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THE EXPERIENCE OF FAMILIES OF CHILDREN WITH CEREBRAL PALSY: MEANINGS AND CHALLENGES OF CARE

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ABSTRACT

The purpose of this paper was that of becoming aware of the experience of the family in caring for children with cerebral palsy. A quantitative research study was carried out in 2014, with nine members of families of children hospitalised in a Paediatrics Unit. The data was collected through a semistructured interview, and the date was then sent on for analysis of content, resulting in the creation of two broad categories thus: Challenges of the experience of learning how to care, and the experience of interpreting the signals emitted by the child. The results show the meanings of protagonist mothers within the experience of caring for their children, permeated with challenges in learning how to care, in interpretation of physical and emotional needs, in the difficulties in getting support from the father or from family members for childcare, and verbal communication, as the child does not speak. Here we have confirmed the importance of health professionals providing the families with more information and clarifications about the illness and its treatment, so the families may be qualified to continue with the care as required and needed by the children, with safety and autonomy.

Keywords: Child Care. Caregivers. Nursing. Family..

INTRODUCTION

Cerebral palsy (CP), or non-progressive chronic encephalopathy is a well-recognised health disorder involving a change in the development of the child’s motor and neurological systems, and which shows itself in early infancy, usually before 18 years of age(1). In developed countries, prevalence has a variation of between 1.5 and 2.5 per 1,000 live births. In Brazil, we estimate that there are between 30,000 and 40,000 new cases every year(2). CP is a chronic and incapacitating disease bringing different degrees of dependence, which therefore brings in its wake a need for constant care by the family. In addition, it is the main cause of serious physical impairment involving children(3).

Among causes related to the onset of CP, premature birth and adverse events during labour are the main features responsible for the malformation of the baby or damage to the baby’s brain, bringing functional limitations, which interfere with the child’s motor activities, intellect, and behaviour, within the child’s daily routine, in aspects such as self-care, hygiene, social interaction and learning(4).

The general clinical situation of children with CP, and their degree of motor malfunction, varies tremendously. These children need care for a long time, which has an impact on the general context and quality of family life, especially in the case of mothers who are usually the main carers of their children. Assistance with daily activities, general care, schooling, and socialization of their children require constant changes through the years(5), also requiring a reorganisation of the lifestyle of all those involved(6).

The family starts organising its activities based on what is permitted by the child’s condition. It is quite common to reorganise time, redefine personal goals and targets, as also professional objectives and even financial resources, based on child care, and the child could become the centre of special attention in the home, making it necessary to have a process of

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readaptation in the structure and operation of the family unit(3).

The child's limitations, brought about by CP and by the child's frail health, tend to place an excessive burden on the parents, who need to tackle the challenge of efficiently taking care of their child and conciliate this task with the requirements of daily family life. In this process, they can experience some moments of insecurity, and care could even be inefficient at the outset. However, as time goes by, they can adapt, becoming in line with this new situation(7).

In this context, care is understood as a way of life, a way of being, and a way of expressing oneself with ethics, in relation to the world, through a firm commitment to contribute to others' well-being. It is through caring that we seek encouragement of the freedom and autonomy of those involved(8), and in this regard the Family exercises care by encouraging the process of growth and development of the child, thereby favouring recovery and also autonomy to take care of the child.

Some families face the challenge posed by adversities in a way as positive as possible, while others face greater difficulties and do not manage to organise themselves(9), as the degree of dependency of the child requires full-time attention. Therefore, carers who are also family members also become people with special needs, and often need help on how to deal with the problem, in order to tackle the adversity resulting from the disease(10).

However, the effective participation of the Family is important, so that the child with CP may attain healthy development; this because the family is responsible for the care of the child, as also general physical, emotional, social and assistential well-being(11). This care goes well beyond the senses and meanings as given by the child and the family to each situation that they have experienced throughout their existence(3).

This situation extends beyond a merely existential connotation for care, as the concept of care is also taken as encompassing an act of relational care. This means care between self and others, and also aimed at other people, involving availability, intentionality and trust(8).

In the light of the diversity of situations and experiences of families when taking care of children with CP, their heterogeneity and also the complex inter-relations between the factors involved and also the challenges posed to children and their families, and also to the professional staff, health services, and educational services, justifies the present study with the intention of answering the following question: how are the experiences of family members caring for children with cerebral palsy? Based on this question, our main aim is that of getting to know the experiences of the family members when caring for children with cerebral palsy.

