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MEANING OF CARE TO THE DISABLED CHILD WITH SPECIAL NEEDS: REPORT OF MOTHERS

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ABSTRACT

This study aimed to understand the meaning of care given by mothers to disabled child with special needs. Qualitative, exploratory descriptive research held from March to April 2012, with 08 mothers registered in the Family Health Units of a municipality in Paraíba, who fulfilled the inclusion criteria: mothers of disabled children with special needs aged between six months and 10 years old. Data were collected through semi-structured interviews and analyzed using the Collective Subject Discourse. For mothers, the meaning of care to children with special needs has proved to be singular, involving specific attention, full of sociocultural values as renunciation and dedication, and determined by the historical and cultural construction of the role of women in the family and society. The lack of social support of this care in daily life affects negatively, the family and social dynamics of mothers. In order to face this reality it is indispensable the support of social networks for child-family binominal.

Keywords: Child health. Nursing care. Family. Pediatric nursing.

INTRODUCTION

Commonly people with disabilities face limitations in their daily life. These limitations are intimately related to the conditions that allow the exercise of autonomy and their social participation, and may interfere with their occupational development or harm it, cognitive and psychological, contributing to their social exclusion(1).

In this sense, it is responsibility of the families, societies and governments to ensure their citizens with equal opportunities in all situations of life so that they can develop their potential including specific care for those people who exhibit demands of special care. The involvement of individuals or group of individuals and organizations that offer assistance and necessary assistance to these people, in order to help them to start or continue healthy behaviors, maintaining and promoting health, which comprises the needed social support(2,3).

In this study, it is understand for special needs, those that disabled child can present, as dependency for activities of daily living, aid for moving, feed themselves. These needs are not only arising from the individual condition of disability, and yes, the dynamic relationship between the person and the environment in which it operates, taking into account the availability of resources of environment and its adaptability(4).

In this sense, the existence of a disability is not necessarily that the child requires a differentiated resource, depending on the type and degree of disability, as well as the effects that result by, in addition to the general conditions of the services that will serve as indicators of whether or not the use of aid and special services(4).

The first space of socialization of a person is the family environment, with the birth of a disabled child, suffers changes affecting the family, not only in terms of reactions and

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feelings of its members, as well as their structure and functioning. In this process, the family, often needs to rethink its organizational structure and form as a group, because the care to the disabled children with special needs requires constant presence of a caregiver who, for the most part, it's the mother(5).

In this sense, an important part of the responsibility of the health care of children with special needs is assumed by families, being parents the main caregivers. During the course of care, they face great challenges that pertain to both the social limits as the emotional and often express feelings of doubt, insecurity, fear and uncertainty(6,7).

The family contributes to the development and security of its members in various ways, either by satisfying their most basic needs, facilitating a coherent and stable development; being encouraging a climate of belonging(7). In this way, it will be with family members that the disabled child with special needs will sustain personal relationships closer and important, in many cases, the only ones. The study(3) highlights that the family, through the relationships built between its members, can provide to disabled children an environment that promotes development.

Among family caregivers, the mother is the main agent of care to the disabled children with special needs, assuming an important role and responsibility in the conduct of the process of care. Thus, it becomes the fundamental character in the care and maintenance of the well-being of the child, which, depending on the degree of dependency for daily activities, requires redoubled attention and supervised(8).

In general, mothers feel burdened to take care of the child with special needs, either by excess of responsibilities, time devoted or lack of social support. The main difficulties presented are of social conviviality, physical and emotional overload, and the complications that result from the need for permanent monitoring by ambulatory health care services and rehabilitation(8).

Reflecting about the responsibility conferred to the mother of disabled child with special needs, the issue that has guided this study was: What is the meaning of care to the disabled child with special needs assigned by the mothers? From this, the objective of this study was to understand the meaning of care dispensed by mothers of disabled children with special needs. The aim is to contribute to the elaboration of possible strategies to facilitate the confrontation of this process.

METHOD

Qualitative exploratory and descriptive study, carried out in the period from March to April 2012, in eight Family Health Units in the urban area of a municipality of Paraíba. Participated eight mothers of disabled children with special needs whose collection closing criterion was of data saturation. The selection of subjects was made by prior consultation to the medical records of families registered in these units, seeking to identify children with any disability. From this information, was performed a previous contact with the family, verifying the existence or not of special needs.

