Home care for child and adolescent with type 1 diabetes mellitus from the care giver's perspective

Cuidado domiciliar à criança e ao adolescente com diabetes mellitus tipo 1 na perspectiva do cuidador Atención domiciliaria para niños y adolescentes con diabetes mellitus tipo 1 desde la perspectiva del cuidador

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ABSTRACT

Objective: to learn family caregivers' perspectives and experiences regarding home care given to children and adolescents with Type 1 Diabetes Mellitus (DM1). **Method:** in this qualitative, descriptive study conducted – after approval by the Standing Committee for Ethics in Research with Human Participants – with 11 caregivers residing in a municipality in northwestern Paraná, data were collected between February and May 2018 by recorded, semi-structured interview, and then subjected to thematic content analysis. **Results:** two thematic categories were identified: "From first symptoms to acceptance of the diagnosis – an ongoing process" and "Difficulties permeating everyday care". **Conclusion:** certain difficulties permeated the care-related experiences, especially as regards correct application of insulin, dietary restrictions, and lack of support from schools in dietary control and drug treatment.

Descriptors: Diabetes Mellitus; Insulin; Health Education; Caregivers.

RESUMO

Objetivo: apreender perspectivas e vivências do cuidador familiar sobre os cuidados prestados às crianças e adolescentes com Diabetes Mellitus tipo 1 (DM1) no domicílio. Método: estudo descritivo de abordagem qualitativa, realizada com 11 cuidadores residentes em um município no Noroeste do Paraná. Os dados foram coletados de fevereiro a maio de 2018, mediante entrevistas semiestruturadas, gravadas em áudio, e, então, submetidos à análise de conteúdo, modalidade temática, após aprovação do Comitê Permanente de Ética em Pesquisa com Seres Humanos. Resultados: foram identificadas duas categorias temáticas: "Dos primeiros sintomas à aceitação do diagnóstico: um processo sempre em curso"; e "As dificuldades que permeiam o cuidado no cotidiano". Conclusão: as vivências relacionadas ao cuidado são permeadas por algumas dificuldades, especialmente em relação à aplicação correta da insulina, às restrições alimentares e à ausência de apoio por parte da escola, no controle alimentar e tratamento medicamentoso.

Descritores: Diabetes Mellitus; Insulina; Educação em Saúde; Cuidadores.

RESUMEN

Objetivo: conocer las perspectivas y experiencias de los cuidadores familiares con respecto al cuidado domiciliario de niños y adolescentes con Diabetes Mellitus Tipo 1 (DM1). **Método:** en este estudio cualitativo y descriptivo realizado - previa aprobación del Comité Permanente de Ética en la Investigación con Participantes Humanos - con 11 cuidadores residentes en un municipio del noroeste de Paraná, los datos fueron recolectados entre febrero y mayo de 2018 mediante entrevista grabada semiestructurada , y luego sometido a análisis de contenido temático. **Resultados:** se identificaron dos categorías temáticas: "Desde los primeros síntomas hasta la aceptación del diagnóstico - un proceso continuo" y "Dificultades que permean la atención diaria". **Conclusión:** ciertas dificultades impregnaron las experiencias asistenciales, especialmente en cuanto a la correcta aplicación de la insulina, las restricciones dietéticas y la falta de apoyo de las escuelas en el control dietético y el tratamiento farmacológico.

Descriptores: Diabetes Mellitus; Insulina; Educación em Salud; Cuidadores.

INTRODUCTION

Among the most prevalent chronic diseases in childhood, type 1 Diabetes Mellitus (DM1) is the most common. Due to its incidence and the aggravating factors associated with its chronicity, it is considered a worldwide public health problem¹.

In the world, there are more than one million children and adolescents with DM1, and its prevalence among children in the preschool years increases at a rate of 3% per year². In Brazil, five to 10% of the population has DM1, which has an incidence of around 7.6 cases per 100 thousand inhabitants under 15 years of age^{1,3}. In addition to its high incidence, late diagnosis is another serious problem with significant consequences in children and adolescents. For this reason, campaigns aimed at increasing awareness among patients, family members, caregivers, educators, health professionals, government officials and society in general highlight the condition of children and adolescents with DM1².

