

Paternal care to children and adolescent with chronic disease: maternal perception

Cuidado paterno à criança e ao adolescente com doença crônica: percepção materna

Cuidado paterno con el niño y el adolescente con enfermedad crónica: percepción materna



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ABSTRACT

Objective: To analyze the maternal perception about the paternal care and to understand how this care is made effective in practical actions in the care of the child/adolescent with chronic disease in the family routine.

Methods: Exploratory-descriptive, qualitative study, carried out at the pediatric outpatient clinic of a public hospital in the state of Paraíba, between November/2013 and April/2014, with 10 mothers whose children had more than six months of diagnosis. Semi-structured interview subsidized the data collection, which was submitted to thematic analysis.

Results: Parents participated in activities such as routine care of the child, medication management, leisure, binomial support and household chores. They took on different roles in the care depending on the availability of time and the maternal freedom given for their participation. Among the separated couples, the distance between parents in the care reflected on the child's health.

Conclusion: It is important to involve fathers in the care of the child with chronic diseases. However, there is a need for a greater involvement of fathers in the performance of this care.

Keywords: Father-child relationships. Child. Adolescent. Chronic disease. Family.

RESUMO

Objetivo: Analisar a percepção materna acerca do cuidado paterno e identificar como esse cuidado configura-se em ações práticas no cuidado à criança/adolescente com doença crônica no cotidiano familiar.

Métodos: Estudo exploratório-descritivo, qualitativo, realizado no ambulatório pediátrico de um hospital público da Paraíba, entre novembro/2013 e abril/2014, com 10 mães cujos filhos tinham mais de seis meses de diagnóstico. Entrevista semiestruturada subsidiou a coleta de dados, que foi submetida à análise temática.

Resultados: Os pais participavam de cuidados rotineiros da criança, gerenciamento do tratamento medicamentoso, lazer, apoio ao binômio e atividades domésticas. Assumiam diferentes papéis nos cuidados dependendo da disponibilidade de tempo e da abertura materna para sua participação. Entre os casais separados houve afastamento dos pais nos cuidados, refletindo na saúde do filho.

Conclusão: A participação do pai no cuidado ao filho com doença crônica é fundamental, porém, ainda faz-se necessário um maior envolvimento deste nos cuidados.

Palavras-chave: Relações pai-filho. Criança. Adolescente. Doença crônica. Família.

RESUMEN

Objetivos: Analizar la percepción materna acerca del cuidado paterno con el niño y identificar cómo dicho cuidado es efectivado en acciones prácticas en el cuidado al niño / adolescente con enfermedad crónica en el cotidiano familiar.

Métodos: Estudio exploratorio descriptivo, cualitativo, realizado en el ambulatorio pediátrico de un hospital público de Paraíba, entre noviembre/2013 y abril/2014, con 10 madres cuyos hijos tenían más de seis meses de diagnóstico. Entrevista semiestructurada subsidió la recolección de datos, que fue sometida al análisis temático.

Resultados: Los padres participaban de actividades como: cuidados rutinarios del niño, administración del tratamiento medicamentoso, ocio, apoyo al binomio, y actividades domésticas. Asumían distintos papeles en los cuidados dependiendo de la disponibilidad de tiempo y de la apertura materna para su participación. Entre las parejas separadas hubo alejamiento de los padres en los cuidados, reflejando en la salud del hijo.

Conclusión: Es importante la participación de los padres en el cuidado del hijo con enfermedad crónica. Sin embargo, aún hace falta un mayor involucramiento de éste en la realización del cuidado.

Palabras clave: Relaciones padre-hijo. Niño. Adolescente. Enfermedad crónica. Familia.

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■ INTRODUCTION

In everyday life, the family of children/adolescents with chronic disease plays an important role in preparing them for the future, teaching them to live with the limitations imposed by the disease and encouraging them to carry out activities that improve their independence in adult life⁽¹⁾.