As a criterion to determine the special needs, children should present at least a demand of care to perform activities of daily living, for example, assistance to loco-mote and/or feed. It was used as inclusion criteria: mothers of children aged between six months and 10 years and with special needs and as a criterion of exclusion: mothers with difficulties in communication. The project was submitted to the Research Ethics Committee, under protocol number: 20111612-070 as advocating the Resolution 196/96 of the National Health Council, having received a favorable opinion. The participants signed the Informed Consent Form at the time of the interviews, where they received information about the research and implications regarding participation.

The data were collected through semi-structured interview, recorded and performed in the mothers' homes, with an average duration of two hours each, with the following main issues: For you, what is it like to have a child with special needs? How do you take care of your child with special needs?

The interviews were transcribed verbatim and analyzed by the technique of the Collective Subject Discourse (CSD)(9). As imagined by its authors, the CSD consists in a mode of discourse analysis obtained in verbal statements or in any discursive manifestation that can be find in texts and written documents. Structurally, it is organized from the use of methodological figures designated as: Anchor (A); Central Idea (CI); Key Expressions (KE) and the Collective Subject Discourse (CSD). The meanings of these figures or steps of an analysis procedure, give the notion of a process of apprehension of meanings that arise in all the lines, which display a collective thought or the representation of the group about a given theme or issue(10).

In the interpretation of testimonies, were established Anchors (A), which resulted in a categorial set of three Central Ideas (CI), highlighting the meaning of care to children with special needs: 1) Care that requires resignation; 2) Distinguished care of other children and 3) Care that requires dedication. From the Central Ideas were built the synthesis-speeches, bringing together all elements of the various testimonies, organized according to the answers given to the central question of the interview script.

RESULTS AND DISCUSSION

In the survey, eight mothers aged between 24 to 38 years old participated of which half was married and other half single. All had another son in addition to the disabled child with special needs. It was noted further, that the family income does not exceed one (1) minimum wage. Towards children, they presented age group between one year and 11 months and ten years of age, being six female and two male. The deficiencies shown were: physical, auditory and multiple, according to ICD - 10 (International Statistical Classification of Diseases and Related Health Problems).

Through incursions in the lines of mothers, it was possible to apprehend the reality in the experience of these actors, about the care of disabled children with special needs.

The first mothers' collective speech presents the meaning of care as that one that gives off of something personal to attend the special needs of their children. It is evidenced as the main providers of necessary means to guarantee the conditions they require to maintain their state of health.

Central idea 1- Care that requires renunciation:

> I'm always giving up other things to take care of him. I take care of him alone, and it was very difficult because I never took care of a disabled person, so for me it was very difficult, but I'm leading a normal life [...]. When I get off from work to get him to do treatment, peoplee are asking if there's no one to take him, because I only have to take him, because I know it's my obligation to bring him to know how's his progress in treating [...] I stop doing things to take care of her, sometimes she asked something and I say it is ok, sometimes she wants me to play with her [...] All he wants to do I do. Because he depends a lot of us and when we don't have time there is even harder. (CSD)

In this speech, it is evident the mother conception that she is only able to provide the child the unconditionally care, leaving the personal issues, such as work, leisure, wills. However, to take it upon themselves to greater responsibility in the conduct of care to disabled children, engage in such a way that they become the main subject of care, however the result to conduct life can reflect on their personal and family relationships.

Study(11) about the quality of life of caregivers of people with special needs, points out that the function of taking care of them is commonly exercised by a family member who assumes the role of primary caregiver, becoming responsible, by care. By passing a very high time attending the needs of the dependent individual, the member may suffer a social stress and have, as a consequence, the removal, often, of their own family, friends and limitation in their social conviviality.

The exclusive dedication to attend the demands of child survival care with special needs can reflect on the welfare of caregivers, leading to a physical, emotional and affective wear. To deal with the situation of stress and suffering triggered by these experiences, appeal to external moderators (family and institutional network) and the internal moderators (sociocultural matrix) for coping(12).

In this context, it reinforces the importance of the family as centralizing core in organizing responses to conflicts generated and its mediation by the conditions inherent to the disability, since it contributes to the development and security of its members in various ways, either by satisfying their most elementary needs;

facilitating a coherent and stable development; and even encouraging a climate of belonging(13).

