

DIABETES *MELLITUS* IN CHILDREN AND ADOLESCENTS: REPERCUSSIONS IN DAILY LIFE OF FAMILIES¹

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ABSTRACT

Exploratory and descriptive qualitative approach that aimed to understand the daily consequences expressed by the family of children and adolescents diagnosed with type 1 Diabetes *Mellitus*. Eleven families of children and adolescents with Diabetes *Mellitus*, all of which were registered in an association for diabetics of Maringá, participated in this study. Inclusion criteria were: being family member of children/adolescents with Diabetes *Mellitus*; aged 18 years or older; being conscious and oriented in time and space, regardless of work functions, social level or schooling and; accepted freely and to participate. Data were collected in September 2012, through interviews using a semi-structured questionnaire. From the thematic data analysis, two thematic categories emerged: Living with a child's illness and; Understanding the need for care expressed by the family: abandonment and neglect. This study allowed us to understand the coping of the families of diabetic children and adolescents across the various changes of life and feelings involved in the process of falling ill, showing the need of health professionals, especially nurses, to provide care to these families.

Keywords: Chronic disease. Diabetes *Mellitus*. Child. Nursing. Family.

INTRODUCTION

Diabetes *Mellitus* is not an isolated disease, but it is a set of metabolic disorders that have hyperglycemia in common, due to problems in the production and secretion of insulin. The incidence of type 1 Diabetes *Mellitus* is 0.5 new cases per 100,000 inhabitants per year, affecting mainly children under five years of age⁽¹⁾.

The most frequent types are Diabetes *Mellitus* type 1, previously known as juvenile Diabetes, which comprises about 10% of total cases, and type 2 Diabetes *Mellitus*, which comprises about 90% of the total cases. There are also other forms of Diabetes, such as gestational Diabetes, caused by the use of medications or other pancreas diseases⁽²⁾.

Incurable chronic diseases affect the individual causing them to re-signify their existence, making adaptations regarding losses, frustrations and limitations. These adaptations are greatly intensified when experienced by children and adolescents, since they are expected to grow, live and develop in a healthy way without the presence of complications in the course of their lives⁽³⁾.

The family is a great ally in conducting the patient

through his/her illness, exerting a great influence in the recovery and helping in the use of resources necessary for the adaptation of this member in an individualized and effective way, reestablishing the integrity of the family⁽⁴⁾. The discovery of a chronic illness in the child or adolescent shakes the family structure, which expresses their emotions through suffering because it is in the child that their future dreams and expectations are deposited, which are interrupted due to their new condition⁽⁵⁾.

In this perspective, the family is crucial for the reconstruction of the health of its members, and the role of health professionals is providing support, strengthen and guidance in the face of difficulties and fragilities experienced in daily life^(3,6-8).

Thus, the relationship between the family and health professionals is an essential element during the care provision. Although this approach emphasizes the essential role played by family members in the life and well-being of the child and adolescent, it is not yet prevalently incorporated into the health care philosophy of national health systems⁽²⁾.

When the nurse tries to understand the family and seeks knowledge to try to understand and provide care for it, they start to understand how the family needs to be included in the care process, especially the primary caregiver. In the face of this theme, the

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following question arose: how does the family experience the onset of *Diabetes Mellitus* in children and adolescents?

The aim of this study was to understand the daily repercussions expressed by the families of children and adolescents diagnosed with type 1 *Diabetes Mellitus*.

METHODOLOGY

This is a qualitative, exploratory and descriptive research. The target population consisted of eleven relatives of children and adolescents diagnosed with type 1 *Diabetes Mellitus* and aged 18 years or over, enrolled in an association for diabetics of Maringá and region, located in the State of Paraná. The inclusion criterion was: being a family member of a child/adolescent with *Diabetes Mellitus*; being 18 years of age or older; being conscious and oriented in time and space, regardless of work functions, social level or schooling; who accepted to participate freely and spontaneously in the research; a who signed the Free and Informed Consent Term.

In 2012, about 350 children and adolescents diagnosed with type 1 *Diabetes Mellitus* were enrolled in this association for diabetics of Maringá and region. The families that participated in the study were located through this registry, through which a telephone contact was made to schedule the interview in only one home visit.

