Network and social support in family care of children with diabetes

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ABSTRACT

Objective: to understand the influence of network and social support in the care of a child with type 1 diabetes. Method: qualitative study, with assumptions of ethn nurs ing, conducted in a reference service specialized in the treatment of diabetes, in 2014, in the city of Fortaleza, state of Ceará, Brazil. Twenty-six members of the family and their respective school children participated in the study. The process of collection and analysis followed the observation-participation-reflection model. Results: the analytical categories showed that the social network in the care of children with diabetes helped sharing of information and experiences, moments of relaxation and aid in the acquisition of supplies for treatment, with positive repercussions in the family context, generating well-being and confidence in the care of children with diabetes. Conclusion: the cultural care provided by nurses strengthens the network and social support because it encourages autonomy in the promotion of the quality of life of children with type 1 diabetes and their families.

Descriptors: Social support; Child; Type 1 Diabetes Mellitus; Pediatric Nursing; Family Nursing.

RESUMO

Objetivo: compreender a influência da rede e apoio social no cuidado à criança com diabetes tipo 1. Método: estudo qualitativo, com pressupostos da etnoenfermagem, realizado em serviço de referência especializado no tratamento de diabetes, em 2014, Fortaleza, Ceará, Brasil. Participaram 26 familiares e seus respectivos filhos em idade escolar. O processo de coleta e análise seguiu o modelo observação-participação-reflexão. Resultados: as categorias analíticas mostraram que a rede social no cuidado à criança com diabetes favoreceu o compartilhamento de informações e experiências, momentos de descontração e auxílio na aquisição de insumos para o tratamento, com repercussão positiva no contexto familiar, gerando bem-estar e confiança no cuidado da criança com diabetes. Conclusão: o cuidado cultural promovido pelo enfermeiro fortalece a rede e o apoio social ao estimular a autonomia na promoção da qualidade de vida de crianças com diabetes tipo 1 e seus familiares.

Descritores: Apoio Social; Criança; Diabetes Mellitus Tipo 1; Enfermagem Pediátrica; Enfermagem Familiar.

RESUMEN

Objetivo: comprender la influencia de la red y apoyo social en el cuidado del niño con diabetes tipo 1. Método: estudio cualitativo, con presupuestos de etnoenfermería, realizado en servicio de referencia especializado en tratamiento de diabetes en 2014, Fortaleza, Ceará, Brasil. Participaron 26 familiares y respectivos hijos en edad escolar. Recolección y análisis efectuados según proceso observación-participación-reflexión. Resultados: las categorías analíticas mostraron que la red social de cuidado al niño con diabetes permitió compartir información y experiencias, momentos de descontracción y ayuda para adquisición de insumos de tratamiento, con repercusión positiva en el ámbito familiar, generando bienestar y confianza en el cuidado del
niño con diabetes. **Conclusión:** el cuidado cultural promovido por el enfermero fortalece la red y el apoyo social, al estimular la autonomía en la promoción de la calidad de vida de los niños con diabetes tipo 1 y sus familiares.

**Descriptores:** Apoyo Social; Niño; Diabetes Mellitus Tipo 1; Enfermería Pediátrica; Enfermería Familiar.

**INTRODUCCIÓN**

Estimates indicated that more than 415 million people lived with diabetes, 5.1 million people died of this disease, and expenses surpassed US$673 billion, due to the treatment and complications of the disease in 2015. The incidence of type 1 diabetes mellitus (DM1) is increasing, particularly in children under five years of age, which represents about 5% to 10% of prevalence of diabetes cases. It is noteworthy that, at present, the primary prevention of DM1 does not have a rationale that can be applied to the general population. The most acceptable proposals are based on promoting breastfeeding and avoiding the administration of cow’s milk in the first three months of life(1).

Type 1 diabetes mellitus can progress with macrovascular, microvascular and neuropathic complications if not properly managed(2). Thus, glycemic control in the prevention of these diseases involves complex changes in the life of the child and the family. New life conditions are established for the child, with the imposition of a restrictive diet, insulin injections, and constant parental supervision(3). However, the interactions among health professionals, family caregivers and other entities that care and support the child-family unit are being expanded.

