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IMPLICATIONS OF CHRONIC CONDITION OF THE CHILD FOR ITS FAMILY

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ABSTRACT

Chronic illness in childhood alters the family dynamics. The objective was to understanding the implications of chronic condition of the child to its family. It is a qualitative study conducted in a pediatric unit of a public hospital in the municipality of João Pessoa, Paraíba, from December 2011 to March 2012, with seven mothers whose children had been diagnosed of chronic disease for over six months. It was used the semi-structured interview for collecting empirical material and thematic interpretation of analysis reports. In the results it is presented the category named implications of chronic condition, with three themes: The diagnosis moment and the beginning of the treatment; Alterations imposed by the chronic condition in the family daily routine; Family members' feelings while experiencing the chronic condition. The changes regarding the child's and family's routine cause pain and suffering, leading to a state of fatigue that can be minimized with the reorganization of the family dynamics, so, as to be adapted to the new reality. Care must be based on household demands, with the implementation of strategies qualified for facing the condition imposed by the chronic disease in the childhood, minimizing the impact of the disease and contributing to the family autonomy.

Keywords: Pediatric Nursing. Chronic Disease. Child. Family.

INTRODUCTION

The prevalence of chronic diseases in childhood and adolescence has been increasing since the 80s in the United States, being that, approximately, 14% of this population has a diagnosis of chronic illness and 9.6% have two or more(1). In Brazil, the Brazilian Institute of Geography and Statistics - IBGE(2) found that 29.8% of children and adolescents aged from zero to nineteen years old have at least one chronic disease. These data are representative and significant for the Brazilian public health, requiring a careful look at this population.

A chronic disease may lead to loss of stability of family life(3). Its main feature is its lengthy course and the fact often be incurable, becoming part by prolonged or indefinite period, the child's life(4). Chronic illness affects the entire family structure as it affects their members emotionally. Fight, battle and sacrifice represent the feelings of the families, how they perceive the moment living and above all, express the idea that suffering can extend over a long time(5).

Illness and chronic condition concepts are interrelated. Chronic disease is inherent to the child and involves biological changes that happen in its body. A chronic condition is broader and more complex, being related to the different situations that are experienced due to diagnosis and treatment, the biopsychosocial framework. Involves changes in daily life that children and their families face as a result of the disease(5,6).

The family is the closest to the child's social unit, of whom it is expected to receive support to face the difficulties. In such cases, family members feel responsible for minimizing the

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conditions that chronic illness imposes, seeking a more satisfactory growth and development possible. They need to learn to living with the disease, overcoming moments of crisis and adapt them trying to restore the balance of their dynamics(7).

The care of children with chronic illness in the family generates the need for social support, whether material, emotional, informational and / or affective(7).Thus, knowledge of family functioning and dynamics becomes important for care, because knowing the strategies adopted to tackle the chronic condition constitutes one of the important steps towards improving the quality of care(3). Identifying the demands of care, as well as joinning the social network that provides family support is essential to establishing a care in the singular, qualified and humanized health. This study aims to understanding the implications of the child's chronic condition for its family.

METHODOLOGY

This is a qualitative, exploratory, descriptive study, conducted from December 2011 to March 2012, in the pediatric clinic of a public hospital in the city of João Pessoa - Paraíba, reference to the treatment of chronic and rare diseases. The inclusion criteria for the subjects were: being a familiar companion of the child in the hospital during data collection; not have communication problems; be responsible for the child with chronic illness for more than six months, because after that time the family has experienced different stages of the disease. The data collection was conducted through semi-structured interviews(8), in the hospital, in a private environment, being recorded and transcribed in full for analysis. We used the criterion of sufficiency(8) for the closure of the collection. The participants were seven mothers. The guiding question of the interview was: “Can you talk about the changes that occurred in the life of the child and its family after the discovery of the disease?”

It was used the thematic analysis for interpretation of reports (8). After transcribing the interviews, there was the first organization of reports, starting a rating. Thus, we plotted the horizontal map of the material; subsequently, in light of the purpose, held exhaustive and repeated reading of texts by making an interrogative relation to grasp the structures of relevance. The procedure allowed us to elaborate rankings by cross-reading. From the structures of relevance, was indicted downsizing classification, grouping the most relevant topics. This process was constructed an empirical category: Implications of chronic condition. Of which three themes emerged: The time of diagnosis and initiation of treatment; Changes imposed by the chronic condition in daily family life; Feelings of family and the experience of chronic condition.