Home care for chronic diseases in childhood and adolescence is still focused on a society with a labor division, whose man's main task is the financial provision and the protection of the family, and the woman's mission is to generate and promote daily care for the child, besides the obligation to administer the activities of the domestic routine⁽²⁾. In recent studies⁽³⁻⁴⁾ the men interviewed corroborated this information when they reported that, for economic reasons, they could not participate in the day-to-day practice of their children. Thus, in most cases, the mother assumes the role of the primary caregiver and has the father as her ally in the process of coping and treating the child with chronic disease⁽⁵⁾. This scenario has been gradually changing due to a new role of women in society, which requires, together with man, the division of the function of family provision and of the domestic activities and care for the children⁽⁶⁾.

Due to this new configuration of roles in the family, the inclusion of the father in the care is essential for the treatment of the child with chronic disease, since this has several implications in the life of the child/adolescent and their family⁽⁷⁻⁸⁾.

Thus, it is believed that studying the dimension of the paternal care to the child/adolescent with chronic disease from the perspective of the maternal figure, the main provider of child care, could guide directions for the health team and, especially, for Nursing, regarding the instrumentalisation of families for coping with chronic childhood and juvenile disease and healthcare. The relevance of the research is in the valuation of the subjective dimension that can intermediate the care relations between the nurse, the family and the child or adolescent.

In view of the above, it has been questioned: For mothers, how does the paternal care for the child/adolescent with chronic disease occur? What is the importance of this care for her and for the child/adolescent? Therefore, the objective was to analyze the maternal perception about the paternal care and to identify how this care is configured in practical actions in the care of the child and adolescent with chronic disease in the family routine.

■ METHODOLOGY

An exploratory-descriptive study, with qualitative approach, developed in the pediatric outpatient clinic

of a public hospital located in the city of João Pessoa, Paraíba. The participants of the research were 10 mothers of children and adolescents with chronic diseases who were accompanying their children in the waiting for the outpatient appointment, in the period of November 2013 to April 2014. The selection had the following inclusion criteria: to be a mother of a child or adolescent with chronic disease under medical supervision in the outpatient clinic of the study service during the period of data collection, and to have been diagnosed with chronic disease for at least six months in order to have had enough time to experience the different phases of the chronic disease and the implications imposed by it. As exclusion criteria, we established: mothers with communication deficits who could not understand and/or respond to interview questions.

The data has been collected through a semi-structured interview, recorded in a digital medium, guided by the questions: "How does the father participate in child/adolescent care?" And "How important is the paternal care to the child/adolescent?". The closure of the collection has occurred through the theoretical saturation, when it had been evidenced that the quantity and the quality of the information obtained was able to allow a deepening of the subject under study⁽⁹⁾.

For the interpretation of the data, the thematic analysis steps have been followed: the organization of the empirical material has been initially made from the interviews transcribed in full, with a horizontal map of the material and beginning a classification of the stories; subsequently, an exhaustive and repetitive reading of the material has been carried out, making an interrogative relation between the reports for the definition of the sense nuclei; then, from the nuclei obtained, the reports have been grouped into thematic categories to perform the final analysis⁽⁹⁾. After this process, the following empirical category emerged: Paternal care for the child with chronic disease: repercussions for the mother and the child.

To comply with the ethical criteria, the recommendations of the Resolution No. 466/12 of the National Health Council have been followed. The project has been approved by the Ethics Committee of the hospital under study, with a favorable opinion (CAAE No. 0466.0.000.126-11/Protocol No. 083/2011). The participants signed the Free and Informed Consent Form in two copies, and have been guaranteed their anonymity in the presentation of the results, by their identification with the letter M, of mother, accompanied by the numeral relative to the order of accomplishment of the interviews.

■ RESULTS AND DISCUSSION

The participating mothers were between 31 and 45 years old, of which, five were married, four were single, and one was in a stable union. They had between 1 and 7 children and had monthly family income ranging from less than one to two minimum wages. As for schooling, one had incomplete elementary education, three incomplete high school, five completed high school, and one was postgraduate. Their children were between 1 and 13 years old and the medical diagnoses were: Congenital renal dysplasia (01); Bronchial asthma (02); Diabetes mellitus (02); Hemolytic anemia (01); Cystic Fibrosis (03) and Systemic Arterial Hypertension (01).

