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ORIGINAL ARTICLE

CARE FOR CHILDREN AND ADOLESCENTS WITH DIABETES MELLITUS TYPE 1

CUIDADO À CRIANÇA E AO ADOLESCENTE COM DIABETES MELLITUS TIPO 1

CUIDADO AL NIÑO Y AL ADOLESCENTE CON DIABETES MELLITUS TIPO 1

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ABSTRACT

Objective: to learn about the strategies used by the family for the care of children and adolescents with Type 1 Diabetes Mellitus. ***Method:*** this is a qualitative, exploratory and descriptive study developed with 12 family caregivers. The data was collected through semi-structured interviews, subjecting them to the Content Analysis technique. ***Results:*** it is related to the main strategy used by the family to care for food adaptation of the child and the adolescent; children and adolescents are encouraged to coexist with others who have diabetes; other families with children with the same condition are sought for the exchange of experience about care. Other strategies are also considered the possibility of family adaptation to care for the child and adolescent and the fact that the adolescents themselves perform their self-care. Conclusion: the educational role of nurses in families is important in helping them to develop effective strategies for the care of children and adolescents with diabetes. ***Descriptors:*** Diabetes Mellitus; Child; Adolescent; Family; Quality of life; Nursing.

RESUMO

Objetivo: conhecer as estratégias utilizadas pela família para o cuidado à criança e ao adolescente com Diabetes Mellitus tipo 1. ***Método***: trata-se de um estudo qualitativo, exploratório e descritivo desenvolvido com 12 familiares cuidadores. Coletaram-se os dados por meio de entrevistas semiestruturadas submetendo-os à técnica de Análise de Conteúdo. ***Resultados***: relaciona-se a principal estratégia utilizada pela família para o cuidado à adaptação alimentar da criança e do adolescente; propicia-se a convivência da criança e do adolescente com outros que tenham diabetes; procuram-se outras famílias com filhos com a mesma condição para se realizar a troca de experiência acerca do cuidado. Consideram-se, também, outras estratégias a possibilidade da adaptação da família ao cuidado à criança e ao adolescente e o fato dos próprios adolescentes realizarem seu autocuidado. ***Conclusão***: conclui-se como importante o papel educativo do enfermeiro junto às famílias no sentido de auxiliá-las no desenvolvimento de estratégias efetivas de cuidado à criança e ao adolescente com diabetes. ***Descritores***: Diabetes Mellitus; Criança; Adolescente; Família; Qualidade de Vida; Enfermagem.

RESUMEN

Objetivo: conocer las estrategias utilizadas por la familia para el cuidado al niño y al adolescente con Diabetes Mellitus tipo 1. ***Método:*** se trata de un estudio cualitativo, exploratorio y descriptivo desarrollado con 12 familiares cuidadores. Se recogen los datos por medio de entrevistas semiestructuradas sometiéndolos a la técnica de Análisis de Contenido. ***Resultados:*** se relaciona la principal estrategia utilizada por la familia para el cuidado a la adaptación alimentaria del niño y del adolescente; se propicia la convivencia del niño y del adolescente con otros que tengan diabetes; se buscan otras familias con hijos con la misma condición para realizar el intercambio de experiencia acerca del cuidado. Se considera, también, otras estrategias la posibilidad de la adaptación de la familia al cuidado al niño y al adolescente y el hecho de los propios adolescentes realizar su autocuidado. ***Conclusión:*** se concluye como importante el papel educativo del enfermero junto a las familias en el sentido de auxiliarlas en el desarrollo de estrategias efectivas de cuidado al niño y al adolescente con diabetes. ***Descriptores:*** Diabetes Mellitus; Niño; Adolescente; Familia; Calidad de Vida; Enfermería.

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INTRODUCTION

Diabetes mellitus (DM) is a highly prevalent childhood disease that has emerged in epidemic proportions in recent years. There is a great economic and social impact for the families of the people who have this disease.[1] In Brazil, the incidence of 7.6 per 100 thousand individuals under 15 years of age is estimated, corresponding to 30,900 children and adolescents diagnosed.[1-2]

It is committed to the diagnosis of type 1 DM (DM1), the life of children and adolescents, as it is an unexpected situation and causes sudden changes in their lives and those around them due to changes in the routine and the necessary procedures for the adequate treatment of the disease.[3] It is important that the family understands the mechanisms of the disease to live with and get involved in the daily care necessary to maintain health and to prevent complications, becoming the challenge in overcoming and accepting.[4]