The importance of the presence of the family in child care is indisputable. However, its ability to care for its members and handle the suffering generated by the impact of outstanding situations, as the experience of disability, congenital malformation or prolonged hospitalization, may be compromised, diminished or absent(14).

In this perspective, the families who experience their living with a disabled son have in mind a fundamental element to strengthen them in the face of the adversity caused by the situation of the child and for the maintenance of functioning and healthy family interactions(14).

In this process, studies(15,16) highlight the role of the health professional, which must be based on the establishment of a close relationship and continuous with the families, rescuing the essence of integral care to apprehend the needs of the other, taking into account social, cultural and affective aspects. Thus, it dislocate the centrality of care in the biological for an expanded care, guided by a sensitive listener and reflective dialogue.

In the process, health team and family can build together enabling strategies for extended care and multidisciplinary that give account of the complexity experienced by the family in their daily lives.

Central idea 2: Distinguished care of other children:

> Because the care is different from the others, there's no way I can handle equal, no, because he needs more. But I treat him normal, I give the same rule for him and his sister [...] I take care of him as a normal kid, but the care is different from other [...] I didn't want to handle differently, I wanted to take care all the same, but there's no way I can not handle all the same, no, because he needs more [...] He relies heavily on me, he is very different from kids of his age. (CSD)

For mothers, the care of children with special needs is coated with a different meaning of other children. At the same time that is specific, is not distinguished, in essence, from that provided to other children. For mothers, the role is a commitment in the physical, emotional and social levels, since, on the condition of caregiver, is responsible for the provision and preservation of life of their children.

Care performed by mothers of children with special needs involves unique and complex actions, continuous and intensive in nature. The mother takes the brunt of responsibility in the creation of the son. Occurs, thus, a relationship of mutual dependence between mother and son. In this way, the mother believes to be fulfilling its role of mother(3). This complex attention required by children becomes a challenge for the mothers, who often lack of mediate it with the other members of the family.

Study(14) demonstrates that triggered changes in family dynamics, due to the presence of a chronic condition, start from the need of repeated visits to health services, the use of medicines, specific care, of recurrences and repeated hospitalizations along the process, reaching all their members. The inability to deal with a new situation affects family relationships, whether between brothers, between parents and children or between spouses.

In this sense, the care of these children require adjustments in all familiar scopes, which makes evident the need of family interaction throughout the dynamics and process of care. Therefore, it is crucial to the active presence of family and social groups.

Many families make explicit difficulties to take care of disabled children with special needs. These require an expanded support and work in family groups to exchange experiences and strengthening of potential in the care for the child, through the support that each member provides to each other, thus contributing to the process of restructuring of family dynamics and rescue of the well-being of all(13).

Central idea 3: Care that requires dedication:

> We have to take care, with patience, lots of patience, if not, he does not go it has to be with a lot of affection, and stuff like that [...] I have a very great care with him [...] We have to pay attention to him, there are things he doesn't understand, then we have to give a lot of attention [...] I take care of him as a normal child. I do what the doctor says, the nurses, I go to the speech therapist, I do everything as it is said and I'm running behind.(CSD)

Some demands of care required by a child with special needs are intense and constitute in challenges to the family caregiver, especially the mother. The CSD shows that the uniqueness of the care of these children involves an extreme dedication, expenses with products and medicines and the search for technical and scientific knowledge of health care professionals.

In the family context, is socio-cultural determined that the woman is the provider of childcare, elderly and sick people. The legacies of the tradition, dedication, selflessness, education and family socialization and female solidarity, combined with the moral obligation that are culturally transmitted to the girls of the family, contribute to them to internalize the primary family caregiver role(6).

The legacy of dedication(6) implies the preference of women for the development of the role of caregiver of children, in particular those with special needs. These legacies reinforces the role of women to care is a social construct ideologically determined, what constitutes a moral obligation. In this sense, it is the responsibility of the women care for the whole family, as a moral obligation socio-cultural built.

By being an activity essentially feminine, is responsibility of the woman not only the task of nursing but also to learn to take care of. In turn, this implies the necessity of having access to information related to knowledge of the field of health(6). The mother caregiver needs a “time”, which is not chronological, but, yes, singular to each of them, depending on its context, of their life story, the smaller or larger influence of sociocultural matrix of care, to elaborate mechanisms to help in the confrontation(6).

