulty in dealing with her illness, tends to isolate herself from her social circle, as this perception causes these children to feel that they are different from their peers<sup>(1)</sup>.

It is possible, however, to infer how difficult it is for the parents to coexist with this situation of illness, often characterized by the feeling of impotence and by the demand for new and specific care, which the parents do not always feel able to undertake. All these questions awaken in the family members the need to learn to deal with previously-unknown feelings, symptoms and therapeutic procedures, as well as also having to learn to control the disease<sup>(3)</sup>.

A fairly common reaction in these cases is parental self punishment, which causes these to adopt a protectionist stance, making the child/adolescent dependent on their care, as well as being a centralizing pole for the attention, concerns and distress of the family<sup>(2,4)</sup>. In this regard, one can see the need for differentiated care on the part of the health professionals, who can direct their work towards care focused on the family and on the child/adolescent with a chronic disease<sup>(1)</sup>.

Thus, one can confirm this study's importance, as it seeks to evidence gaps highlighted by the main caregivers of the children and adolescents with T1D, so as to support the work of the health professionals in implementing strategies which can better empower these caregivers. In the light of the above, the study's objective was defined as learning how the family care for the children and adolescents with diabetes mellitus type I takes place.

## ● METHODOLOGY

This is exploratory and descriptive research, undertaken in the municipality of Paranavaí in the Brazilian state of Paraná (PR), in the ambit of the Primary Healthcare Centers (UBS). This municipality had, in 2010, a population of 81,590<sup>(5)</sup>, of whom 24,308 were children and adolescents. In the health area, the municipality had 16 Family Health Strategy (ESF) teams, distributed across 15 UBS.

Those who contributed to the study were those family members of the children and adolescents with T1D aged 18 years old or over, and whose child/adolescent affected by the disease was aged one year old or over. The data were collected in the families' homes, between the months of April and June 2012, through semistructured interviews. The instrument used in the interview was a script elaborated

by the authors, made up of two parts: the first addressed aspects related to the sociodemographic characterization of the subject, while the second was a semistructured script with questions based on the study objective.

A survey was undertaken in the municipality's 16 ESF teams with the nursing team and community health workers (CHW), locating 11 families with children/adolescents with T1D; of these, only seven families accepted to participate in the study upon invitation, which took place through a home visit.

The contributors were selected according to the following criteria: to be the main caregiver of the child/adolescent with T1D; and for the time since the child's diagnosis to be over one year. To ensure anonymity, the family members were identified using the letter P followed by Arabic numerals from 1 to 7, in accordance with the order of the interviews. Regarding the children/adolescents who were the children of the study participants, these were identified using the letter F followed by Arabic numerals from 1 to 7, referring to which family member she was the child (F1 – child of family member 1).

For the interpretation of data, the interviews were transcribed in full and subjected to a process of content analysis of the thematic modality(6), respecting its stages: the first was the organization of information, using procedures of skim reading, hypotheses, objectives and the elaboration of indicators in order to provide a basis for the interpretation; the second was the codification of the data, through registration units; and the last stage of categorization was when the elements were classified according to similarities and differences, being re-grouped by their common characteristics. Two Thematic Categories emerged: Change in eating habits: the family coexisting with diabetes, and Dietary control: constant vigilance of the child/adolescent.

The project was approved by the Standing Committee for Research Ethics with Human Beings, of Maringá State University (Decision N. 16829) and followed the precepts of Resolution 466/2012<sup>(7)</sup> of the Brazilian National Health Council for research with human beings.

## ● RESULTS

The study had as its participants seven family members of children/adolescents with diabetes mellitus type I, of whom six were mothers and one a father, as may be seen in Table 1. Regarding the contributors' children, the majority were adolescents and had been diagnosed with the disease for over three years (Table 2). The study's thematic categories are presented in sequence.

### Change in eating habits: the family coexisting with diabetes

One of the changes caused by T1D which stands out the most is represented by food, and is related to the physiological dysfunction of the metabolism of carbohydrates. These changes were indicated by the study's informants when they report that the main way of dealing with the disease was to implement changes in the child/adolescent's eating habits – and, further, the attempt to extend these changes to the other members of the family.