Paternal care to children with chronic disease: repercussions for the mother and the child

Not long ago, the responsibility for the child/adolescent healthcare was almost exclusive to the mother, however, nowadays, the father has become more involved in this care⁽¹⁰⁾. With the new characteristics of the family composition and the empowerment acquired by women in the society, men have assumed roles that were once exclusive to women and vice versa, such as the involvement in child care^(8,11).

Given the new position assumed by the father in the family^(6,11), the mothers report their participation in the care of the child with chronic disease, mainly in aspects related to sleep and rest, food, hygiene, leisure and some child/adolescent disease care activities.

[...] He [father] stays with him, puts him to sleep, plays with him (M01).

He helps with the medication, with the nebulization schedule [...] stays with the children, puts them to sleep [...] he cares more than I do (M06).

At home he recalls the time of his son's medication [...]. At night, if it starts to rain, he [father] takes care of the boy, he will cover him [son], see if it is not dripping in the room (M07).

Fathers who participate in the development of their children, becoming involved in care, take on a new role in the family environment that is called "participatory parenting", which is characterized by the involvement in the children's routine, in activities related to education, food, hygiene and leisure⁽²⁾.

Besides the participation in the care of any child/adolescent considered normal by the society, it is important

that the father can share with the mother the new routine imposed by the chronic disease, since the implications triggered by the infanto-juvenile disease bring an overload of care that may alter the daily life of the child/adolescent and their caregivers⁽⁸⁾. In this regard, in a study⁽⁴⁾ with parents of children with chronic diseases, the fathers have reported that the maternal overprotection, sometimes, interfered with paternity, when women did not trust men's ability to take care as well as they do. Corroborating this thinking, the mothers who participated in this study believe they are better prepared to care for their children.

Only with me, nothing with him. Mother is mother, we are always on top (M02).

Because the father does not have to be present all the time. But the mother I think that has more responsibility when it comes to embracing (M04).

The one who participates most in the care is me [...] I am the one who takes the lead of everything, he worries more when the medicines are over, but who really cares is me (M08).

Because the father does not have the ability, nor the obligation to perform certain care for the child, the mother puts herself above the father, assuming the responsibilities. Faced with this maternal posture, many fathers get used to the situation, not routinely collaborating with the care of the sick child/adolescent. This reality may show that the mother does not need help or support to care and/or cope with her children's disease. These mothers only accept parental support when they need to be absent:

He [father] only helped with medication; if it was necessary, then he would do it. I would go out and warn him: at this time is this, 'x' drops or pills [...] when he has doubts, he calls and asks (M02).

I advise, I say: "look, it's like this, you have to take this, 'x' drops," "help me clean it up here," "put a wet cloth on him" (M04).

It is understood that, because the father does not have an openness to participate in the daily care, the mother needs to guide him whenever she needs to be absent as a result of the father not knowing the demands of the child on a daily basis. Fatherhood is understood as a process of internalization of molded and reconstructed ideas, from instructions, incentives and cultural changes, going beyond

the biological condition^(3,12). Therefore, it is necessary the stimulation of the mothers to the fathers' participation in the care of the child, in order to expand the roles in the family nucleus, besides those culturally imposed by the society.

In this sense, we can observe the growth of a generation of men who are interested in learning how to perform household tasks, in addition to being more affectionately close to their children, sharing with the mother the daily care activities⁽¹¹⁾, as identified below:

He [father] cooks better than I do (M02).

Because when he [father] is at home, I do not even care. He wakes up, makes breakfast, gives food to the children... Sometimes I leave to work in the morning, and in the afternoon I'm not at home, so in the morning he organizes the children's lunch on time, he does everything (M06).

Although there is evidence of a greater participation of the fathers in the care of children/adolescents with chronic disease, when it refers to the accomplishment of household activities, these are not yet very present, as found in this study, in which only two fathers are participative. Often, due to the responsibility for the family financial support, men are forced to be away from home, not prioritizing the activities of the home and caring for their children, leading them to be inexperienced when performing these tasks⁽¹³⁾. Corroborating the findings, it has been observed in this study that the mother, when having a formal job, is supported by the father when the father offers more time to participate in these activities.

Another care of the paternal figure is the management of the child's treatment:

He [father] participates more by alerting, asking. "Did you make the insulin? Did you make the blood glucose?" He worries [...] he cares a lot about her treatment [daughter] (M03).