In order to plan and develop health actions tailored to families in situations of chronic illness, knowing the family context is essential. This action goes beyond the institution and its rules, and is based on the individual commitment of each professional(4). Children’s chronic illnesses can trigger many family conflicts, such as financial difficulties, reduction or interruption of leisure time; overload of the primary caregiver, and family breakdown, with negative repercussions for the whole family(5).

Family, understood as an organization, is a place of mutual support and, with this feature, it provides fundamental support for those who are sickened. The suffering caused by illnesses not only affects the life of the person who experiences it, but also the lives of those directly involved, who care and are distressed by the suffering of others(6).

Stress when facing a child’s chronic illness is a multidimensional process that manifests itself in various forms (complications, treatment, social relations, among others) and leads to an experience of suffering. The family shares this suffering, and becomes the main source of both physical and psychological support, an issue that is also inherent in the social network(7).

It is noteworthy that the structural dimensions that make up social networks are: size (number of people with whom they have social contact), density and integration (number of close people), and composition and homogeneity of members (degree of similarity between individuals such as age, socioeconomic status, among others). The main functions are: social companionship, following the person or family for them not to feel alone; emotional support, for comfort; cognitive guidance and advice, for information; social regulation, for recalling social norms. This network of interaction and care also offers physical resources, services and new contacts, including the person or family living in other networks in order to promote the exchange of experiences(8-9).

The social network of the families with children with a chronic disease can be considered a strategy to improve quality of life, both at the beginning and in the course of the disease. However, despite the significant increase in research on this topic in recent decades, little is known about the network of families of children with chronic diseases, given that one of the main characteristics of chronic diseases is continuous care(10).

In this context of care and commitment to child health, nurses can seek strategies for the promotion of family and social interaction, reinforcing sources of support to encourage the child-family unit welfare. It is noteworthy that nurses should be open to listen and communicate sensitively with the family caregiver of children with chronic conditions, in order to know and understand their multiple experiences and difficulties, conflicts, unions, relationships, interactions and retroactions, so that they can encompass the child, the family and its members as care units, addressing them in their multidimensionalities. Involving the family and the relationships within the family system can strengthen ties, produce and maintain channels of communication that are open to the management of care(11). Thus, professionals can obtain elements for proper planning, to overcome the drawbacks arising from the disease(12).

These families’ need for approach of the sociocultural context motivated this research, based on the theoretical and methodological assumptions of the Theory of Culture Care Diversity and Universality(12), because we consider them an important rationale to investigate these experiences, and which can support a creative and reflective nursing care that is consistent with the health needs of children with type 1 diabetes.

A child and its family are considered a unit of care, and in case of chronic diseases such as diabetes, it should be supported by a network of social support, which can be added to the professional care. Therefore, this subject emerged in the process of care and education, derived from the question: What is the influence of a social network in the care of children with type 1 diabetes mellitus? In view of the above, the objective of this study was to understand the influence a social network has on the care of children with type 1 diabetes.
**METHOD**

This is a qualitative study, with assumptions of ethnonursing, with the aim to assist nurses to systematically record people’s lifestyles, allowing the identification of different ways of living, and their experiences to guide care. The participants were 26 family caregivers and their respective school-age children with type 1 diabetes mellitus. Data were collected from January to November 2014, primarily in the reference outpatient service for treatment of diabetes in the city of Fortaleza, state of Ceará, Brazil. The information was supplemented at home with four families chosen for convenience during the contacts with a researcher, who participated in their experiences in that space. The selection criteria were: family caregiver and children diagnosed with type 1 diabetes for at least six months that are being followed at the research site, clinically stable at the time of data collection, and with no symptoms of hyperglycemia or hypoglycemia.