METHODOLOGY

The methodology used was that of a qualitative study, carried out at the Paediatrics Unit at a University Hospital in a municipality of the southern tip of the Brazilian state of Rio Grande do Sul. The participants in the research study were nine carers of children diagnosed with CP who met the following criteria for inclusion: be the main family member caring for the child; be aged 18 or over; and provision of direct home care to the child. There was the exclusion of carers who, even though they were present during the hospitalization of the child, did not actually provide the child with care.

The carers were contacted in the paediatrics ward itself, while the child was hospitalised. The invitation was made personally to the family members, by the researcher herself, explaining the goals of the study, the methodology used, and the way in which the data would be collected. The data was collected between August and September 2014, in a room adjacent to the paediatrics unit, with the use of semistructured interviews, each being 40 minutes long on average. The respondents were asked about their experiences with care for the child.

The data was analysed using a process of analysis of content(12). This analysis comprises three stages. In the stage of pre-analysis, there is the floating reading and also the hypotheses are drawn up. The second stage involves the exploitation of the materials with the encoding of the data and classification in categories. The last phase includes the treatment of the results obtained, inference, interpretation and further considerations. The categories are subjected to discussion by specialized authors who have studied these issues.

The ethical aspects of research involving human subjects have been respected, in line with the terms of Resolution No. 466/12. The anonymity of the participants has been assured, and their utterances have been identified in the text by the use of the letter F followed by the number corresponding to the interview. The research study was approved by the

Health Area Research Ethics Committee, in favourable statements No. 108/2014 and CAAE 33017714.9.0000.5324. The collection of data got under way after the participants signed the Informed Consent Form (ICF).

RESULTS AND DISCUSSION

The study had the participation of nine family carers, all of whom were mothers of children with CP. Their ages ranged from 23 to 35. Five did not complete their elementary education, two did not finish secondary school, and two were secondary school graduates. Regarding their professions, seven were homemakers, one seamstress and one shop attendant. Turning now to family income: one did not say, one earns half a Brazilian national minimum wage (salário mínimo, or SM); two earn one SM, two earn between two and three SM, and two earn between four and five SM. Seven live in stone houses, one in a house of wooden construction, and one in a mixed house. In each household there are between three and seven people, thus: two cases of three residents in the house; four of four, two of five, and one of seven.

With regard to children with Cerebral Palsy (CP), five are boys and four are girls. Their ages range between six months and eight years. Five were diagnosed with CP at birth; one at three months, one at nine months, and two at 18 months. All the children had been hospitalised on several occasions since birth, at least once a year. All the children had delayed neuropsychomotor development, and made use of anticonvulsant drugs. Three attend a special infant school, and the others stay at home with their families, not carrying out any kind of activities outside the home.

The findings suggest that the mothers are the main carers of their children with CP. The analysis of data generated the following categories: Challenges in the experience of learning how to care, and The experience of interpreting the child's signals, in order to care.

Challenges in the experience of learning how to care

With regard to the experience in the first acts of caring for the child, we noticed that the mothers felt challenged by their child's poor health conditions, which requires that the mothers learn skills to deal with the needs shown by CP. Being close to the health team, observance of their activities, and paying attention to their guidance: these factors were essential so that they could get to know situations involving the universe of health care that their children need.

The mothers also mentioned that the start of the learning process is beset with difficulties; however, with the help of health professionals, the guidance was gradually absorbed and practiced, and the process of acquisition of knowledge in preparation for care started to be addressed by them.

> It was, you know, sort of by surprise, over hedge and ditch. It was very difficult at the beginning. (F7)

> It was difficult to start with. I didn't even know what to do, to be honest. Then, as time went by, and helped by doctors and the rest of the team that helped us, and gave us preparation by showing us what to do and what not to do. (F5)

> We are still being trained. This training started when he was still in Intensive Care. (F6)

> When I went to the neurologist for the first time, he gave me an explanation about what I wanted to know, as I knew nothing about the disease. We would see children like this, but as I never paid attention to the details [...] the neurologist told me: "Mum, it's going to be like this, and you are going to need a lot of patience. (F9)

For some mothers, taking care of a child with special health needs, as is the case of CP, generates fear and anxiety, mainly due to the little that is known about the disease, as also about its treatment and unexpected situations; they deal with major challenges to overcome lack of preparation to cope with the child's changes, over time learning to coexist with the health problem, with feelings of insecurity, and suspicion(13).