The study was developed in accordance with Resolution No. 466/12 of the National Health Council. The research project was approved by the Research Ethics Committee, under Protocol No. 083/2011. All participants signed a consent form, their reports were identified by the initial "F", accompanied by the corresponding numeral order of the interviews (F1… F7), ensuring anonymity.

RESULTS AND DISCUSSION

Family members who participated in the study were seven mothers whose children had the following diagnoses: Nephrotic Syndrome (two children); Congenital Dystrophic Epidermolysis Bullosa; Down syndrome, Cushing's syndrome; Severe persistent asthma, treatment refractory (chronic use of corticosteroids); Thrombocytopenic Purpura; leukemia; and chronic neuropathy. The setting time of diagnosis of chronic disease ranged from six months to five years. Only one of the families resides in the city of João Pessoa, the remainder being derived from the cities or the state. Four families survive with only one minimum wage monthly (then worth $ 622.00), three of which have as their sole source of fixed income sick pay. The other families have a monthly income ranging from two to eight times the minimum wage.

IMPLICATIONS OF CHRONIC CONDITION

The moment of diagnosis and the beginning of the treatment

Families who experience a chronic disease in childhood traverse a path that is related to their life history, their way of life, customs, values, financial condition and bonds established. At the time of establishment of diagnosis of chronic disease in children, family feel the need for an open, accessible, insightful questions of communication, since sometimes lack the knowledge of what is said. This can bring misunderstandings of the disease, which causes feelings difficult to be faced, such as shame and despair.

> The doctor broke the news; I didn't know the names, this disease, what it meant. Because she looked, looked at my babies and scared me, he said: "This boy is not supposed to be here, just like the others, this boy has Down Syndrome". [...] [The doctor] should have talked first and we have not spoken in the tone she spoke. [...] My roommates until ignored [...] the way the doctor broke the news. They said: "she should come to you and talk, explain, but the way she said, it's as if the child were contaminated." Ready, went into despair (F2).

Health professionals responsible for informing the family the diagnosis of a chronic disease, must demonstrate sensitivity to the suffering experienced. Thus, spaces need to promote listening, dialogue and clarification of doubts, being receptive and understanding expressed in the face of (9) and family demands that moment reactions. The family needs to receive information about the health status of children, diagnosis, treatment, prognosis and examinations to be performed(10).

The diagnosis definition of a chronic illness is a difficult time, so the family must feel welcomed and supported by the people who are on your side this time. It is important to provide a natural and humanized care, with actions that are significant to the family as living together, establish a relationship of trust and companionship, demonstrating readiness to help, offer words of love and comfort, provide information about the disease . Moreover, the act of stooping to listen to family can create space for listening to the emotional demands and expand the possibilities of the family leave be careful while seeking means to create autonomy in child care.

The mother undergoes an intense psychological distress upon learning of the child's illness and his alleged life of suffering that comes to think about the possibility of ending the life of the child and herself, as a way to escape the experienced situation. The mother asks why her son living with the disease, and not her. She would trade places with her son to spare him from suffering. In this context, crying, grief, sadness, despair, rejection, waiver and donation are the main feelings experienced.

> It crossed my mind playing it downstairs [motherhood] and I also [emotion]. [...] I was desperate, crying nonstop, didn't want to eat, not to get close to him. [...] After four months was that I got used to it (F2).
>
> It was very difficult; I cried a lot. God wanted to give me him like this. I have to accept (F6).
>
> I said: why God doesn't take me? Why didn't God put me in his place? (F5).

The diagnosis of a chronic illness is difficult news to be received by the family, and their reaction is expressed in suffering, because, when giving birth to a child emerge hopes and dreams for its future, which are interrupted by the new condition. Initiation of treatment is also permeated by anxiety and fear of the unknown, both the child and their caregiver. In this experience, the child is subjected to many invasive procedures, usually painful.

> I know I cried a lot, desperate, he was crying on the one hand, and I crying on the other. He was not used to, [...] they punched him all, for the exams (F4).

When a child develops a chronic illness, your life and family life undergo rapid and intense transformation. From one moment to the next she finds herself in a hospital, a strange environment, often hostile, surrounded by strangers, which will be subjected to tests and invasive and painful treatments, being away from your environment, family and friends. Regardless of their age and their cognitive ability to understand the reality that surrounds her, she somehow realizes that something serious is happening to him and fearful(11). In turn, the family lives with their children new experiences, whose reactions may vary according to the severity of the disease, the demands on its management and the amount of support available.