He [father] was involved, worried, he asked, "how is he [son]?", "Is he [son] behaving well?"; "Did he [son] eat anything?"; "Does he [son] have pain?" (M04).

My son takes many medications, sometimes the father does not know the name of all the remedies, so he [father] says: "The nine o'clock remedy has he [son] already taken it?"; "Son, do not go out in the sun"; "Son, put on the mask"; "Son, it's going to rain"; he [father] is always careful (M07).

When it comes to the family routine of a child/adolescent with chronic disease, it is necessary for parents

to be present in the care of the child/adolescent, in order to divide the necessary tasks in order to face the disease and to minimize the overloads generated by the care management⁽¹⁴⁾.

Some fathers do not participate in routine of care procedures, but they participate in being attentive and concerned about the child's health⁽²⁾, wanting to know everything that goes on regarding the new routine, through questioning the mothers regarding the child/adolescent care⁽¹⁴⁾. Most fathers have been very attentive to the child's health, and it is possible to observe in the speeches that, even if they do not take care directly, they follow the process up and, sometimes, they are present in it.

Regarding the care for the treatment of the disease, a child was reluctant to let the father perform certain procedures because the child trusted in the care provided by the mother.

She [child] has a resistance towards the father doing any procedure. He [father] does not do it because she does not like it [...] when he gets close to her, she says: "No, no, it's Mom, Mom already knows, Mom already knows!" There I say: "Let your father" and she says "no, no, no" (M03).

As the mother is always in touch with the child, the child feels safe in relation to her care, due to the confidence built up over time, which makes them distrust and create resistance when the father or anyone else tries to perform such procedures, since other people do not actively participate in this ritual in the daily life of this child.

Financial support is another form of paternal care identified in the speeches:

At that time he [father] was unemployed doing "chores" not to let anything miss for people in the house (M01).

He [father] participates in buying medicine (M02).

The father's role as a financial provider in meeting the needs of the family still seems to be the most common form of parental involvement⁽¹⁵⁾. The financial difficulty is a factor that influences the quality of care provided; because adequate medication, transportation and food are fundamental for a better quality of life of the child/adolescent with chronic disease. The financial support is often one of the overloads of child care, generating stress factors for the caregivers. The mother finds it difficult to stay in the labor market and, at the same time, to meet the needs of child/adolescent care. Then, in some cases, the provision of financial resources becomes the sole responsibility of the father⁽¹⁵⁾.

Because of the cultural position of the paternal role in the family, as a provider of financial resources and bureaucratic matters, the father does not identify as his the responsibility of caring for the child, but as a responsibility of the woman⁽⁶⁾. A study⁽³⁾ carried out with men who were fathers for the first time showed that, although they recognized the importance of their role in their children's lives, they also believed that the woman had a closer relationship with the children because of the physical experience of the pregnancy. In detriment of this lack of understanding about their position as a father, some mothers reported the passivity of men in assisting them in the new routine of care to the child/adolescent with chronic disease:

I called him because I had to come [to the doctor's office], [but] for him [father] to enter the doctor's office, he will not go in, I can call, but he has no initiative to go [...]. I always have to be in ahead of it (M02).

When she [the child] is asleep, I also check the blood glucose, then I take it and tell him: "Go, do it, she's sleeping, she can not see." Then he [father] goes there and does it (M03).

I have to say, "Come on, man, help me." He has no initiative, no (M04).

The lack of paternal initiative is a factor that potentiates the maternal overload. Many fathers become accommodated due to the position of leadership of mothers, thus, not having the initiative to care for their child. The father can and should have broad participation in the child's life⁽⁶⁾. It is possible to improve this aspect by inviting the fathers to participate in routine appointments, treatment and, whenever possible, making schedules more flexible for them to be present⁽¹⁶⁾.

The father also offers care to the child/adolescent with chronic disease by providing playful moments, such as playing:

His father [...] stays with him [son], plays, showers, goes to the pool, goes cycling (M01).

They play video game, watch television together, go horse-back riding (M04).

They [father and son] play soccer, go for a walk [...] are together at all times. At home they play video game, all together, they seem all kids (M06).