Thus, the social support network to which she has access, the sharing of information, experiences and social interactions with healthcare professionals in a dialogical relationship, can contribute to the exchange and the sharing of experiences of care with the other members of their social support network.

FINAL CONSIDERATIONS

In response to the objective of this research, it was evidenced that the meaning of care to children with special needs assigned by the mothers, concerns the singular character of this care, involving specific attention, differentiated from that afforded to other children. This care is translated by means of socio-cultural values like renunciation and dedication, determined by historical-cultural construction of the role of women in the family and in society.

Such a situation delegates to these mothers, the exclusivity of care to children, making them realize themselves indispensable, to the point of compromising their personal dynamics and quality of life, with possible physiological, emotional and social consequences. The situation worsens when is evidenced in the absence of satisfactory support reports along the route involving the care of children.

Therefore, it is imperative that the awareness of health professionals and family members on the difficulties presented by these mothers in the confrontation of special conditions imposed by the disability of their children. That way, it opens up the possibility of being established a relationship of sharing care and decisions, reinforcing the autonomy of mothers for that care, but also the mutual cooperation with the greater involvement of other members of the family.

Considering that these families also depend on the support and nursing care, it is essential that this class can contribute with their knowledge and practices to enhance the bargaining power of mothers in caring for children with special health needs. The monitoring of families, the creation and encouragement of participation of support groups and health education, as well as the need to encourage social support network are essential for the re-orientation of the care provided by mothers to children.

It is stressed the importance of health professionals become aware of the existence of this clientele and develop programs of attention and support to these women. It is necessary to reorient the professional practice leaving to reproduce the dominant ideology in the daily activities of care to disabled children with special needs, thus enabling the insertion of other subjects in the process of care, in order to built a shared experience in which everyone can take their part, without overloads or larger repercussions for caregiver mothers.

SIGNIFICADO DO CUIDADO À CRIANÇA DEFICIENTE COM NECESSIDADES ESPECIAIS: RELATO DE MÃES

RESUMO

Objetivou-se compreender o significado do cuidado dispensado por mães à criança deficiente com necessidades especiais. Pesquisa qualitativa, exploratória descritiva realizada de março a abril de 2012, com oito mães cadastradas nas Unidades de Saúde da Família de um município da Paraíba, as quais atenderam aos critérios de inclusão: mães de crianças deficientes com necessidades especiais com idades compreendidas entre seis meses e 10 anos. Os dados foram coletados por meio de entrevista semiestruturada e analisados pela técnica do Discurso do Sujeito Coletivo. Para as mães, o significado do cuidado às crianças com necessidades especiais revelou-se singular, envolvendo atenção específica, repleto de valores socioculturais como a renúncia e dedicação, e determinado pela construção histórico-cultural do papel da mulher na família e sociedade. A falta de apoio social no cotidiano deste cuidar afeta negativamente a dinâmica familiar e social das mães. Para o enfrentamento dessa realidade é imprescindível o suporte de redes sociais de apoio ao binômio criança-família.

Palavras-chave: Saúde da criança. Cuidados de enfermagem. Família. Enfermagem pediátrica.

SIGNIFICADO DE LA ATENCIÓN AL NIÑO DEFICIENTE CON NECESIDADES ESPECIALES: RELATO DE MADRES

RESUMEN

El objetivo fue comprender el significado de la atención dispensada por las madres al niño deficiente con necesidades especiales. Investigación cualitativa, exploratoria descriptiva realizada de marzo a abril de 2012, con 8 madres registradas en las Unidades de Salud de la Familia de un municipio de Paraíba, las cuales atendieron a los criterios de inclusión: madres de niños deficientes con necesidades especiales con edades comprendidas entre seis meses y 10 años. Los datos fueron recogidos por medio de entrevista semi-estructurada y analizados por la técnica del Discurso del Sujeto Colectivo. Para las madres, el significado de la atención a los niños con necesidades especiales se reveló singular, envolviendo atención específica, repleta de valores socioculturales como la renuncia y dedicación, y determinado por la construcción histórica-cultural del papel de la mujer en la familia y la sociedad. La falta de apoyo social en lo cotidiano de este cuidar afecta negativamente la dinámica familiar y social de las madres. Para enfrentar esta realidad es imprescindible el soporte de redes sociales de apoyo al binomio niño-familia.

Palabras clave: Salud del niño. Cuidados de enfermeira. Familia. Enfermería pediátrica.

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