The data were collected in September 2012, using a semi-structured interview script, containing questions elaborated by the researchers. The most relevant aspects of the presented problem were considered, namely: what was your reaction when discovering the diagnosis of *Diabetes Mellitus* in your child? What were the changes that occurred in your family? What kind of concerns did you start to have about your child? How is the family's daily life in relation to the care of the child/adolescent with *Diabetes Mellitus*? What were the biggest difficulties with the treatment for your child? And for your family?

The semistructured interview was composed of open and closed questions, which aims to collect data pertinent to the research objectives, allows the flexibility of the subjects' thinking and also opens the possibility to discuss the proposed theme⁽⁹⁾. Data collection was completed with eleven participants, since the content of the interviews, as judged by the

researchers, reached the data saturation criterion, when no new information was added by the subjects.

After data collection, the interviews were recorded, transcribed in full and submitted to the thematic content analysis proposed by Minayo⁽⁹⁾, aiming to identify the cores of meaning that make up the communication of the subjects, relevant in relation to the proposed objectives. To do so, the following steps were performed: pre-analysis; exploration of the material; and treatment of the results obtained, with the definition of categories of analysis, inference and interpretation. Through this process, two thematic categories emerged: Living with the child's disease; and Understanding the need for care expressed by the family: abandonment and neglect.

The research was submitted and approved by the Ethics and Research Committee of Unicesumar (CEP) according to Opinion No. 75645/2012, in compliance with the norms established in Resolution 466/2012 of the National Health Council.

In order to keep the names of the interviewees confidential, we sought to identify them by codenames of feelings that were experienced during the interviews: Concern, Overcoming, Serenity, Acceptance, Attachment, Hope, Affection, Love, Endearment, Complicity and Dedication.

RESULTS AND DISCUSSION

Eleven relatives of eight children and three adolescents, who had a diagnosis of type 1 *Diabetes Mellitus*, being nine mothers and two fathers, participated in the study. The age of the family members ranged from 33 to 46 years, all of whom were married. With regard to schooling, one of the parents had an incomplete doctorate, four had completed higher education, four had completed high school and two had incomplete secondary education. Of these, three did not work outside the home, while the others had an employment relationship.

Monthly family income ranged from three to more than six salaries. As for religion, seven of the respondents are Catholics and four are evangelicals. Regarding the time of diagnosis of *Diabetes Mellitus*, six children had the disease diagnosed from one to four years, two children and two adolescents had been diagnosed from six to nine years old and a teenager had been diagnosed for more than 11 years.

The experience with these families made it possible to understand the repercussions in the daily

life of parents whose children are affected by a chronic illness, as this transformation leads to a deep alteration in the familiar nucleus.

Living with the child's disease

The discovery of the disease is unexpected for both the subject and their relatives, thus representing a change in the values that preceded the disease, making the future uncertain. Treatment is long-lasting and with a slow evolution, and may have several implications, such as restricted diet and change of lifestyles⁽³⁾.

In this sense, family members are often in conflict with their children, due to the demands of changes in food habits that are required after the onset of the disease:

[...] I constantly argue with her about food; it is a constant fight because she cannot control herself. (Affection)

[...] Because every day I have an argument with her; she does not want to eat lettuce, does not want to eat the tomato, does not want to eat fruit; she wants to eat chips, eat cookies. At school, she wants the girls' snacks, you know?! (Overcoming)

It was evidenced in a similar study that family members get overprotective and are concerned with food control, imposing strict rules and keeping watch in the family and social environment to avoid a dysfunction in the glycemic balance of their children and adolescents⁽¹⁰⁾.

Another factor that provokes conflicts in the family nucleus is related to the exclusive dedication that parents and friends provide to the sick child:

[...], But these days the other (daughter) said, "mother, I wish I had Diabetes". I replied, "But why do you wish you had Diabetes? One day they will discover the cure of Diabetes and your little sister will not have Diabetes anymore, no one else will have it in this house". Then she said, "But I wish I had it because I wanted to do the tic test." Then I said that she could do the tic test whenever she wants, and she said, "But I wish I had Diabetes because M.'s friends, everyone is around M." (Hope)

The above testimony revealed that the disease was considered to generate feelings of jealousy among the siblings, mainly due to the overprotection that parents demonstrate towards the child with Diabetes Mellitus. Relatives are not always able to give attention and care to healthy children, and end up focusing their

attention on the sick child, generating anger and jealousy between the siblings⁽⁷⁾.