The father seeks to develop activities that provide the amusement for the child⁽¹¹⁾, which is both enjoyable and

brings a sense of normality to the family life. This is an extremely important type of care for the health of children and adolescents, especially those with chronic diseases, who tend to live with the exhaustive routine of healthcare services.

Fathers have sought information about paternity and its importance in order to act in the most appropriate way in child care⁽¹¹⁾, therefore, although the father, due to several factors, usually spends less time with the child/adolescent, it does not mean that he is less participatory, attentive or less affectionate than the mother⁽¹⁵⁾.

Regarding the father's attention and concern about the hospitalization process of the child, some authors have shown that the father contributes by offering emotional support to the mother, who normally accompanies the child during hospitalization, bringing more security so that she can play her role⁽⁸⁾, because she identifies in the father a source of support for coping with the treatment of the disease:

So he [father] could not stay to sleep, nor could stay all day long, but at the visit time he came, he called every day and he also had to give assistance to the other two who were at home (M01).

Because even though he [father] was not with me in the hospital, but his presence, his support, at least at home, calling, "Do you need money?" "Do you need me there?" It is valid, worrying is a lot (M04).

Although the father often does not participate as the primary caregiver or companion of the child during the hospitalization process, he is involved in performing the care by offering emotional support, attention and financial support⁽¹¹⁾. This type of support is fundamental for the psychological comfort of the mother, even though it does not alleviate the maternal overload, she knows that she can count on the support of her partner⁽¹⁴⁾.

As for the emotional aspects regarding the chronic disease of the child, the paternal figure, apparently, for the most part, is less fragile in the face of the implications imposed by the disease, being able to act more calmly when it comes to the necessary confrontation for living with the illness of a beloved one. A study⁽¹⁷⁾ shows that the father is able to offer emotional support to the mother regarding the child's disease, facing the difficulties of the new routine together. The couple must create a stable and embracing environment that can serve as a mutual support and to other family members⁽¹⁷⁾. The mothers of this study explained the importance of parental involvement in the family environment:

It is mainly love, patience... it is fundamental the participation of the father and the mother (M02).

The shared responsibility, because it gets too overwhelming [for the mother when she does not have the support of the father] (M03).

All the importance, because the father is the foundation of a house... it is not only a matter of care, it is love, brotherhood... the mother cannot replace the love of a father (M04).

The physical and affective presence of the father is important for both the mother and the child as he is seen as a source of home security⁽¹⁸⁾. The love of the father in relation to the family is essential and irreplaceable. In addition, father's accountability for day-to-day care with the mother reduces the burden on both.

In the mother's perception, the father's participation in child care is related to his daily workload:

It is because he works, he is at home mostly at night; when he needs, he does it (M02).

He saw that he had to help, but when it comes to bring us to the hospital, no, because he worked hard [...] could not come with me, I always came alone (M04).

She already stayed at the hospital, she spent six days with pneumonia and every day he went there, he was not there with her only because of his work (M05).

The mothers justified the smaller parental participation in the treatment outside the home due to the lack of time, because the workload makes it impossible for the father to accompany the child during the hospitalization process, making it difficult to even visit. One of the biggest problems regarding the child/adolescent with chronic disease is the financial expenses. Thus, the risk of job loss causes many fathers to be absent in the direct care of the child due to the exhaustive work routine⁽¹⁹⁾.

The mother recognizes that, in exceptional cases, such as an emergency situation in the child's health or situations in which she cannot be present, the father takes care of it.

To be present at an appointment only if it is emergency ... When it was an emergency that he [son] was very tired, we would go to the hospital soon, he [father] would come in with me, help, but from the routine appointments, he does not participate, no, we are never together (M02).

If I am not there and they are alone, he will do it (M03).

[...] I work, I come home late [...] he gives food, he takes care of the medication treatment, nebulization (M06).

The fear of losing the child or that the child has any complication due to the lack of care is what awakens in the father the need to take care of the child/adolescent with chronic disease. A study⁽¹⁰⁾ states that fathers make significant modifications to their routine to accompany the child, to provide home care in the absence of the mother, to be with the sick child in the hospital, what provides fathers with a closer relationship with their children. However, it has been observed that some fathers do not participate in the care of their children, especially in cases of marital separation. In these circumstances, the mother becomes the sole responsible for the care of the child with chronic disease, intensifying the maternal load:

He does not participate in anything, I am the father. (M09).

