



EXPERIENCE OF MOTHERS IN THE CARE OF CHILDREN WITH TYPE 1 DIABETES

VIVÊNCIA DE MÃES NO CUIDADO À CRIANÇA DIABÉTICA TIPO 1

EXPERIENCIA DE MADRES EN LA ATENCIÓN A NIÑOS DIABÉTICOS TIPO 1

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Descriptive qualitative study aimed to understand the experience of mothers in the care of type 1 diabetic children in a unit of Tertiary Reference in Diabetes, located in Fortaleza, Ceará, Brazil. Data were collected through semi-structured interviews with 12 mothers of diabetic children, aged 3-12 years. The results were analyzed using the techniques of thematic analysis of Bardin, with these highlighted categories: multiple feeling generated in the impact of the diagnosis; mother facing the competitiveness of affection among the children, the experience of the mother in the expansion of the *locus* daily care. Conclusion: the disease affects the whole family, and the burden of care falls on the mother in all aspects of the disease, professional support is necessary, once the assistance provided by the mother goes beyond the diabetic child care related to metabolic control.

Descriptors: Diabetes Mellitus; Child Care; Chronic Disease; Nursing.

Estudo descritivo qualitativo com objetivo de compreender a vivência das mães no cuidado das crianças diabéticas tipo 1 em uma unidade de Referência Terciária em Diabetes, localizada no município de Fortaleza-Ceará, Brasil. Os dados foram coletados mediante entrevista semi-estruturada com 12 mães de crianças diabéticas, na faixa etária de 3 a 12 anos. Os resultados foram analisados a partir das técnicas do conteúdo de Bardin, emergindo as categorias: Múltiplos sentimentos gerados no impacto do diagnóstico; Mãe enfrentando a Competitividade do afeto entre os filhos; A vivência da mãe na expansão do *locus* cotidiano do cuidado. Conclui-se que a doença afeta toda a família, porém a responsabilidade do cuidado recai sobre a figura materna em todos os âmbitos da doença, fazendo-se necessário apoio profissional, visto que a assistência prestada pela mãe ao filho diabético vai além dos cuidados relacionados ao controle metabólico.

Descritores: Diabetes Mellitus; Saúde da Criança; Doença Crônica; Enfermagem.

Estudio cualitativo descriptivo, con el fin de entender la experiencia de las madres en la atención a los niños con diabetes tipo 1 en unidad de Referencia Terciario en Diabetes, en Fortaleza, Ceará, Brasil. Los datos fueron recolectados a través de entrevistas semiestructuradas con 12 madres de niños diabéticos, con edades entre 3 y 12 años. Los resultados fueron analizados a partir de las técnicas de contenido de Bardin, las categorías emergentes fueron: múltiples sentimientos generados en el impacto del diagnóstico; madre frente a la competitividad del afecto entre los niños; experiencia de la madre en la ampliación del lugar de cuidado diario. La enfermedad afecta a la familia, pero la responsabilidad de la atención recae en la madre en todos los aspectos de la enfermedad, siendo necesario el soporte profesional, pues la asistencia prestada por la madre al niño diabético va más allá de la atención relacionada al control metabólico.

Descriptor: Diabetes Mellitus; Cuidado del Niño; Enfermedad Crónica; Enfermería.

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INTRODUCTION

In Brazil the estimate figure of diabetic people is around 8 million, there are no exact data about children and adolescents with this pathology, but the incidence of *Diabetes Mellitus* type 1 (DM1) has increased, particularly among children under 5 years. The main characteristics of the disease are: daily need of insulin in the treatment with labile metabolic control, oscillation of glycemia and a high tendency to develop ketosis and coma⁽¹⁾.

The fact that *Diabetes* type 1 is considered incurable brings about feelings of guilt, anxiety and expectations of recovery, characterized by a period of loss of structure and uncertainty in the members of the family. The parents, besides the difficulty to understand the universe of feeling emerged with the impact of the diagnosis, must help the diabetic child and the healthy child to understand the changes that will happen⁽²⁾. So, in order to reach efficiency of the treatment in metabolic control, it is fundamental that feelings are overcome, so that the child can have confidence in the process of changing of eating habits, social life and insertion of medicine.