The data collection process was guided by the Observation-Participation-Reflection (OPR) model, which consists of primary observation and active listening; primary observation with limited participation; primary participation with continuous observation; and primary reflection and confirmation of findings with informants. In the phase of participation and continuous observation, the interview was guided by the following questions: How has care for your child with type 1 diabetes been? Do you have anyone to help with the care for your child? Talk about it. These questions were made to the caregiver in charge, who talked about the daily routine related to daily care, to family and social relationships. As family members were accompanying their children in outpatient care or at home, children occasionally gave their opinions and participated in the interview, which was important to understand family experiences in coping with type 1 diabetes. Throughout the talk, the researcher encouraged them to talk about the social support received. Thus, children’s participation in the production of data was considered.

The information was recorded, with reports of impressions from the researchers in a field diary. The analysis followed the systematics established by ethnonursing: after transcription, the component descriptors were identified and then contextual systematics established by ethnonursing: after transcription, the analysis followed the Observa-

**RESULTS**

During the course of research, at several times, families reported the support and availability of people and institutions, generating greater confidence in several moments of care, and in coping with a painful life. In their reflections, the researchers sought to understand and interpret the culture of informants, and the meaning they attributed to the social network and support in the care of children with diabetes, which will be addressed in the following categories.

**Network and social support to families of children with type 1 diabetes**

When coping with a painful life, children and caregivers find encouragement, support and assistance for the care from persons and entities considered their supporters: family, school, friends, religion, health staff, and groups formed in social media. They are referred to as major sources of support and interaction with family and children with diabetes.

For caregivers and their children, family members and relatives are at the heart of the social network, being the mainstay in their lives, strengthening the bond with the child and its family members, those who participate in the best times and also in the most challenging situations. These interactions promoted affective, emotional and financial support in child care, as reported:

When I need to take her to a hospital or for consultation at the Diabetes Center, her uncle takes us, he helps us a lot and his wife too, buying medicine when necessary; syringes, they always helped me. (C22’s mother – 9 years)

My aunt stays with me when my mother has something to do. She takes me to my friends’ birthday parties. (C25 – 10 years)

In his last hospitalization, I got so upset, because of his situation, it was so severe that I do not even like to remember, were it not for my mother, who was always near me, I wouldn’t get through it. (C6’s mother – 11 years)

Her godmother always calls her, she helps me in everything, when she sees a different thing he can eat, she buys it, always remembers of him. She takes him to her house; when he is there I get calm because she knows how to do everything, she even gives insulin. (C4’s mother – 8 years)

School and friends also represent important social media in the experience of children with a chronic illness, mainly in diabetes control, identification and correction of abnormal glucose, as well as in preventing hypoglycemia:

When I got dizzy at school, the teacher looked for Dx [glucose] and told my grandmother that I had low glucose. (C5 - 9 years)
My friend already knows that when I get cold and still, it is because my blood glucose is low. Once she saw me like this she took sugar with water and gave me. (C8 – 10 years)

However, there are some different attitudes in the speech of the children about some school friends, in which the interaction had a negative impact on the child’s life, when classmates and other friends do not consider that the child has DM1, or when they do not collaborate following the diet because the child with diabetes has dietary restrictions:

In my classroom they [colleagues] know I have diabetes, but there are some of them who do not care about that. They say I’m a fussy eater, and give me chocolates [candies] and big big [chewing gum]. I say I cannot eat that, and they still do not believe it. I take the chocolate and keep it to my sister. I feel like eating them, but it is just for a while. (C9 - 9 years)

My friend lives on my street, he knows that I have diabetes, but sometimes he forgets it and when I go to his house, he gives me cake and juice; then I eat a very small piece, because it is sweet. (C19 - 11 years)

In the social network for children and family, there is also religion, which is a spiritual foundation for families. In general, family members participate in meetings, Masses, and religious groups, to affirm faith in search of a miracle. For children, the church refers them to a sacred space, but where it is religious groups, to affirm faith in search of a miracle. For children, the family knows that there are trained and committed professionals in child care.

I have great faith, pray the rosary every day and go to Mass every Sunday with my sister-in-law, I hope he will get better each day. God is very powerful and makes miracles. (C6’s mother - 11 years)

My grandmother takes me to meetings in her church that are only for children; I like it because it is exciting, the teacher reads the Bible, tells things about Jesus and then we can play. (C17 - 11 years)

The church is the only place where I still go, the Minister knows our suffering, and always makes a prayer that makes us more hopeful. (C21’s mother - 10 years)

The support system offered by the health team consists of embrace, listening and dialogue while experiences of care of children with diabetes are shared. It is essential that the family knows that there are trained and committed professionals in child care.