It is noted that the suffering caused by illness does not only affect the life of the person who experiences it, but also in the lives of those who directly involve themselves, care for and are afflicted by the suffering of the other.[5] However, interactions between health professionals, the family and other caregivers and supporters of the child / adolescent-family unit.[6]

It is observed that DM1 interferes not only in the life of the child and the adolescent, but also in that of the family and social group, imposing profound changes in their routine. This results in a diversity of feelings such as anger, pain and isolation due to the complex nature of the disease and the confrontation with the need for a new life.[7] It is inferred that a common reaction of families to the disease, due to the concern with the clinical situation of the child or adolescent, is the need to carry out a greater vigilance and supervision of them.[8]

It is possible to seek strategies, in this context of care and commitments to children's health, by the nurse, to promote family and social coexistence by reinforcing sources of support that favor the well-being of the child / adolescent-family unit. It should be emphasized that nurses must be open to hearing and communicating in a sensitive way with the caregiver family, in view of the chronic condition of DM1, in order to know and understand their multiple experiences, as well as difficulties, conflicts, interactions and feedbacks, so that, in this way, it can be characterized as an effective unit of care addressing it in its multidimensionality. Linkages can be strengthened, produced and maintained open channels of communication important for the management of care by the involvement of the family and by the relationships existing in the family system.[9]

The need to familiarize themselves with all these issues with the need to learn how to deal with previously unknown feelings, symptoms and therapeutic procedures, as well as to learn to perform the therapeutic control of the disease.[10]

OBJECTIVE

- To know the strategies used by the family for the care of the child and the adolescent with Diabetes Mellitus type 1.

METHOD

This is a qualitative, exploratory and descriptive study, in a University Hospital in the South of Brazil, in the environment of the Integrated Diabetes Center (ICD). It is explained that ICD is a service that began its activities in 1999 and is presented as a reference in the care of adults, children and adolescents with DM. The following actions are developed, together with the Municipal Health Department, aiming at integrating the different levels of health care of people with DM: diagnostic, therapeutic and educational.

The sample of this study was composed by twelve relatives of six children and six adolescents with Type 1 Diabetes Mellitus who were consulted in the ICD. The following inclusion criteria were listed for this study: to be the main family caregiver of the child or adolescent with DM1, to accompany him/her during the consultation and to provide direct care. It is further added that the child should be five years of age or older and the adolescent, up to eighteen years incomplete. The family caregivers who, at the time of data collection, were not accompanying the child at the visit were excluded from the study. After the orientation about the objectives and methodology of the study, the Free and Informed Consent Term was signed by the participants.

The data was collected in the second half of 2017, through semi-structured interviews with each participant, in order to obtain a better understanding of the reality of the phenomenon under study. Family members were contacted to present the research and to invite them to voluntarily participate in the study, scheduling the day of data collection and questioning them about their experience in the care of the child / adolescent with DM1 and the strategies used to the care.

Data was analyzed and interpreted according to the technique of Content Analysis.[11] It is reported that the first stage of the Content Analysis is the pro-analysis, in which the organization of the material occurred, that is, a quick reading of the interviews was carried out in order to visualize the particularities of each subject that contributed to the elaboration of the initial ideas. The material exploration phase was carried out in the coding of interviews with numbers, letters, or both, so that the clippings that interested the research were grouped into similar nuclei of meaning that gave rise to themes or categories. In the treatment of the results, the analysis and discussion of the speeches obtained from the interviews of the participants were carried out based on theoretical reference and on the sensitivity and experience acquired in the research trajectory.

Resolution 466/12, which governs research involving human beings, was respected. This research proposal was submitted to the Research Ethics Committee in the Health Area - CEPAS of FURG, approving it with opinion 114/2017. Participants and their speeches were identified with the letter F followed by the interview number.

RESULTS

The characterization of the study participants and the categories formed from the data analysis are presented below.

♦ Characterization of children and adolescents participating in the study

To participate in the study, 12 children and adolescents with DM1 attended at the ICD were collected during the data collection period. It was found that six were male and the other six were female, and their ages ranged from seven to 18 years, with the mean age being 12 years. Diagnostic time was eight months to 14 years, with four years being the most reported time as diagnosis time. It is pointed out that nine children and adolescents had siblings and three had incomplete secondary education, seven had incomplete primary education and two had incomplete higher education.

As regards the number of hospitalizations, six children and adolescents reported only one hospitalization, three children and adolescents reported several hospitalizations, not knowing how many, and the other three reported not having any hospitalization, all of them being hospitalized. hospitalizations due to glucose decompensation; none of these children and adolescents attended self-help groups and all participants reported, as a continuous medication, only insulin.