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In this context, family is especially important, as it represents affective, instrumental, and informational support, therefore, it is fundamental for those who are ill⁴. The implications of the disease do not only affect the life of the person who experiences it; they also affect those who get directly involved, care for and are affected by the suffering they observe¹. This is exacerbated when the patient is a child or adolescent.

Thus, it is important to have a multi-professional approach in the care of children and adolescents with DM1 and their families. In addition, knowledge and understanding of how family members care for children and adolescents with DM1 in their daily lives can guide health care interventions and enhance home healthcare^{5,6}.

Adherence to treatment for a chronic condition such as DM1 requires changes in the lives of children, adolescents and their families. Changes in lifestyle are necessary and include physical exercises, painful procedures such as blood glucose tests and frequent injections of insulin, and dietary restrictions⁷.

Considering these treatment requirements, family members, especially those who take on the responsibility for caring for the patient, need to acquire specific knowledge about food composition, signs and symptoms of hypoglycemia, hyperglycemia, preparation and administration of medications¹.

Adaptation to the changes required by the disease and its treatment is fundamental for the quality of care. Children and adolescents need family support, as they cannot be responsible for these changes alone. In these cases, health education must be even more effective, involve all family members and encourage them to develop self-care skills in diabetes⁷.

Therefore, this study aimed to comprehend the perspective and experience of the family caregiver regarding the care provided to children and adolescents with DM1 at home.

METHOD

Descriptive qualitative study, carried out with caregivers of children and adolescents with DM1, living in a city in the Northeast of Paraná. The estimated population of the city is 87,850 inhabitants⁸, and it is fully covered by 24 Family Health Strategy (FHS) teams, distributed in 16 Primary Care Center (PCC).

Participants were selected from a list provided by the Municipal Health Department, containing the full name and address of the children/adolescents. Family members who met the following inclusion criteria were included in the study: 18 years or older and primary caregiver for at least six months. Caregivers with wrong or non-existent addresses were excluded. Thus, 11 caregivers participated in the study.

Data were collected from February to May 2018, through semi-structured interviews that were previously scheduled and carried out in a private location in the caregivers' homes. Interviews had an average duration of 25 minutes and the audio was recorded with the participant's consent.

The instrument used in the interviews was a script with questions on socio-demographic characteristics and the following guiding question: *tell me how it is like to take care of the "child" with DM1*. In addition, three support questions were used: What are the strengths and difficulties of daily care? How is this care developed when the "child" is not at home, when they are at school for example? How do you evaluate the care you provide?

The interviews were transcribed in full and subjected to thematic content analysis, following the three preestablished stages⁹.In the pre-analysis, data was organized, transcribed, and separated. Then, the empirical material was read for an initial identification of relevant aspects. In the stage of material exploration data was classified and grouped. Specific terms were identified by colors and gave rise to the categories. Finally, in the data analysis stage, the categories were further analyzed along with the empirical findings, constantly considering the objective of the investigation. Thus, two thematic categories were identified: From the first symptoms to accepting the diagnosis: a constantly ongoing process; and the difficulties of daily care.

The study was approved by the Research Ethics Committee with Human Beings (CAAE: 86435718.3.0000.0104). All participants signed the Informed Consent Form (TCLE) in two copies. To guarantee the anonymity of the sample, their reports are identified by their kinship with the child/adolescent and the age of the caregiver, followed by the classification of the patient as child or adolescent, current age and age at diagnosis (Ex: *Mother, 38 years old - teenager 14 years old/13 years old)*.



RESULTS AND DISCUSSION

Of the 11 caregivers in the study, ten were mothers and one was a father. Ages ranged between 30 and 46 years. Five participants were married, six had more than eight years of education and three had a family income of up to one minimum wage. When asked about the care provided to the child/adolescent with DM1, ten of them reported that they felt able to provide home care and nine were satisfied with the care they provided for their children.