However, some parents state that it is important for children and adolescents to be treated equally with other siblings:

[...] I do not see her as sick, I see her as a normal girl. If I need to scold, I do it, when I need to discipline I do it. So, her brother and she are treated the same way. (Overcoming)

The way parents conduct care during treatment with the child is important so that he/she understands that his/her illness does not provide a differentiated treatment over healthy children. A study observed that both the child and the adolescent with Diabetes feel the same as their peers and seek to lead a normal life, even with the limitations imposed by the disease⁽¹¹⁾.

It is also known that family and friends influence the control of the disease regarding the follow-up of treatment and control of the diet, which was evidenced in the speeches of Hope and Overcoming:

[...] all her friends put my daughter's name on the names of their dolls. And they all have Diabetes. So it is treated naturally. If someone takes something to school, everyone already takes the diet version [of that thing]. If we go to a party, everybody cares about her, it has been very easy. Of course she leads a normal life; she has some limitations, but it is much better for her to have Diabetes than if she could not walk. (Hope)

[...] When the little device beeps, her friends keep calling her and she says: "I know, I know." She can handle it very well. (Overcoming)

Insertion of children and adolescents with Diabetes Mellitus in social life imposes challenges in the follow-up of the diet; however, social interaction with friends can also be a fertile field for coping with the disease, providing a fundamental support to help overcoming difficulties and providing a healthy living facing the chronic condition⁽³⁾.

The family, as a collaborator, represents a favorable factor to maintain the glycemic control and the well-being of their children⁽⁷⁾. It is paramount in treatment and care, helping to adapt to the new chronic condition⁽¹¹⁾.

Given this, family acceptance is extremely important for the life of children and adolescents diagnosed with Diabetes Mellitus, since children's behavior depends on how parents deal with the situations resulting from the disease.

When the child accepts it and does not get rebel, the relative feels more confident and family living becomes calmer. However, some children show embarrassment at having Diabetes, as in the case of Affection's daughter:

She is very ashamed of having Diabetes. In front of her friends, she does not use it [insulin injection], she is ashamed to use it, only in front of the most intimate friends, and she does not like to take it to school [...] (Affection)

Children and adolescents' embarrassment of having Diabetes *Mellitus* interferes with the care of the disease, evidencing the difficulty in accepting their chronic condition⁽⁶⁾.

According to Overcoming and Hope, the children initially presented a non-acceptance behavior on the chronic disease:

[...] In fact, she had several phases of acceptance, right?! At first she got that hope that it was like a flu, that she was going to get cured, because she is a child right? And then she saw that she was taking a while to get cured. Then, she saw that she was not going to get cured and she had to accept it, then she started to accept, but blamed God in the middle of this whole story [...] (Overcoming)

[...] She has already gone through some stages, of course. At first she was very small, so she did not want to take insulin; it was a time-consuming process (Hope)

Upon receiving the diagnosis, children and adolescents do not accept Diabetes because they do not know how to deal with an incurable disease and the situations arising from it. Acceptance occurs in a multifaceted way, in which the acceptance of oneself comes first and, over time, the acceptance of the disease⁽¹²⁾. The testimony of Dedication allowed us perceiving a feeling of revolt by her daughter when comparing herself with the brother who did not experience the disease:

Her relationship with her brother is normal, but sometimes she complains, like, "You do not have it, you can do everything." (Dedication)

Food control that permeates Diabetes *Mellitus* triggers conflicts in the family. This is because other relatives want to eat sweets, sugars and chocolates, causing in the sick child and adolescent the feeling of frustration and envy of their relatives⁽³⁾.

Interestingly, in our research, adolescence was mentioned as a more difficult phase of chronic disease control, in relation to childhood, due to the greater autonomy and independence of adolescents.