When *Diabetes* is associated with childhood, it is necessary to have the presence of a caregiver to learn how to deal with the symptoms, therapeutic procedures and abilities for the learning of the metabolic control. Researches show that the mother is the main responsible person in the therapy of the child's chronic disease showing that the mother suffers and gets sick with the child and so, she attentively listens to the orientations of the health professionals⁽³⁻⁴⁾.

The phase of bigger suffering for the family is the diagnosis in which they experience a period of crises characterized by destructuring and uncertainties in dealing with symptoms and treatments to reorganize life. But, it is in the phase of acceptance of the disease

that they understand the process of care without fear. The health professionals' support is indispensable in order to direct the adequate actions of health in order to reach family reorganization and therapeutic handling⁽⁵⁻⁶⁾. In this perspective, the health professional, involved in the assistance to the diabetic child, must program new practices of care able to promote metabolic control, reflecting fragile points of the education in health in the context of acceptance.

The need to know the changes occurred in the family, after the diagnosis of the *Diabetes Mellitus* (DM) in childhood bring about some questions: How do mothers feel facing the responsibility of taking care of a diabetic child? What is the daily life of a diabetic child at school and in the social and family environment?

In order to guide and stimulate the caregiver, it is determinant that the health professional knows the reality, the feelings in changes occurred after the diagnosis and, besides that, make him understand the care of the child in the behavioral, affective and cognitive areas. Therefore, the objective is to understand the experience of mothers in the care of the child with *Diabetes* type 1, in a unit of Tertiary Reference in *Diabetes*.

METHOD

A study of descriptive character was made focusing the qualitative approach, aiming to describe and to explore aspects of a situation, as well as work with the universe of meanings, motives, aspirations, beliefs and attitudes, which correspond to a deep space in the relations, the processes and the phenomena which can not be reduced to operationalization of variables⁽⁷⁻⁸⁾.

The present study was made in the Center of Tertiary Reference in *Diabetes*, located in the county of Fortaleza, CE. Twelve mothers of children with *Diabetes*

Mellitus type 1 participated. The following criteria of inclusion were adopted: mother with child diagnosed with Diabetes type 1 for less than one year, to have the child follow regular attendance in the Center of Reference and the mother must have legal age.

For the data collection the semi structured interview was used having the following guiding questions: How do you feel facing the responsibility of taking care of a child with Diabetes? What is it like for you the life of a diabetic child in the daily school, social and family activities? The questions were submitted to a pre-test confirming adequacy for the population inquired.

The statements were totally recorded and transcript. For the data analysis the technique of the Analysis of Content ⁽⁹⁾ was used, with these steps: pre-analysis or organization of the material; explorations of this material through identification and codification or categorization and interpretation of the results.

The ethical aspects were present throughout the research, based on Resolution no. 196/96 of National Counsel of Health ⁽¹⁰⁾, including the approach of the principles of Bioethics. The objective of the study was made clear, followed by the presentation and signing of the Informed Consent Form (ICF). Regarding the rights of the citizen and preserving their anonymity, the mothers were identified by the sequence of the interviews: M1, M2 (...), M12.

The study was submitted to the Committee of Ethics in Research of the University Hospital Walter Cantídio (HUWC), having been approved by legal opinion no. 0290601.

RESULTS AND DISCUSSION

Description of the Subjects

The age of the mothers ranged from 22 to 54 years. Women with consensual union were predominant

(eight). Of those, four had a child, one had two, six had three and another had five children. Regarding the level of instruction the ones who had incomplete grade school presented a higher incidence; two worked outside their houses and the other ones were housewives. Most of the mothers (eight) lived with a monthly income of less than three hundred and eighty reals; the other ones did not have any income once they lived in their parents' house.