♦ Characterization of the family carers participating in the study

Twelve family caregivers of children and adolescents with DM1 attended at the ICD during the period of data collection were enrolled to participate in the study, and all were female, with 11 mothers and one grandmother. The ages ranged from 26 to 74 years, with a mean age of 41 years, and 11 families lived in the municipality where the ICD is located and only one in the city. Six families reported income of two minimum wages, two family members reported a minimum wage, two other family members reported, respectively, three and four minimum wages, one did not know how to specify and, finally, a family caregiver reported income the amount of R$ 163.00 referring to the Bolsa Família, and four people, on average, live with this income.

Regarding the level of education, a total of five full-time high school students were presented; four, incomplete high school and three referred respectively incomplete elementary education, complete elementary education and complete tertiary education. It turns out that, as far as the profession was concerned, seven were from home; one, domestic; one, nanny; one, merchant; one, librarian and one, vigilante. As for self-help groups, 11 did not attend them and only one reported participating in self-help groups on Facebook and, for the most frequent health service, seven relatives reported searching for the nearest Basic Health Unit, while five reported to seek, mainly, the ICD.

♦ Categories generated from data analysis: Adapting the diet

♦ Adapting the diet

It should be noted that one of the main strategies of family care concerns the adaptation of the child and adolescent's diet, since it seeks to maintain a healthy diet.

> *Food, I try to keep as healthy as I can, but I can not always. (P7)*

Sweets are eliminated from the diet and more whole foods are used.

> *Now, not so much, when I was younger, yes. I stopped making sweets, desserts. (P11)*
>
> *The only thing that changes for him is rice, I like brown rice, I always make lentils, but for the rest, it's normal. The only thing that is different. So if I buy whole-wheat cracker, everyone eats. I do not want him to think that he alone has to eat whole food. (P10)*

> *I buy everything without sugar, I limit it a lot. I buy those sugarless boulders, you know? I am especially careful about the quantity. (P1)*

The feeding schedule is controlled to avoid changes in blood glucose.

> *I try to keep food on schedule. I take good care of him, but sometimes he's kind of rebellious. (P5)*
>
> *He has to eat every three hours, but I've noticed that his fast is every two hours, always, in the interval, I give a fruit to glucose does not download. (P7)*
>
> *Generally, I take care of the schedules, she does not spend much time without eating. She eats brown bread. I take good care of these things. (P6)*

Make sure the child always has a snack in the bag.

I always bring something to eat in the bag when I go out with him. I'm always watching to see if you have any different symptoms. (P9)

Adheres to the same child's food, in some situations, by the whole family, as a form of encouragement and example.

> *Everyone ended up adjusting to her food and, in the end, it was good. (P8)*
>
> *Every family has changed, we are trying to get into our daughter's mood by eating better. (P2)*
>
> *I try to talk to everyone at home about food. We try to eat the same things she does, even though she's a teenager, I try to do my best to set an example. (P4)*
>
> *Lunch and dinner everyone ends up eating the same thing. We are learning to change, too, for our son. (P9)*

It differs totally in other situations, the feeding of the child as a way to guarantee their specific food need.

Different food from my siblings, I mean, snacks. (P9)

♦ Encourage the coexistence of children and adolescents with others who have Diabetes

It was pointed out the importance of the coexistence of the child and the adolescent with others who have DM.

> *I think he should have more contact with other diabetic children. (P7)*

♦ Exchange experiences with other families with children with DM1

Other families with children with the same condition are sought to exchange experience about care.

> *I even thought about looking for other mothers with diabetic children, but I'm very communicative and let him be too. There is a father and mother who are not like me. (P7)*

♦ Caring for self-care by the teenager himself

> The adolescents themselves were able to perform their self-care.
>
> In fact, she even helps me, right? As she is already 18, taking the periods of rebellion, she is already getting used to caring. When she was small, only myself. (P10)
>
> At age ten, my daughter learned and applies insulin alone. *(P6)*

DISCUSSION

The family, in view of the diagnosis of childhood DM, is required to adapt to provide healthy habits and a quality of life for the child and adolescent. It was found in a study that families, in order to deal with this new reality, implemented changes in the habits not only of the child, but also expanded them to other members by inserting foods that were not previously part of the menu and excluding the not healthy.[10]

It is sought for an adequate diet and for the introduction of foods that can replace the candy consumed previously, without causing harm to the health of the child, and its satisfaction are the changes of habits cited by the families. Thus, it was observed the good acceptance of the rest of the family regarding the food modifications at home.[12]