Changes imposed by chronic condition in everyday familiar

The duration of the chronic condition is reported as intense suffering, with changes in daily life, especially the primary caregiver of the child. This gets overloaded due to the availability required for activities related to childcare. This fact gets to be reported as a trauma whose only coping strategy is found religiosity.

> Has five years to come in this suffering, he suffers and so am I. [...] Don't leave home, I'm just with him. It's like a trauma that never ends. [...] Looked at him, I saw him suffering and couldn't do anything, just gave the God [crying] (F1).

> Who stays whith the child when it gets ill it’s me, here in hospital (F7).

In process of hospitalization of a child it is necessary to reorganize the family dynamics, so that one of its members, usually the mother, assume the monitoring and care of the sick child. This often implies in her having to forego the housework, turn your work routine and delay the implementation of its plans and commitments(3). Words such as isolation, trauma and suffering that were previously not part of the child caregiver vocabulary, become part of your daily life.

The family accompanying the child during hospitalization moves away from other children and reports this fact with concern, but believes that nothing bad will happen.

> His brother tires that goes into oxygen. If I'm here [hospital], but I'm worried about him too (F2).

> We think more on the minor [son], than in toddlerhood. I hope it all works out (F4).

Healthy children of the family of a child with chronic illness suffer with the reduction of attention and care that are directed to them; the mother reports that dedicate herself more intensively with the sick child during hospitalizations; as well as at home. Thus, she cannot afford to taking care of another child's health and worries about the situation, because she perceives that is excluding it.

> I take more care than the other [child]. Don't leave with any unknown person. [...] The other my older boy tires just like this. [...] She [a doctor] said that maybe he will need up to a surgery, then how am I going to take care of the older if I'm alone with this? (F2).

The family reorganizes to continue the child's treatment. Parents can not always give healthy children the attention they need or wish to receive. The lack of complete family in the home, which occurs during the child's hospitalization and the need to get under the care of other people, is perceived by his brother, as a situation of distress, difficult to be faced, so the nostalgia is present(12).

Tackling chronic condition is sacrificing and hard to be experienced. Often, the problems are related to transport to the completion of treatment, the physical environment of support homes and hospital. However, families find strength to continue fighting because their priority is the recovery of child health.

> We arrived yesterday, we went out to 08:00 of the night [...] and we arrived at 04:00 in the morning. We spent the night apart without sleep, and arrived [in Home support]. [...] I've been with this child, tired, I already live. [...] With a child, and comes in a car crowded, crowded. [...] It gets bored, all night without sleep, sit in a Chair and wait for the rest of the day, so that I could follow the fight. Because the person who has a sick child, have to go through everything, but it's not easy (F1).

> It’s not soft you spend the night apart without sleep, spend the night right up on that couch here [at the hospital] (F2).

The continued stay of a family caregiver during hospitalization is stressful, since you miss your family and your home, and is subjected to uncomfortable accommodations(13). It is important to reflect on the structural and administrative measures in the hospital context, so that actions that ensure comfort and privacy escort, seeking the positive impact that provide children are implemented(14).

There are numerous difficulties experienced, among which stand out the financial. Family resources are reduced and insufficient to the point of be situations where some families go hungry. A child needs a different diet, use of medications, trips to medical appointments and payment of such consultations, when they are in private institutions.

> Four years of suffering, through necessity, well say hunger. [...] Neither the milk he drank strong, was mostly water. [...] I didn't have a gain. [...] The money the school [bolsa família] others [sons], was to buy the milk. [...] And, his meds also were missing. [...] The buck him [illness], for himself, his food and the drugs are expensive. We

> need a lot at home. [...] Five people in a House, passes need even (F1).

> Had had no month of full purchases, because you had to have money for the trip and the query that is private (F3).

Spending to cope with the chronic condition are numerous, among them stands the carriage for carrying the child's treatment, which appears as a burden on the family budget(5). There are families who have only one source of income, and therefore undergo financial need. In a live grounded by dietary restrictions and comfort with debts that hinder the fulfillment of their needs, the family tries to survive.

It is noticed that the money received by the Bolsa Família, the healthy children program is used with the child who has the disease. This may raise concern for the mother because she is getting something out of the family to meet the unique needs of just one child(15).