The transcendence of the analysis brought about the following categories: multiple feeling generated in the impact of the diagnosis; mother facing the competitiveness of affection among the children, the experience of the mother in the expansion of the *locus* daily care.

Multiple feeling generated in the impact of the diagnosis

The perception generated with the diseases, without censorship, without thinking in right or wrong reveals that the role of protection that the parents established with their children is something intrinsic in the relationship. The manifestation of DM evidences that the emotional area is the one to become weakened and jeopardized, once the mothers project dreams and a long life in the children and with the impact of the diagnosis, this projection is compromised. However, fear and anguish continue, even after the impact of the diagnosis and show that the unknown situation requires emotional balance, so that despair does not interfere in the care.

The DM modifies the every day lives of people and requires adaptation in the psychological, social and physical domains, which makes evident the need of family interaction all along this process⁽¹¹⁾. The family requires emotional support to help and cope with reality and in the capacity of care as stated in the following lines: *I was shocked, desperate, cried a lot, I don't even like to remember (M1). I was and I am still afraid, caught me by surprise*

(M3). *I was afraid, but because the diabetes is good, I am more relaxed* (M4). *My anguish goes on. I feel sorry for my son, I haven't gotten used to it* (M12).

Under such approach, the mother who has difficulty to accept the disease needs professional help at the moment she is in the first aid post, continuing the treatment. The nurse must interact facing an interrelation with the mother and this situation and introduce the child to the outside world and not to the diabetic-intern world.

The work of education in health with the parents will make the acceptance of the child to the new condition of disease easier, considering the family unique in the determinant role of the development of sociability, physical welfare and affectivity, especially during childhood⁽¹²⁾. On the other hand, the nurses are still rooted to assistential practices which value the clinical finds and do not consider individual finds which are strengthened with the beliefs. So, there will be no contribution in the approximation of the mothers to the child care and therefore the practice will not impact on the epidemiological indicators which portray the damage to the health of the diabetic child.

The discovery of the diagnosis of a chronic disease when related to the non acceptance of the mother, interferes in the child's welfare, occasioning stress and suffering, requiring overcoming of challenges presented in the daily life, such as the increase of care in terms of constancy, vigilance and intensity⁽¹³⁾. When the difficulty of care is associated to the family income, the following occurs: *Suffering, especially for us who are poor and can't provide the right treatment, I feel incapable* (M2). *I don't accept this disease and I have no money to pay for what he needs, the health post gives the medicine. And the rest? I fear not to have money to buy the food which should be given to him* (M7).

Under such approach, the difficulty in care is related to the purchasing power of the family that depends on the availability of food, quality of housing and access to essential services, such as sewage and health assistance. The feelings related to the condition

of life makes us infer that the diabetes means more than a set of symptoms, once it has representation in the professional, psychological and personal life.

It is known that the family needs preparation to provide assistance to the child and accepts the challenges of the treatment, giving attention to the child care in a chronic disease, which consumes time and provokes the loss of privacy, in order not to provoke social and emotional isolation⁽¹²⁾. The mother's schooling is influent especially regarding opportunities of job and wages and so it improves the parents' purchasing power.

The schooling and the profession of the caregiver can directly interfere in the family income and indirectly in the capacity to efficiently manage the subjects inherent to the health care. *I don't trust leaving him with anyone, nobody does it the way I do, I wanted to be able to work and have money but I prefer my child alive* (M8). The mothers' attitude can exclude the child of the real world besides awakening a feeling of excessive dependence, mistrust and emotional instability, fear of adversities and insecurity of the outside world. *It is as if he depended only on me, I don't have a job because of my child, because I think he will get worse without me* (M5). The parents' overprotection interferes in the development of the autonomy and can disguise an unconscious rejection⁽¹⁴⁻¹⁶⁾.