*[...] There are no sweets in my house! Lots of fruits, plenty of greens... [indicating the food which was being prepared] Healthy! That is chicken breast that I am cooking. (P1)*

*It changed quite a lot, the food changed. We already took care with this a little, but not so much, we've cut down on frying quite a lot, in particular, sweet things... (P2)*

*We changed how we eat, because of him, you know?... Eating only a little, not very much sweets, reducing the sugar, sweetener for him. (P4)*

*Sweets, pasta... I used to make quite a lot. Now I have cut back, I changed from white rolls to wholemeal. (P7)*

In this way, some foods which had not been part of the family menu came to be included, while others were adapted or excluded.

Table 1 – Socioeconomic characteristics of the family members of children/adolescents with diabetes mellitus type I. Paranaíba, PR, Brazil, 2012

Code	Gender/Relationship	Age	Educational level	Monthly Family Income
P1	Female (mother)	29	Senior high school incomplete	1 minimum salary
P2	Female (mother)	55	Higher education	Over 3 minimum salaries
P3	Female (mother)	63	Primary/Junior high school incomplete	3 minimum salaries
P4	Female (mother)	36	Senior high school complete	3 minimum salaries
P5	Female (mother)	43	Senior high school complete	3 minimum salaries
P6	Female (mother)	32	Senior high school complete	Over 3 minimum salaries
P7	Male (father)	45	Senior high school complete	3 minimum salaries

Table 2 – Characteristics of the children/adolescents with diabetes mellitus type I. Paranaíba, PR, Brazil, 2012

Code	Gender	Age (years)	Time since diagnosis with T1D (in years)
F1	Male	8	3
F2	Female	14	8
F3	Male	12	3
F4	Female	9	6
F5	Male	15	15
F6	Female	12	2
F7	Male	18	1

### Dietary control: supervising what the child/adolescent eats

It is common to observe, among the family members, attitudes of concern in relation to controlling what the child/adolescent eats, both in the domestic ambit and in other scenarios of social coexistence of these families. Furthermore, the adoption of constant supervision, or even the imposition of strict rules, reflect these caregivers' attempts to avoid, at any cost, the harmful repercussions of the glycemic imbalance in their children.

*Sometimes I despair about the food... Because that is what needs to be controlled most, and I need the help of the family, and I don't have any support. They [family members] eat sweets near her [the adolescent] and she starts wanting to, but they aren't bothered about this... (P2)*

*In school, we have to control his food! You can't give him just any old thing. We have spoken with the teacher, she knows about everything. The difficulty is not letting him eat everything he wants to. (P3)*

*You have to be caring about it all the time, and even so, sometimes you fail and diabetes increases, and she has to go into hospital. We are worried about everything because she is different. She is a weak little girl and you have to treat her completely differently from the others. She is much more delicate. (P5)*

With this aim, the family members come to exercise the role of supervision regarding what their children ingest, and impose rules, not only in the domestic ambit but across the entire social context.

## ● DISCUSSION

The American Diabetes Association<sup>(8)</sup> emphasizes, as the main aims of the Medical Nutrition Therapy for the patient with T1D: a) to prevent chronic complications through the correct nutritional intake accompanied by changes in lifestyle; b) to maintain the pleasure of feeding oneself, limiting only specified foods (in accordance with scientific evidence); c) to meet the individual nutritional needs, in accordance with cultural and personal aspects; d) to motivate the patient regarding the regulation of changes; e) to integrate the insulin therapy regime into the patient's lifestyle.

The impact caused by dietary changes in the family scenario arises as a result of the needs or demand for controlling the disease, as studies indicate that nutritional therapy is an essential part of the treatment of diabetes mellitus<sup>(8-9)</sup>. However, dietary restructuring is one of the most difficult changes that the family has to face in coexisting with diabetes, as it entails restrictions and limitations which were previously unnecessary<sup>(10)</sup>.