I think it is important to come here for consultation, we learn a lot about insulin; I learned how to apply insulin with the nurse, she taught me and then I had to do the same, we really learn it. The nutritionist and the physician taught how to count carbohydrates; it was a bit difficult, but then I learned. (C22’s mother - 09 years)

I love everyone here. They treat us well, have that concern whether the child is well, how the food intake and blood glucose are. (C2’s mother - 10 years)

However, it was observed that some families showed anxiety and doubts, particularly regarding drug treatment. In this case, nurses tend to focus more on the guidelines of insulin therapy. When confirming this information, a mother said that the nurse prioritized information about the care with insulin. However, the way the teaching-learning process was conducted may have been inadequate, with no opportunity to enable the mother to deal with insulin therapy, an essential treatment to the child:

In the beginning, I had many doubts; on the first day, the nurse explained me how to prepare insulin, prepare Dextrostix, and apply it as well. She talked a lot, but it was too much. When I got home I could not remember anything. I was too afraid to apply the wrong insulin, there was no one to help me; I called the doctor, but she did not answer. I got the prescription and went to the pharmacy, where the boy explained to me, I understood a little and gave it to my daughter; I was trembling, because I’d never held a device like that [syringes], nor had I perforated anyone, you can imagine doing that to my daughter. (C3’s mother - 11 years)

The context of the guidelines in the nursing consultation was not favorable, making the assimilation of information by this mother difficult, probably due to time constraints, because she was waiting for the next consultation with another professional. Poor participation and the way the mother was approached did not make the learning process easier either.

The temporality experienced by families in the permanence of the disease, and of daily care of the child, generate feelings of helplessness, as they reported.

It would be great if this work [visits] from you continued; we need a lot someone to follow us, there are days when the child is well, others when it is uncontrolled [glucose]. There are things that we know how to do at the time, but later we forget. No one came here, they say that these health workers visit the homes, but they have never come here; you can imagine doing that. (C12’s grandmother - 7 years)

The speech from this grandmother reveals the need for continuing professional monitoring of the health demands of a child with type 1 diabetes who sometimes presents glycemic changes. The visit of the researcher was emphasized by the family as an opportunity of child’s follow-up, clearance of doubts, having a characteristic of social support. Thus, the family felt supported and confident to act during care; however, this does not happen on a daily basis.

Interactive technology as a support strategy to families of children with diabetes

Throughout observation and participation, in moments of interaction with children and their families, we identified a new social and cultural context among mothers, the support network that was informally formed by them in social media (WhatsApp and Facebook), one that is not only a means of communication, but also social ties of knowledge share.
regarding child care, which, in a way, helped in relational needs and in overcoming difficult times.

In in-person meetings, the coordinator of the group called “Pancreas Families” in the aforementioned social networks, invited the researcher to participate as a member. Thus, it was possible to follow the messages, images, informative texts and photos shared. At times, we tried to talk to these mothers, strengthening these relationships and focusing on ways of care for DM1 children.

This group was created in the second half of 2014. Initially, only mothers and children who were followed in the service participated; however, other mothers and children throughout Brazil, involved in another social network of the group coordinator, expressed their willingness to integrate, which was readily granted. Thus, mothers and children interact and are strengthened every day through this communication device, which offers their members essential and detailed information about a subject of interest in relation to care, and the means of access to materials and services. It is important to highlight that the group coordinator sells some customized artifacts of the group “Pancreas Family” and part of the profit generated is used to acquire materials for the families of children who have difficulties accessing material that is suitable for the treatment.