This reflection was observed in the following testimony:

[...] Because I know that adolescents with Diabetes are difficult. Today I have all the control, but I sought to know how the teenager is, [...] and teenagers have no responsibility, so I have a lot of concern about it. (Overcoming)

Adolescents are summoned to take responsibility for performing their own care, being independent of the family, because dependence can hinder the empowerment of taking care of themselves and of their illness. However, when their immaturity arises for having to take care of themselves as in the administration of insulin and the control of their diet, family members get concerned⁽¹¹⁾.

The autonomy of the adolescent generates concern in the relatives due to the risk of not adhering correctly to the treatment. On the other hand, in childhood, dependence on the family causes stress and suffering, especially for the responsibility of performing certain procedures, specifically the administration of insulin, as observed in the words of Overcoming and Attachment:

[...] I thought, how I will pierce a child all the time, in a little while, the leg, the arm, how are they staying? (Overcoming)

Why with my daughter? [...] until then I had never seen a case of a child aged one year and eight months developing Diabetes. So, I was upset. At the beginning, when I was going to inject insulin I was like, my God, I cannot do it, I used to cry because I did not want to do it, my daughter was a baby. (Attachment)

The beginning of treatment for family members is surrounded by anguish and fear of the unknown, as the child is subjected to various invasive procedures that usually refer to pain⁽⁵⁾.

In living with the disease, they create a variety of ways to cope with the chronic condition, such as seeking information and acquiring skills to manage adverse conditions arising from the disease. This can be observed in the speeches of Overcoming and Concern:

We went after information about what the disease really was. (Overcoming)

I had to learn very fast how to apply. (Concern)

The caregiver is ready to cope with the illness despite suffering and lack of support. Being a caregiver represents an experience filled with doubts, uncertainties and discoveries, as it is a challenge with

daily, solitary and no-ending struggles. They donate themselves wholeheartedly, seeking the best care⁽¹³⁾.

Most of the relatives used defense mechanisms with the intention of maintaining hope that one day there will be a cure to the disease:

[...] My hope is that medicine will advance and there will be a cure for this disease. (Serenity)

[...] Because then I would give everything I have to take her to Canada, where there are studies on the cure of the disease. (Hope)

[...] My concern is when will the cure for Diabetes come, when will they invent the artificial pancreas because I cannot accept it [...] (Complicity)

Similar results were found in a study where participants emphasized that hope for healing is a form of support to adapt to the new structures that remodel in their lives. Some parents have hope in scientific advancement; others find comfort in religious faith⁽⁵⁾.

Another situation observed in the interviews of the family members was the constant search for a treatment that could bring the cure of their sick relative, as perceived in the following speech:

[...] I say "son, let's pray to our heavenly Father because He'll help you and the doctor will find the cure" and I always say that to him [...] (Endearment)

Faith and hope for cure were evidenced in our study, similar to the findings of the literature, as favorable factors for the adaptation of the disease⁽⁵⁾. International study shows that families develop strategies to cope with the disease, in which religion and spirituality are fundamental tools to help in the acceptance of the new chronic condition⁽¹⁴⁾.

Understanding the need for care expressed by the family: abandonment and neglect

At the moment of diagnosis, aiming to live well with the disease, the family seeks, through the health professionals, an explanation for the causes of the problem, how the treatment works and what the main changes in their daily life will be. In addition, there is a search for positive aspects regarding the child's development that ease the suffering and facilitate the acceptance process⁽¹⁵⁾. Thus, monitoring the family members of children and adolescents with Diabetes *Mellitus* is crucial.

The analysis of the interviews evidenced that all the relatives, independently of the social level, reported the absence of follow-up by the health

professionals in the region where they lived. This suggests that health actions aimed at the follow-up of patients with Diabetes *Mellitus* have not been resolute and effective:

[...] I receive no follow-up of any primary care program. (Endearment)

[...] I wish I had a follow-up, because no one ever comes here, no one ever comes to ask how things are; the community health workers do not come and ask: "So, how are you? Do you need any medicine? ". (Love)

A study identified the difficulty to find professionals who want to partner with the family about care and that family members frequently experience impositions and demands, and it is difficult to find professionals who value them and provide a warm and humanized care⁽¹³⁾. The reports of Love, Affection and Overcoming showed they receive care from the health team, but they also demonstrate some dissatisfaction with the care received:

We are humiliated at the health unit, it is difficult [...] to stay the whole morning; they treat you badly; it seems like we will be begging for that, you know?! This is the greatest disappointment. I have come crying from the unit many times because of this, you know?! (Love)

I do not receive any other follow-up, and I do not even want it because they are unwilling. It takes three months to schedule a medical appointment; public health is a shame. (Affection)

Actually I went once in the unit and they gave me information I already knew; it was a very empty thing, very useless, right?! I was told that type 1 Diabetes is like this, there is nothing we can do, and I already know this. I have not sought a support group anymore, because for me it was very depressing, it was not worth at all. (Overcoming)

In the search for care in health services, the caregiver faces the lack of sensitivity of health professionals and the scarcity of resources in the basic units. A study points out that the relative seeks health care in basic care, but does not receive the necessary and resolute treatment due to lack of professional qualification, which makes them seek alternative care through private health care⁽¹⁶⁾.

In the relations with practitioners, the relatives emphasize the lack of communication; they reported feeling despised, being treated only as those that perform care to the child. For this reason, they end up

omitting themselves because they feel coerced to answer only what they are asked⁽¹³⁾.

The families' reports also showed the lack of a support network as an aid in coping with the experience of their child's illness.

I wish we had a support group. Nothing is offered in terms of integration for children and families. When the mother of another child discovers [the disease], she has to turn to another mother who already has a sick child to know which doctor they should look for. Mothers get lost; sometimes a mother calls another mother for friendship, if you have no friendships, you get lost. (Dedication)

[...] I think there is something missing that we need to have, even for those who use the SUS [Brazilian public health system]. I know some people who use the public service; they suffer a lot because they have no guidance. (Endearment)

In view of the above, relatives showed the desire to receive support from health practitioners, from someone who is willing to listen and understand their fears, making them less worrying, facilitating the adaptation and living with the disease. In this perspective, the support of practitioners to relatives of diabetic children and adolescents is essential⁽¹⁵⁾.

Faced with the lack of support from primary health care practitioners, as evidenced by the testimonies, the families of children and adolescents with Diabetes *Mellitus* seek actions to cope with the disease in the association for diabetics, which offers a support network for these patients and their families through groups, lectures, guidelines, among many other things that permeate the daily life of a patient with Diabetes *Mellitus*, as well as by offering a convenience store where products used by diabetic patients are sold, such as supplies and dietary foods at more affordable prices.

The health practitioner, especially the nurse, should recognize the importance of the family as an ally in the provision of care, and these professionals must offer them support, guidance and care to answer questions and to assist in the difficulties permeated by Diabetes⁽³⁾.

Thus, nurses must be able to exercise this mediating role, as an educator and agent of social transformation, both in the field of curative assistance and in health promotion and prevention of complications. This represents a facet of the humanization of care to be rescued, and a commitment to be assumed by professionals in order to achieve the long-awaited quality of health care⁽¹⁵⁾.

FINAL CONSIDERATIONS

This study made it possible to understand the coping of family members of diabetic children and adolescents. It evidenced that many changes in life occur regarding the process of becoming ill and these often cause conflicts in the family, which demonstrates the importance of support for the diabetics and their families who need to learn to deal with this new situation.

The present study also showed that the feelings of living with the sickness of a child are distressing; however, the parents do not lose hope of healing and struggle to provide quality of life for their diabetic children. These results highlight the need of the health professional, especially the nurse, to provide care to these relatives. Nevertheless, this researched allowed us realizing that this support/monitoring/care has not been efficiently offered to family members to help them cope with the illness process of their children.

Thus, the accomplishment of this study does not seek to emphasize the family's responsibility in the control and treatment of Diabetes, but proposes that an exchange is established, a partnership between relatives and health professionals, thus seeking to insert the diabetic child and adolescent, the family and the professionals as co-responsible in the accomplishment of comprehensive care to the diabetic patient.

We believe that this interaction may provide to family members, children and adolescents with Diabetes an improvement in family dynamics, resulting in health promotion for patients with Diabetes *Mellitus*.