He has no part in anything, not at all. Neither financially nor emotionally does he care about anything. Neither in relation to school, health, food, medication... even while we lived together, he was not participatory either, it was all on me (M10).

The overload of the primary caregiver is potentiated when there is no one to share the daily assignments, since the routine visits of visiting doctors, hospitals and the need to ensure medication care, add to the factors that lead to stress, by triggering the absorption of the implications of the disease for herself/himself⁽⁵⁾. Thus, the mothers reported that they would like greater involvement of the fathers in care:

So when he gets hospitalized, for me, the father should come at least two or three times in the week, because I am the only one who stays with him [...] sometimes I complain to him [...] I've already spent 21 days; sometimes his grandmother came, but it is not the same thing. (M08).

I would like him to participate [...] Unless he was emotionally present, pick up the phone and call [...] It is a very large overload you take care of two boys alone (M10).

The father is part of the support network with the mother. It is in the family that the child/adolescent with chronic disease looks for to main a source of support for coping with the disease⁽¹⁴⁾. The paternal presence is important because it helps to build, along with the dedicated attention

of the mother, the basic fundamentals of the autonomy of the child/adolescent⁽²⁾.

While identifying the importance of paternal care to the child, the mothers reported how they would experience the chronic disease of their children and adolescents without the fathers' presence and participation.

I' would have found a way, but thank God, he's a father and a husband. (M02).

Lost, if I were without him (M04).

It would be difficult, very difficult [...] he helped me a lot and even today he helps me ... A blessing, I say he is a gift from God in my life (M06).

[...] If the father was not on my side I would not have been able to do it (M07).

It is possible to observe the important role that the father figure plays in the family, especially when the family is experiencing difficulties, having to cope with the adversities caused by the illness of a child.

Oh, they [father and son] are very much attached, besides the question of the treatment itself, she is very attached to him (M03).

They are two friends, more than father and son, they are very close friends, they are partners in everything (M04).

In the father and child relationship, the fathers have showed to be friends, doing activities for their child's enjoyment, which greatly appeals to the child/adolescent and increases the bond between them, making clear the emotional support provided by fatherhood⁽⁶⁾.

In view of the context identified in this study, it is evident the importance of nursing to support parents, orienting them to the reorganization of roles in the care of the child with chronic disease⁽¹⁸⁾. Family and child-centered nursing care will support parents in developing care strategies to prevent unnecessary overload and wear on the family unit, by contributing to the recognition of roles and co-responsibility of both in care, and meeting the demands of the family.

■ FINAL CONSIDERATIONS

The father participates in several forms of care for the child with chronic disease, mainly by being attentive and

concerned about the health of the child/adolescent. This activity occurs, most of the time, with the promotion of leisure activities, guaranteeing well-being and joy for the child. Even though they were identified as a minority, some fathers were very participative in the care of the child/adolescent, helping the mother not only with the treatment, but also in the domestic activities and daily life of the family. However, there are mothers who still want this greater help from their partners in the accomplishment of the activities of the home and which involve the care of the child/adolescent with chronic disease.

Regarding the father's participation, the importance of sharing responsibilities was evidenced so that the mothers feel more relieved and less burdened as to the responsibilities assumed towards the illness of the child.

Thus, the study brings as contributions to nursing and other health areas, in addition to teaching, research and extension, the need to value the identification of strategies that instrumentalize and stimulate fathers' participation in the care of the child with chronic disease. To that end, it is necessary to guide them in the correct performance of the procedures and the importance of involving the family members in the care delivery, in order to minimize the overload of the main caregiver. Nursing should identify the fragilities of the families and instrumentalize them so that they can get along with the child/adolescent with chronic disease to face the implications and demands of the condition, providing adequate support for the performance of the care.

The need for new research, through the paternal perception, in order to address the care of the child/adolescent with chronic disease with a focus on the difficulties found in the caring process is emphasized. The limitation of the study is related to the fact that it was performed in a single place, that is reference in the treatment of chronic child and juvenile disease.

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