It deserves attention of health professionals in relation to prejudice the child's illness, which often happens due to lack of knowledge. This attitude causes suffering to the child and his family, bringing as a result the insulation. Those who experience chronic condition needs to establish strong and enduring bonds in order to have qualified and continuous support in coping with the chronic condition.

> Others scoff at as if they were sick. Sometimes, arrive at home and have schism until taking water, because he thinks the disease takes [passes]. [...] Some help and others do what they do with us. [...] We're thinking about how people will react when they see [...] Why the hurt is great (F1).

Neighbors, friends or strangers can cause deep sadness when making biased comments or launch different perspectives on the child. Prejudice and disregard in relation to the situation of the disease are more fragile elements. Thus, it is evident that the family needs emotional support and guidance for coping and strengthening forward to these experiences(16). Health professionals can minimize the suffering of the family to offer information, demystifying the disease with the people of the community.

The production expanded and comprehensive health care is not easy to achieve, but it is real and possible when guided by dedication, desire for transformation, appropriate working conditions and time(6). This mode of organization of the work process embraces the demands of the family, because the host is not a space or place, but an ethical position that involves sharing of knowledge, creativity and anguish in the modes of care delivery(17). A welcoming practice is concerned with the suffering of others and requires establishing a relationship, accountability and problem solving. There are diseases triggered by a difficult and emotional situation for the family, dealing with the chronic illness of a child creates a psychological impact that needs to be careful.

Feelings of the relatives in living of chronic condition

Hope is always present in families experiencing chronic condition because the dream of seeing their children healthy accompanies them. For that seek God, trust in Him and deliver yet experienced in their hands. Believe that with the medicine, the cure will be achieved, restoring health to your child. This is the gift that the mother wants to receive.

> I have a lot of faith in God first, and in doctors. I think they are very good. [...] And who knows if doctors don't find the remedy for cure. Hope I have is this. [...] Is the greatest gift of my life, that they can give me is to find out what my son has (F1).

The families find, in the union of hope with faith, a great strength to withstand the difficult moments. Hope deposited in the future proved to be important for the maintenance of health care and also as a stimulus of life for all people who share the experience of illness(18).

Faith in God, it is often the only source that the family has the hope of a future with your child free of the disease. For her medicine already exhausted its possibilities of healing. The mother expressed her confidence in God and shows that the man has lost credibility because this fills him with doubts and uncertainties.

> He [doctor] said he had managed to do chemotherapy. This boy was to be [...] in intensive care. But they couldn't find parking space. After two days, appeared a vacancy, but he has improved. The other day he [doctor] said: "let him improve for us to start the new treatment". I said, Doctor, but you said you had no way! [...] Forget medicine, but for God nothing is

> impossible. When the doctor says there's no way, God says I am here (F5).

When scientific knowledge has no effective results or a good prognosis, spirituality provides the necessary strength to face the moment. While recognizing the importance of knowledge and multidisciplinary care, family searching in hopes his faith healing and development of children. It seeks to recover the child, whose limits of medicine are set. In the face of suffering, turn to spirituality to realize the precariousness of the elements of medicine(9).

The strong bond with God motivates the struggle for recovery. For families the science is not the only source of explanations of the reasons for what is happening. When the predictions are bad, spirituality encourages and produces hope or acceptance of the conditions imposed(19).

Family members believe in God and thank for the improvement in the health condition of their child, and feel good about any improvement achieved. Perform comparisons with the development of other children with special needs. This attitude can be seen as acceptance and family composition on the condition experienced.

> I see my son, in view of what was, well. Have these problems, I know it's not easy, but I am happy, lively, thanks to God, he says, he plays, and everything (F1).

> The person spends nine months with the child in her belly, we want to perfect. But I have to thank God, because he walks and is different from a lot of kids. Attend FUNAD and see much. I feel sorry for those kids (F2).

The conformism appears as a way to accept what you can not change, so the phase of overcoming arises, having faith as a background(9). Over time the family learns to live with chronic disease in children and the effects caused by it in their lives. Thus, begins to resign on the condition and gives continuity to life, emerging feelings that had ceased to exist, as the joy and cheer. The mental health care of the family is critical in this process and, therefore, important to maintain hope, desire and freedom in the choice and family reorganization for a less traumatic adaptation.

Chronic illness in childhood is related to some families, the various feelings that cause sorrow to the hearts of those who experience them. The pain was present in several reports presented in this study. However, you realize that you can live qualified way, even though a child diagnosed with a chronic illness in the family. For this, it is necessary to reorganize and establish ties with people that may be available to assist families in their real needs.