The interviewees contributed to unveil the daily routine of the family nucleus of the child and adolescent with type 1 Diabetes *Mellitus*, since understanding how the insertion of this disease occurs in the family context and what its repercussions are is essential for the elaboration of strategies that help these individuals in their daily routine. Relatives who have been represented by parents as primary caregivers should be allies of health professionals in the struggle to improve the quality of life of their child. A limitation of this research was that interviewees were not composed of grandparents, uncles and other relatives who could be the main caregivers.

The present study made it possible to show that care provided to the child/adolescent with chronic illness by their relatives necessarily implies that the

well-being of one directly affects the condition of the other. The link between parents and children is evidenced with the discovery of the diagnosis.

Thus, knowing and understanding the experiences of people in face of *Diabetes Mellitus* is crucial to

create subsidies and instruments to qualify nursing care for these families.

Assim, conhecer e compreender as vivências diante da *Diabetes Mellitus* é necessário para criar subsídios e instrumentos no sentido de qualificar a assistência de enfermagem a essas famílias.

DIABETES MELLITUS NA INFÂNCIA E ADOLESCÊNCIA: REPERCUSSÕES NO COTIDIANO DOS FAMILIARES

RESUMO

Pesquisa exploratória-descritiva de abordagem qualitativa que teve como objetivo compreender as repercussões cotidianas expressas pela família de criança e adolescentes com diagnóstico de *Diabetes Mellitus* tipo 1. Participaram do estudo onze familiares de crianças e adolescentes com *Diabetes Mellitus*, sendo todas cadastradas em uma Associação de Diabéticos de Maringá. Os critérios de inclusão foram: ser familiar de criança/adolescente com *Diabetes Mellitus*; ter idade igual ou superior a 18 anos; estar consciente e orientado no tempo e espaço; independente das funções que exerça, do nível social e da escolaridade. Os dados foram coletados em setembro de 2012, por meio de entrevista utilizando um questionário semiestruturado. Da análise temática dos dados emergiram duas categorias temáticas: Convivendo com a doença do filho; e Compreendendo a necessidade de cuidado expressa pela família: o abandono e o descaso. Esse estudo possibilitou a compreensão do enfrentamento dos familiares de crianças e adolescentes diabéticos diante das diversas modificações de vida e sentimentos envolvidas no processo do adoecer, demonstrando a necessidade do profissional de saúde, principalmente o enfermeiro, em realizar os cuidados a esses familiares.

Palavras-chave: Doença crônica. *Diabetes Mellitus*. Criança. Enfermagem.

DIABETES MELLITUS EN LA INFANCIA Y ADOLESCENCIA: REPERCUSIONES EN EL COTIDIANO DE LOS FAMILIARES

RESUMEN

Investigación exploratorio-descriptiva de abordaje cualitativo que tuvo como objetivo comprender las repercusiones cotidianas expresadas por la familia de niños y adolescentes con diagnóstico de *Diabetes Mellitus* tipo 1. Participaron de este estudio once familiares de niños y adolescentes con *Diabetes Mellitus*, siendo todos registrados en una Asociación de Diabéticos de Maringá, Paraná, Brasil. Los criterios de inclusión fueron: ser familiar del niño/adolescente con *Diabetes Mellitus*; tener edad igual o superior a 18 años; estar consciente y orientado en el tiempo y espacio; independiente de las funciones que realice, del nivel social, y de la escolaridad. Los datos fueron recolectados en septiembre de 2012, por medio de entrevista utilizando un cuestionario semiestruturado. Del análisis temático de los datos surgieron dos categorías temáticas: Conviviendo con la enfermedad del hijo y; comprendiendo la necesidad de cuidado expresada por la familia: el abandono y el descuido. Este estudio posibilitó la comprensión del enfrentamiento de los familiares de niños y adolescentes diabéticos frente a las diversas modificaciones de vida y sentimientos involucrados en el proceso de enfermarse, demostrando la necesidad del profesional de salud, principalmente el enfermero, en realizar los cuidados a estos familiares.

Palabras clave: Enfermedad crónica. *Diabetes Mellitus*. Niño. Enfermería. Familia.

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