The financial difficulty is a factor that influences care once the medicine, transportation and adequate food are not always covered by the monthly income. The insertion of the woman in the working market makes the assistance to the child difficult, and the financial resource becomes a responsibility of the father alone, when he is present. On the other hand, the mother who does not work experienced conflicts. This is stated in the interviewees' discourses of this study. *I need to work every day, I wanted to be able to take care of her, I can't take her to the doctor, I don't give an insulin shot. The one who does these things is my sister; I know I could take better care* (M6). *I need to work every day, but my heart is in my hand, I go to work waiting*

for the worst news. If I could I wouldn't work. I have to trust in other people (M10).

An expressive number of women is inserted in the working market and contributes to the family income. Besides maternity, they worry with academic achievement and value the construction of the professional carrier, suggesting the condition of success. In this context, the woman's work many times guarantees the family living and it becomes a necessity, not a professional achievement^(12,17). In order to reach the metabolic control of the diabetic child it is necessary to improve the provision of materials, equipment, diet, but these items become distant due to the costs.

A study has revealed that this role, once taken over by the woman has a repercussion in the family dynamics, in conjugal matters, as well as in the education of children⁽¹⁸⁾. In this sense, the subjects have the challenge of conciliating the mother functions with the professional ones. The link of the mother who works and takes care of the diabetic child suffers changes, but the determination to follow the daily care and to keep the relationship with the children persists.

Accepting the restrictions that the diabetes *mellitus* imposes are difficult, especially when the child requires changes day-by-day and many times the parents are not prepared to make those changes. The food habits characteristic of northeastern culture are part of the food resignation of the diabetic child and become a grief to the family; this is noticed in the crying and intonation of the mother's voice. *I feel different of those who have a normal child; they can give sweets, flour and tapioca for the child to eat (M8). I am different of the mothers of other children, he cries when he wants the food of other brothers, when it is the time for corn, I spend all the time saying no (M9).*

The emotional condition marked by the practice of care generates overload which is not overcome in the family dynamics. Studies show that repeated visits to doctors, hospitals and the need do assure that the medication is given at the specific time form factors which potentize stress, making the mother absorb the

disease for herself⁽¹³⁾. What is missing in the health services in order to minimize such effects? The discourses are impregnated with frailties and feelings of impotence which demonstrate the insecurity in the public health system, that continues being excluding and unfair.

Facing the competitiveness of affection among the children

The behavior presented by the brothers of the diabetic child reveals change in the mother's attitudes and provokes reactions of revolt and jealousy in the children, resulting in new difficulties. *The other one rebels against the sick child, feels jealous and even anger and I still have to split them to avoid fighting (M4). My other daughter is jealous and keeps complaining that I don't like her, but it is not like this, it is because the sick one deserves more care (M7).* The adversities extend to the other children because of the mother's intensified attention to the diabetic child. *The other children even pretended to be sick to call my attention (M9).*

Based on the above considerations, the differentiated behavior with the diabetic child becomes comprehensive, depending on the age of the brother, on the jealousy and on the anger. But the health professional can and must act with the proposal of showing the family that the other children are able to understand the situation, provided that there is clarification on the diabetes and the treatment. The collaboration of the family is one of the favorable determinants for the success of the metabolic control and the welfare of the child and his family.

A research made with 54 family members of children and adolescents with chronic disease showed that 39% of the siblings reacted with sympathy; 22% with jealousy; 19% with disdain; 14% with aggressiveness, despair, concern and yearning. According to the interviewees, some of the siblings, confronted with the growing attention of the parents to the sick child, demonstrated jealousy, concern and emotional instability⁽¹⁷⁾.