The 11 children/adolescents in the study were between six and 15 years old. Seven were male, and the age of diagnosis of DM1 was between two and 13 years old. Regarding home care, five children/adolescents were responsible for the daily administration of insulin. Six already needed urgent care for glycemic control, six had a family history of DM, and nine had to stabilize blood glucose more than three times a day.

From the first symptoms to accepting the diagnosis: a constantly ongoing process

The onset of some symptoms and changes in behavior were the main warning signs and reason for seeking assistance.

I realized that he started losing weight, too much weight, all of a sudden. He started peeing in bed, I thought it was absurd, going back to peeing in bed [...]. (Mother, 38 years old - Adolescent 14 years old/13 years old).

He started to lose weight very fast, he would wake up many times at night to pee. We suspected it was diabetes [...]. (Father 36 years old - Adolescent 12 years old/8 years old).

He started to drink a lot of water and pee a lot. He started to pee in bed, and he hadn't done that in many years [...]. (Mother 39 years old -Child 9 years old/07 years old).

The diagnosis of DM1 of the child represents a difficult experience that causes anguish and suffering, especially for those who take on the responsibility for caring and monitoring treatment, most often the mother.

My heart hurts, but I have to give her that insulin. To this day, I still cry sometimes, but it is for her own good. Sometimes I fight her, she cries, but it is for her own good [...] (Mother, 45 years old -Child 11 years old/02 years old).

It's sad, but you have to take care. You have to be strong, put God in front of you and take care of them(Mother, 30 years old -Child 06 years old/05 years old).

It's very difficult, but unfortunately you have to take care of them. God wanted it that way. (Mother, 33 years old - Adolescent 14 years old/03 years old).

The feelings experienced and evidenced in the statements corroborate what has been pointed out in the literature^{6,7,10}. The sadness reported by the mothers is due to the loss of the dream of having a healthy child, which is replaced by a life of worries, pilgrimages, fears and uncertainties.

As it is a chronic disease that affects the biological and psychosocial spheres, DM1 requires daily care and treatment throughout life. The changes in life habits related to food and physical exercise can make it difficult to adhere to treatment 11.

This experience is also marked by insecurities, concerns about the child's physical health and uncertainties about their future:

Today I can say that it is not a problem that he is diabetic. It's not a problem yet, we don't know what the future holds (Mother, 41 years old - Adolescent 13 years old/04 years old).

We think about the future, I don't know how it will be, I don't know his life expectancy (Pai, 36 years old - Adolescent 12 years old/08 years old).

Concern and uncertainties about the child's future are constant and are justified by the possibility of physical, psychological and social complications⁶. These feelings are often outweighed by acceptance and resignation with the child's morbidity:

It's not good, but we have to get used to it. I got used to it, but I can't tell you it's good to be a mother to a diabetic child, it is not. It is very bad. (Mother, 40 years old - Adolescent 15 years old/11 years old).

We would like him to be 100% healthy. But there are children that are worse than him, with much more severe diseases. We have to be structured and get used to the situation. (Mother, 41 years old - Adolescent 13 years old/04 years old).

The fear of the unknown is gradually replaced by encouragement to deal with the new circumstances. In the meantime, the participants reported receiving support in the different levels of health care, especially in the first months after diagnosis, which was essential for learning how to deal with the disease and its treatment.



I was very afraid to inject insulin at first, because of the syringe. Then, the girls at the health unit taught me and now I got used to it. The nurse also comes here once a month and guides me, it helps me a lot. (Mother, 40 years old–Adolescent15 years old/11 years old).

They taught me everything I needed to do in the health unit, they guided me. It was excellent for me, because at that time I was very shocked. (Mother, 38 years old - Adolescent 14 years old/13 years old).

I learned a lot from them, because the unit was close to home, they always had meetings there. I learned how to dispose, how to apply, how to store, how to care. (Mother, 41 years old - Adolescent 13 years old/04 years old).