The health team, especially nursing professionals, who are in daily contact with the child and his family in the hospital environment, need to understand the implications of chronic condition and have sensitivity to realize that they, even without the need to care exteriorizem internally are calling for caution(20).

FINAL CONSIDERATIONS

The study showed implications those families experiencing from the definition of the diagnosis. At first there is much suffering upon receiving the diagnosis and early treatment are moments of sadness and despair, questions and misunderstandings. The donation and waiver are present, especially in the life of the primary caregiver, bringing change in their daily lives, as is fully dedicated to the care of the child. Healthy children also suffer; they feel excluded from the mother's care, which is dedicated to sick children. Transportation expenses for the completion of treatment, medicines, food and consultations, intensifying financial difficulty, moreover, the uncomfortable physical environment of support homes and the hospital makes the everyday more sacrificing family. Also experience prejudice people known about the disease.

Over time the family acquires forces and shall adapt to changes and sufferings in order to accept the chronic condition. To minimize distress, it is necessary to reorganize the family dynamics and adapt to this new reality. The knowledge of the implications of chronic condition provides subsidies for health professionals, especially nursing staff, can base their practice on the demands made by these families and implement strategies for qualified care.

The research development happened in just a scenario, which prevents the generalization of findings. Note however that the results of this study open up possibilities for the development of other research that contributes to the development of strategies for health education in order to provide autonomy to the family and conditions confronting chronic disease in childhood, passing through the exchange of experiences in order to discover, together with families, appropriate paths in the care process.

IMPLICAÇÕES DA CONDIÇÃO CRÔNICA DA CRIANÇA PARA SUA FAMÍLIA

RESUMO

A doença crônica na infância altera a dinâmica da família. Objetivou-se compreender as implicações da condição crônica da criança para a sua família. Estudo qualitativo realizado na clínica pediátrica de um hospital público da cidade de João Pessoa, Paraíba, no período de Dezembro de 2011 a Março de 2012, com sete mães que acompanhavam seus filhos com diagnóstico de doença crônica há mais de seis meses. Utilizou-se a entrevista semiestruturada para coleta do material empírico e a interpretação temática para análise dos relatos. Nos resultados apresenta-se a categoria Implicações da condição crônica, com três temáticas: O momento do diagnóstico e o início do tratamento; Alterações impostas pela condição crônica no cotidiano familiar; Sentimentos dos familiares na vivência da condição crônica. As modificações na rotina da criança e sua família geram dor e sofrimento levando a um desgaste que pode ser minimizado com uma reorganização na dinâmica familiar, adaptando-se à nova realidade. O cuidado deve fundamentar-se nas demandas das famílias, com a implementação de estratégias qualificadas para o enfrentamento da condição imposta pela doença crônica na infância, minimizando seu impacto e contribuindo para a autonomia familiar.

Palavras-chave: Enfermagem Pediátrica. Doença Crônica. Criança. Família.

IMPLICACIONES DE LA CONDICIÓN CRÓNICA DEL NIÑO PARA SU FAMILIA

RESUMEN

La enfermedad crónica en la infancia cambia la dinámica de la familia. Este estudio tuvo el objetivo de comprender las implicaciones de la condición crónica del niño para su familia. Estudio cualitativo realizado en la clínica pediátrica de un hospital público de la ciudad de Joaõ Pessoa-Paraíba, en el período de diciembre de 2011 a marzo de 2012, con siete madres que acompañaban a sus hijos con diagnóstico de enfermedad crónica hace más de seis meses. Se utilizó la entrevista semiestructurada para recogida del material empírico y la interpretación temática para el análisis de los relatos. En los resultados se presenta la categoría Implicaciones de la condición crónica, con tres temáticas: El momento del diagnóstico y el inicio del tratamiento; Alteraciones impuestas por la condición crónica en el cotidiano familiar; y Sentimientos de los familiares en la vivencia de la condición crónica. Los cambios en la rutina del niño y su familia generan dolor y sufrimiento, llevando a un desgaste que puede ser minimizado con una reorganización en la dinámica familiar, adaptándose a la nueva realidad. La atención debe basarse en las demandas de las familias, con la implementación de estrategias calificadas para el enfrentamiento de la condición impuesta por la enfermedad crónica en la niñez, disminuyendo su impacto y contribuyendo para la autonomía familiar.

Palabras clave: Enfermería Pediátrica. Enfermedad Crónica. Niño. Familia.

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