The main emphasis on the main care of children and adolescents with DM was emphasized by the family: strict dietary control (84.8%); the application of insulin (49.4%); monitoring; the caster; packaging (16.1%); physical activity (16.1%), among others. However, the difficulties encountered at the beginning of the adaptation phase were mentioned, with the most frequent being glycemic control (37.6%) followed by food restriction, with 11.8%.[13]

It becomes the coexistence of children or adolescents and the family with others who find themselves in the same reality a fundamental social support network in the sharing of information. It was observed, in a study carried out in Ceará, that the creation of a group in a social media made available on the Internet helped in the interaction of mothers and children from all over Brazil. It is strengthened on a daily basis and essential and detailed information on a particular subject of interest in relation to the care and means of accessing materials and services related to diabetes.[14]

It is possible to perceive, in relation to the family in the face of the discovery of the diagnosis of DM, its importance as a support network for the adaptation process to take place in a positive way. It was verified, therefore, before the possible changes occurred in the relationship between the members of the family with the beginning of the disease, the presence of the union helping in its strengthening and adaptation.[15]

It was also observed that the DM impacts the routine of the family generating changes in some leisure activities and in the social relationship. He referred to the possession of extra attention with the child in festive events by one of the relatives. It is difficult to understand the deprivation of the child in front of these social events, often for the same, requiring the constant presence of a professional that helps and guides families.[15]

Modifications are presented to the child and adolescent with DM in their daily lives, demanding willpower, behavior change and adaptive attitudes. Thus, adapting to the requirements imposed by chronic childhood illness is a complex process that will depend on the external and internal factors that will be influenced, also, by age and development. It was also verified that one of the recurrent difficulties of DM is the food restriction, which becomes more arduous for the child or the adolescent when the same lives with people who do not share this situation.[16]

It is a great challenge to provide comprehensive care for patients with diabetes and their families to health professionals, since the process of changing habits is directly related to the lives of family and friends. It is thus possible to confront the support provided and the support of professionals and social support networks, which, gradually, the child and the adolescent will acquire autonomy to manage their life with the disease in order to live with quality.[16]

It is necessary to raise awareness that the child or adolescent with DM is and exists in its totality and is inserted in different environments and that these can influence, positively or negatively, their experience with the disease and their living. One can contribute, through the knowledge about this subject, so that the family, the school and the health professionals can intervene from a socio-environmental approach.[17]

Some studies that addressed the understanding about the necessary care for the disease were mentioned regarding the need for self-care by the child and the adolescent, mentioning the children: fruit consumption when they presented hypoglycemia and not fed in case of hyperglycemia, in addition to using insulin to improve their clinical condition. It is detailed that in this study there were no cases of rejection regarding the administration of insulin and the verification of capillary glycemia.[18]

In a study with adolescents, food control, physical exercise, correct medication use, regular follow-up with the health professional, and foot and skin care were mentioned as self-care measures. It was found, therefore, that 44.7% of the interviewees practiced four or more of these measures paying attention, mainly, to measures of glycemic control.[19]

CONCLUSION

The objective of this study was to know the strategies used by the family to care for children and adolescents with Type 1 Diabetes Mellitus. It was verified, with regard to the impact of the diagnosis, that it is common to hospitalize the child in the emergency with severe hyperglycemia, to consult for another reason and to receive a diagnosis of hyperglycemia, being common, including, its hospitalization. In other situations, it was found that the family perceives that the child or adolescent is showing signs and symptoms of DM.

Families were not aware of the possibility of a child having DM. After diagnosis, information is sought that subsidizes care for children and adolescents with DM.

From the data of this study, the experiences of families in the care of children and adolescents with Type 1 Diabetes Mellitus are complex, involving a web of relationships from the discovery of the diagnosis, to the family organization for care. The recognition of the family as an active subject in care for the planning of care and support actions becomes important. In this sense, it is necessary to establish a partnership with the family, opening up listening and welcoming spaces for a shared construction of child/adolescent care with Type 1 DM.

It is concluded that the nurses' work with the family, children and adolescents with type 1 DM can serve as a stimulus and motivation for the caregivers, minimizing their fears and anxieties, strengthening them as caregivers and reducing the risks of DM complications and better quality of life. life. Through effective communication of the nurse with the family, effective interactions and better knowledge about their real care needs are facilitated, facilitating the sharing of knowledge, experiences and strategies of care with them.

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