The reports of the caregivers highlight the importance of health education, which helps them recognize the severity of this morbidity¹², the relevance of the treatment and management of the disease. A proactive work of professionals with an emphasis on education can create positive experiences, alleviate fears, increase knowledge about diabetes and its complications, and enhance the implementation of care actions¹.

The difficulties of daily care

After the diagnosis, the need for daily care generates doubts and negative feelings, especially in relation to insulin administration, which is perceived as one of the main difficulties of home care at the beginning of treatment.

In the beginning, I found it very difficult, because I had never been in a situation like this. I had already seen it on television, and I thought: if it were my son, I wouldn't have the courage. At the time when I found out, I wouldn't inject it, my ex-husband would do it. I cried because I didn't want to do it, I couldn't do it [...]. (Mother, 30 years old - Adolescent 13 years old/09 years old).

I let her do it. But I must look to see how many units she will inject. I get confused sometimes. So, I think it's best to leave it to her. I don't have much control [...]. (Mother, 40 years old -Adolescent 15 years old/11 years old).

I have a lot of difficulty, sometimes it gets a bubble. I don't understand why. I already told the doctor and he said it was the way I inject it. (Mother, 42 years old -Child 10 years old/09 years old).

The difficulties reported by caregivers in relation to the daily care of children with DM are in line with the findings of other studies^{7,10}. The responsibility is usually attributed to mothers and overwhelms them. They need psychological strength to accept and to convince their children to recognize the importance of treatment.

For some caregivers, dealing with dietary restrictions on a daily basis is the biggest challenge. This is more common for parents of pre-adolescents and adolescents.

There was a time when he would eat all the food portions, which were separated individually in small pots, reserved, everything counted. He started getting them and eating everything at once. (Mother, 41 years old, Adolescent 13 years old/04 years old).

Her diet is very strict, she must follow a diet and I try to control it. When I'm at home, I can do it, but when she's alone, I think she gets out of the line [...] (Mother, 30 years old -Adolescent 13 years old/09 years old).

Dietary changes mark the lifestyle of children and adolescents with DM1 and their families and represent a difficulty in daily care, regardless of the time of diagnosis of the disease. It is a major challenge^{7,10,13}, as an adequate diet is essential for metabolic control⁵.

The difficulties related to food in the school environment are another cause for concern, as it can be seen in some reports:

Now that she started going to school, her diabetes is already going up. It's like that, it goes low and comes back high. I don't know what she eats there. (Mother, 45 years old – Child 11 years old/02 years old).

At school it's difficult, the teacher said I have to send him with a snack, but children are difficult, they don't want to eat that. Sometimes I let him eat a little. He comes home from school with more than 500 of blood sugar. (Mother, 30 years old -Child06 years old/05 years old).

The lack of integration between the health and education sectors makes adherence to treatment more difficult. The school is often unprepared to support these students, so it is difficult to continue the treatment carried out at home. This makes it impossible for the child to attend school full-time.

The school is a problem, it is full-time, but he only stays until 11:30, because no one gives him his insulin. They don't want the responsibility, because they are afraid. (Mother, 42years old -Child 10 years old/09 years old).

These results corroborate what has been identified in other studies, which pointed out difficulties in relation to the care of children and adolescents with DM1 in the school context. These difficulties are mostly related to diet, insulin



administration and especially lack of knowledge, which would allow education professionals to identify early signs and symptoms of hypoglycemia and hyperglycemia^{10,14}.

The difficulties experienced in daily life are also related to the assistance offered by the Unified Health System (SUS). Participants expressed dissatisfaction with the delay in getting specialized tests and the need to pay for some of them.

[...]it's awful, when we need an exam it's very hard to book it. When we can do it, we have to get there at dawn, and face a long line. It takes too long, that's why I can't wait for the SUS, because her needs are urgent. We have to tell the truth [...]. (Mother, 46 years old - Child10 years old/ 08 years old).