Some mothers and children participating in this study were in the group and shared experiences and/or doubts related to insulin therapy, acquisition of inputs for the treatment and insulin pump, carbohydrate counting and actions when facing situations of loss of glycemic control. Other issues, such as rides with the kids, were also discussed. The following reports show part of this interaction:

I didn’t know how to apply insulin correctly, then in the group [Pancreas Family] I got to learn it, with other mothers, how to make the carbohydrate count and correction bolus with rapid insulin, for her to go to a birthday party or eat a sweet, I still ask them [mothers] a lot of questions when I have doubts. Now she uses the pens that one of the mothers indicated, it is much better. I talked to the doctor and she prescribed, the problem is that sometimes there aren’t disposable pens, but only the bottle. I didn’t know that she is entitled to have these pens and insulin pump, no one told me. (C3’s mother - 11 years)

I thank God I have found this group. Do you know when you think no one is going through the same problem as you? It was horrible to know that my son had diabetes; I thought only our family was passing through this, but it isn’t like that, many parents go through the same problem. Then when I met the mothers from the Pancreas Family I felt stronger, one gives strength to the other. Despite this suffering they taught me that my son can have a normal life, go to a party, go out with school friends, play, because the other kids with diabetes do so. It was very difficult because I didn’t let my son do anything and gradually other mothers showed me that my son is normal. (C25’s mother - 10 years)

These caregivers shared experiences and important tips on care, being able to provide greater comfort and freedom to DM1 children. The more experienced mothers suggested the carbohydrate count as an alternative in glycemic control regarding preferences and children’s participation in social events such as birthday parties. Importantly, the carbohydrate count with correction bolus should be indicated and carefully guided by the health team accompanying the child. In this study, few children used this resource, but they had family involvement and help to follow the treatment carefully.

DISCUSSION

Support networks are important resources in the health care of DM1 children. Some authors state that the promotion and protection of individual and group health involve the construction of social ties and relations of solidarity among people and groups(13).

From this perspective, the speeches of the participants showed the presence of relatives, such as uncles, godmothers and grandmothers in important events and decisions, as well as the significant participation of these people in the life and care of DM1 children. They were remembered as a source of support in times of distress when the child was hospitalized, during the purchase of materials and food needed for the management of the disease, and in times of leisure and celebrations.

Strong and intense ties transform the emotional climate of the family system, reduce stress, decrease risks of ruptures, resulting in greater organization of this system, with a positive contribution to the care of children with chronic conditions(11).

Emotional support was also highlighted in the child’s socio-cultural interaction with their friends and schoolmates, who showed affection and care in situations of glucose changes. However, some children expressed dissatisfaction with living in this interaction of friendship, because at several times they were encouraged to eat foods that are not recommended. The real meaning of this disease was not understood by friends and colleagues. Friends, while recognizing the other’s limitations, do not always respect, especially in younger children’s experiences who live the present time without greater concern for the future - a childhood condition.

The authors of another study found similar results, i.e., positive attitudes were revealed through friends’ demonstrations of companionship when facing situations experienced by children with diabetes mellitus, including glycemic complications. Negative attitudes were related to diet and prejudice(14).

These families remain firmly with their beliefs and are daily strengthened through religion, a spiritual mechanism that is capable of restoring hope in the midst of suffering. It is understood that nurses, when seeking understanding of spirituality and other cultural aspects, can understand some attitudes and behaviors of the child-being acts and of their family, helping in decision-making related to therapy. They can base on the knowledge of the culture, and negotiate or keep health promoting practices(15).

It is suggested that the focus on spirituality when caring of people with diabetes be strengthened by seeking for the development of important aspects such as self-esteem, happiness,
optimism, hope, faith, satisfaction and strengthening of social and family relationships to support the person. Spirituality conveys security, serenity to the family and, in a sense, control of stressful situations through which these families go during the course of treatment\(^{16-17}\).

Issues such as the progressive involvement of the family with the child, through education, support, and sharing and transfer of responsibilities, are aimed at the development of self-care, increased knowledge of the child, appreciation of their experiences, and support offered by the social network, which includes the work of a specialized interdisciplinary team that strengthens diabetes control based on close interaction among the child, family, nurses and other members of the health team\(^{18}\).

This aspect is valued in cross-cultural theory when it refers to the care phenomenon as a support behavior, and to training of individuals or groups with special needs, seeking to mitigate or ameliorate the human condition or way of living\(^{12}\). Thus, it is relevant that nurses encourage families to establish and keep networks for social support in the relations of child care.