The experience of the mother in the expansion of the *locus* daily care

The school promotes educational opportunities for disabled children with limited activities or with restrictions in social participation, including chronic diseases, physical problems and/or other types of limitation⁽¹⁹⁾. But it is the place in which the child is exposed to physical activities, improper food and unprepared professionals in handling hypoglycemic crisis and ketosis. The incapacity of the health professionals regarding the correct handling of the disease awakens the maternal behavior such as: *I am afraid she falls down at school and it may take long to heal, she can eat some sweet of a classmate and start a crisis (M7). At school she had a crisis, only God didn't let her die. Now, when she goes to school I keep imagining someone arriving with bad news (M1). The school became a place where everything seems dangerous, the classmates with the sweets, the number of students, the physical education that is very early and she doesn't want to eat before leaving. She doesn't go for a walk without me (M12).*

Undoubtedly, the unsatisfactory metabolic control in those children results in atrophied growth and severe hyperglycemic or hypoglycemic crises, affecting the neurological development. The diabetes type 1, at a very early age, can develop structural anomalies of the brain and the cognitive function⁽²⁰⁾. The daily care with food, monitoring of the capillary blood glycemia, recognition of the first symptoms of hypoglycemia are essential for the metabolic control. However, the diabetes type 1 represents an incumbency of the family and the health services.

The study showed that, although the teachers know what DM is, they don't know the signs and symptoms of hypo and hyperglycemia, the therapeutical approaches and the main behavior to be adopted in the glycemic incident that might occur⁽²¹⁾. So, the health professionals of the strategy of the family health must identify diabetic children in order to call parents and teachers to discuss diabetes at school.

A research shows that the family presents hesitancy to the school environment because of the insecurity regarding the preparation of the features in dealing with the children. A safe environment is the one which has trained people to measure glycemia and recognize and treat a case of hypoglycemia⁽²²⁾.

The participation of the spouse with little intensity and complicity reveals a lonely maternal care: *My husband doesn't know about diabetes, he never went to a consult, so I don't trust leaving my son alone with him for a long period (M3). The mothers express the father's passivity regarding the situation of the child. My husband goes away; it seems he doesn't want to get involved in order not to suffer. And when my daughter asks if she can eat something he tells her to ask her mother (M9).* This behavior generates the understanding of individual responsibility in the woman creating a discomfortable situation in conflicting moments in the conjugal relationship leading her to experience adverse situation to the welfare of the family.

It is believed that the father must be a collaborator in the therapeutical process of the Diabetes *Mellitus*, once he is an ally in obtaining adequate health orientation and in the process of coping with the disease.

Although studies show the mother as the main caregiver of the diabetic child, the inclusion of the father is essential for the progress of the treatment. However, the function of financial provider is the father's responsibility, the one who must supply everything at home, working overtime. It is expected that the conditions of life get better but the familiar cost of the low paternal involvement in the education of the children is high^(5,10).

FINAL CONSIDERATIONS

The set of information obtained in this investigation of qualitative nature, contextualized in time, and venue of its making, therefore, does not intend to generalize the results found but to bring

significant contribution for the services of health and the comprehension of the experience of the mother in the care of the child.

The thematic showed that the repercussions caused after the diagnosis were negative and implied in the establishing of family reorganization. The parents' concern refers to the constant occurrences of decompensation, which show the lack of balance of the metabolic situation, generating a higher possibility of complications, which jeopardizes the quality of life in the future. The caregivers see the diabetic child as a fragile and sick person.

It is remarkable that the positive confrontation can be found from the acceptance of the disease, so it is possible to provide the search of information as well as the attempt of adaptation of the family routine aiming at softening the feelings of dependence, mistrust, emotional instability and insecurity arising from the diagnosis of the diabetes *mellitus*.

The chronic disease affects the child and the family but the responsibility is predominant in the mother, who feels indispensable and irreplaceable in taking care of the child, thus resulting in overprotection which can exclude the child of the real world, besides awakening feelings of dependence, mistrust, emotional instability and insecurity.

The strategic role of the health professional in dealing with the family and not just with the sick child is highlighted, once it reduces the difficulties throughout the treatment. The educational and assistential attention to the mother-child binomial, emphasizing the process of the communication/orientation in health must favor the reduction of anguish and at the same time consolidate a technical support for the confrontation of the process of the disease.

The acting of the nurse is based on the above considerations, which means attention, objectivity, solicitude and individual care, once it makes sheltering

possible. The multidisciplinary team must call and mobilize the parents in order to minimize interfamily conflict and delay in the development of the child.

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