It could be better, it's not good, it could improve in everything. I'm lucky, because I get all her drugs for free, but it is rare to find an exam that is available here at the clinic. Sometimes you still find two, sometimes none, and you have to pay for them, even if you can't afford it [...] (Mother, 30 years old - Adolescent 13 years old/09 years old).

Discontent with care is also related to the fact that health services do not provide the essential supplies for the management of blood sugar.

I think there are things they can improve. Like this repair insulin, we must buy it. Folks who use the pens do not get the tips with needles; they must buy them. There are days when you get there to get the strips and there is none. The box with 50 strips costs 100 reais. You don't always have 100 reais available. (Mother, 39 years old, Child09 years old/07 years old).

Health care is pointed out by family members as part of a fragile system, as it does not provide enough supplies for daily care and does not offer the consultations and tests necessary for the proper monitoring of health conditions. It was evidenced that caregivers often face difficulties when using the health system. This result was also identified in a study carried out in Ribeirão Preto (SP), with eight caregivers of children and adolescents with DM1¹⁰, which found that the insulin provided by the health system was not effective in controlling the disease, requiring the use of analogous insulins, which represented a greater financial burden for families¹⁰.

It is important to note that mothers are usually very involved in the treatment of their child. They often give up their personal life to dedicate themselves to caring for their child and strive for care to be conducted as correctly as possible.

It is hard to take care of a sick daughter, to work outside, to have to be the father and the mother at the same time. It is not easy to have to miss work to take her to the doctor 2 to 3 times (Mother, 30 years old - Adolescent 13 years old/09 years old).

I say: you cannot say that I was negligent, ever. Maybe he can complain about me being too careful. (Mother, 41 years old -Adolescent13 years old/04 years old).

A study shows that when the child/adolescent is diagnosed with DM1, their suffering is extended to the whole family, especially to mothers, as it is necessary to modify routines and habits. Many family members do not know how to act when faced with this disease and need to receive guidance¹¹. In this perspective, guidance is considered the main strategy for health promotion and prevention of aggravations related to the disease¹⁵. This is because for those who live with DM1, knowledge about their clinical evolution, control measures, treatment and complications is essential and contributes to therapeutic adherence and a positive prognosis in the evolution of the disease.

The present study showed that caregivers have information about the disease and strive to care for their children. However, they face difficulties with eating habits, metabolic control, and medication administration. Thus, all health professionals working in the primary, secondary, and tertiary levels are responsible for providing guidelines and coping strategies for the child/adolescent and their family, indicating the adjustments necessary for better metabolic control^{1,4,16}.

In this perspective, professionals must develop creative strategies that raise awareness among caregivers for their daily practice and among children and adolescents so they can actively participate in their care. This can be done through health education actions, creation of support groups and actions integrated with other health care sectors, respecting the principles of individuality and family context¹⁶.

Thus, the involvement and support of a multi-professional team can assist in the difficulties related to care and contribute to the adequate management of the disease¹⁴. The positive impact of the work of health professionals in this context, especially nurses, has been highlighted in the scientific literature, with emphasis on the appreciation and support for children/adolescents, caregivers and their families, in the hospital, in Primary Health Care (PHC), and at home^{11,12}.



CONCLUSION

The results of this study allowed to understand the perspectives and experiences of family caregivers caring for the child/adolescent with DM1 at home. It became evident that having a child with DM1 is a difficult experience, and acceptance of the diagnosis is a constantly ongoing process, although the anguish and suffering eases over time, giving space to resignation.

In addition, it was possible to observe the difficulties experienced in home care, especially in relation to the correct administration of insulin, dietary restrictions, the lack of support of the school in diet management and drug treatment, and the limitations of health services. These results reinforce the importance of intersectoral actions in the follow-up of these families, recognizing that, during childhood and adolescence, professionals working in the school environment can be very important in conducting and controlling treatment.

The limitations of this study are related to the number of participants and the single city analyzed, which prevents the generalization of the findings. However, the findings are considered valid, as they demonstrate similar conditions to those verified in other studies. Thus, there is a need for further studies on the subject.

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