It is necessary to bear in mind that changing habits – whether to do with food or of any other nature – involves more than simply ceasing to do something or changing to do it in a different way. Such changes are reflected directly in the socialization of the individual, as became evident in one study<sup>(11)</sup> in which the authors mentioned that the children with T1D believe that all the care measures which must be taken in relation to the disease directly hinder their social life. This causes the same to feel not only different to the other children, but also deprived of a precious time in their lives, as this must be set aside for the numerous care measures to be taken in the control of the disease, to the detriment of other transient, and more pleasurable, activities.

In this aspect, emphasis is placed on the possibility of the occurrence of difficulties in understanding and/or acceptance on the part of the child/adolescent, as a result of the need to “let go” of certain pleasures, and of the routine which is common to other children of the same age. The role of the parents or guardians, in this scenario of transition, becomes an element which is fundamental for the therapeutic success and the ensuring of future standards of quality of life of these young patients<sup>(12-13)</sup>.

Characterized as a disease of childhood and adolescence, T1D emerges, in the majority of cases, in a phase of life in which the individual does not yet possess sufficient competences for their self-care. Indeed, in most cases, the disease arises in children of an age group in which the cognitive skills and emotional maturity are not yet sufficiently organized for planning or for decision-making in relation to their therapeutic regime<sup>(11)</sup>.

The reports allow it to be evidenced that, in spite of the diagnosis having occurred over three years previously in the majority of cases, the family still have difficulties in their routine with a child/adolescent with T1D. In this scenario, the demands related to the rigorous control of food not only have repercussions in the therapeutic process, but also have implications for the entire process of socialization of the child and of her family.

There is, therefore, an expectation on the part of the parents in relation to the behavior of the other family members, in the sense of co-responsibilization regarding the diabetic child's dietary control, and so as to avoid the child's frustrations in relation to dietary deprivation.

Dealing with the wish to eat, and with the guilt for having eaten what one should not have, is one of the difficulties in the process of coexisting with the disease. These aspects are perceived mainly in the child's environments of social coexistence, such as school, where the child is obliged to take her lunch from home, which restricts her participation in the shared meals and, consequently, hinders the social interaction process in this environment<sup>(4)</sup>.

At the same time, it is known that one intrinsic factor for there to be development of self-care in the child is the involvement of friends, parents and the extended family in the therapeutic process of the disease; and this involvement promotes the increase of the child's self-confidence, and also the understanding regarding the importance of adhering to the correct treatment<sup>(12)</sup>.

For the child/adolescent with T1D, the management of the disease is directly related to how much she understands her state of health, as well as other important aspects such as: self-care, the school routine, and the support of friends, family, and health professionals. Regarding the role of the health professionals, one has to emphasize the importance of the work of the nurse, who must be alert to the assessment of these aspects, in order to identify them and hence to plan and implement intervention strategies which facilitate the care for the entire family and for the child/adolescent<sup>(1,12)</sup>.

To this end, the nursing professional must involve the family in the care for the child/adolescent with T1D, so as to empower its members to face the limitations and challenges imposed by the disease. It is also necessary to encourage the autonomy of the children/adolescents and their family members, such that these may act as information multipliers, helping other people who need support in the treatment of diabetes<sup>(9)</sup>.



## ● CONCLUSION

The study made it possible to understand the extent to which diabetes mellitus type I significantly changes the way of life of the patient and her family, principally in relation to the dietary aspects. The change in eating habits resulting from T1D brings important changes in the participants' family, social and economic routine, as well as concerns with the children following the appropriate diet in environments outside the family context, such as, for example, the school – where the parents cannot exercise constant and effective surveillance in relation to what their children actually are ingesting.

The parents reported that the difficulties in maintaining appropriate eating for the children/adolescents with diabetes can hinder the patients' capacity to adhere and to control the disease, as they lack the emotional maturity, and are not fully developed cognitively, for effective self-care.

In this way, the need emerges for an individualized family approach on the part of the multidisciplinary health team, allowing the same to express their anxieties and conflicts in dealing with T1D, such that they can plan care in which the family is an active agent in the management of the care for the disease. On the other hand, the good relationship between the child, family and health professional facilitates the treatment and control of the disease, as well as establishing bonds of trust and respect between the family members and health team.

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