The second category pointed out that online communication among mothers of DM1 children through social media favored interaction, information and provided significant help in the lives of these families.

Thus, mothers, when continuously sharing anxieties, fears, knowledge and achievements in the care of DM1 children, found in social media a strategy for support and exchange of experiences among them, somewhat mitigating their painful life, since health is like a culturally defined and formed welfare state. Health actions should therefore be able to maintain or help individuals or groups to perform their daily activities in a culturally expressed, beneficial and standardized way\(^{12}\).

This virtually constituted group enabled a network of support and guidance to the lives of these families, which facilitated care. For example, mothers who had access to materials and supplies for the treatment of children in larger amounts or when the child was changing to another regimen, often made them available on social media to other children who did not have the same ease in acquiring them.

Some researchers assure that with the internet and social media, numerous virtual networks have become very useful tools for both health professionals and for the people involved in the health and disease process, contributing positively to coping with chronic diseases, either through health-related content available or chatting\(^{19}\).

Therefore, it is necessary to develop formal actions that facilitate these mothers' meetings, in order to strengthen ties of solidarity, since they share facilitating and hindering factors in having a child that requires care beyond that required by a healthy child. Moreover, this type of approach gives visibility to socio-cultural issues, which are little valued by professionals\(^{20}\).

The mothers participating in this group interacted and developed strategies to bear the suffering caused by their children's chronic illness, a fact also observed in another study with mothers of hospitalized children. Mothers begin to relate to others almost instinctively, create bonds of friendship, become united and, in this exercise of solidarity and mutual support, get to sympathize with the suffering of others, while seeking to comfort each other. Thus, mothers build a network of mutual support so they are able to go through this painful period of illness of their children\(^{21}\).

Therefore, interaction via an online community, valued in nursing activities, will change the nurses’ approach, favoring that they get closer individuals living with diabetes, making this tool a way to support and comfort children and families. One should recognize and value the role of culture in health, in the healing process and treatment, recognizing two care systems - the popular and the professional\(^{12}\). These dimensions are essential in the nursing practice, since nurses have care as the essence of their profession.

One of the limitations of this study was the difficulty for scheduling home visits due to the routine of each family and the distance of their residences, as most came from the countryside. Thus, further research in the home environment are suggested for a better understanding of the social and welfare network, aiming to guide actions and decisions in the care of DM1 children.

**FINAL CONSIDERATIONS**

The development of this study used the ethnonursing model, beginning with the early observations, concluding with the reflections of the researchers. The method used allowed to approach the experiences of families and children with diabetes and the influence of the network and social support, the positive meaning for those who daily live with procedures, which sometimes are painful for the child and family, but need to be ameliorated with personal, professional and collective efforts. Moreover, the characters face difficulties in access to services and materials that meet the pressing needs of the child; therefore, an interaction is needed, beyond the family and professional environment, relying on a social and health care network to reduce the burden on parents, and the suffering of children.

Family resilience, supported by religion, friends, school and health staff contributed to the development of strategies for coping with a chronic illness and adversities that permeate child care. The link among family members provided, besides social support, affection and financial aid. The school and friends also revealed themselves as DM1 children’s supporters, when they pay attention to the clinical manifestations, such as glycemic de-compensation during school activities, and report to caregivers, or intervene directly, a source of support that is recognized by families. Even so, there were times when the children faced difficulties in living with schoolmates who have a free diet, while they needed to follow the recommended diet; sometimes they felt encouraged to accept the food offered, which is supposed to create embarrassment for these children.

The group formed in social media represented a new form of interaction and exchange of maternal experiences in the care of children with diabetes. Families found in the group a support strategy, a way for acquiring experience, generating
well-being and greater confidence in dealing with the child with diabetes. Cultural care promoted by the nurses also strengthened the network and social support since it encouraged autonomy in promoting quality of life for DM1 children and their families.

In order to fill in the gaps of this study, we suggest that further research be developed on other social care and support networks to these children with chronic conditions and who are dependent on care technologies.

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