In the narratives on the process of preparation to care for a child with CP, we see that the health team is the initial support that provides care while also teaching the family to provide care. For the family of the child with need for constant care, and the support of the health professional, there is a need for the presence of more information about the disease and adaptation to the specific needs of the family involved in the care(14).

For some mothers, the fact that they are not prepared to take care of their children also helped to generate anxiety; they report caring in their own way and learning through daily experience in caring. This aspect could be linked to the difficulty in the assimilation of the information and guidance that has been passed on by the health team, or the absence thereof.

> [...] I had no preparation at all. That is what happened: on the first day I got very anxious at shower time, as this is the first time I have coexisted with a child like this. (F3)

> Nobody explained anything to me. [...] In fact, an explanation was given, but I forget many things. I take care of the child in my own way. (F8)

> “We learnt each thing at the right moment. There was no initial preparation of any kind. It was daily practice that made me learn everything I know today, to be able to take care of him”. (F1)

The narratives show that some information supplied by the members of the health team have not been well understood by the mothers, while on other occasions the guidance may not have been given at the appropriate time during hospitalisation. The expression of difficulties experienced by the mothers should be understood by the health professionals and also generate facilitator processes during the family’s experience with the disease, both for the carer himself or herself, as also for the health team, that should get the family involved in situations of learning, to care for the child with CP(14).

Another challenge refers to the centrality of care in the maternal figure, and this is proved by the significant presence of mothers at the hospital, as carers of children with CP. Some mothers participating in the study, in fact, said that they are responsible for the entire process of caring for the child, also mentioning the difficulties found by the family to contribute towards childcare.

> [...]Look, the preparation was more on my part, than of the child’s own father. (F4)

> His father does not help at all, and does not even offer to. He could easily help, or say: - I shall pay for someone to come over to help out. And then we have the trips […] he comes here and goes there. What maid would be willing to travel? Someone to help out would be good. Sometimes, you need to get out and see things, arrange his medications, go to the Courts, here or there. I go out, and my sisters call me within the space of five minutes: - Will you be long? Are you going to be long? They do not let you have any time to yourself. I haven’t even arrived at where I am going. It is very difficult. (F5)

> I get home, and I ask if anything happened to him: no, nothing, but then I look at the pillow, and at his bed, and the secretion is there. He takes his food with chocolate, and when he coughs he throws something out. Then I know he coughed, as the sheet gets stained. Then he says he did not cough. So, I am very much afraid. It is terrifying. What person shall be here, in hospital? And who will be here, taking care of him? (F2)

Among the needs of children with CP, we have daily physical care, hygiene, urination and defecation, feeding, administration of medication, positioning, comfort and other eventual elements, such as trips for doctor’s appointments, therapy, and requests for benefits. The narrative suggest that the mothers say they fully take on such assigned responsibilities, but still feel lack of support from their partners and other people in the family, to share this responsibility.

Taking care of someone means a need for intimacy, sheltering and assignment of importance. Even so, there may be resistance and complexities within the act of caring, especially when this brings a change in the family dynamics, with a negative repercussion on the life of the main carer of the child(15). Some mothers feel overloaded by the routine of care and also by the lack of trust in other people who could make sure of the quality of the care that the child needs.

The daily lives of these mothers are transformed as soon as they take over full-time care of their children, without the help of other people. Indeed, many give up part of their social lives to be able to give exclusive dedication to their children. Therefore, the mothers take on a high probability of physical exhaustion, as also emotional and marital fatigue(11,15,16).

Another situation that is tricky to handle has been the harm caused to the health of the child, dependent on mechanical ventilation. The mother reports a feeling of desperation with regard to the possibility of rehabilitation that could make it feasible for the child to return home. In some cases, even with the efforts made by the family in favour of the physical care of the child, the permanence in the hospital environment ensures the necessary advanced life support.

> “For us, this is most difficult, as when we think that he is making progress, and that there is a hope of returning home, everything comes back again. There is some little problem, and he needs the breathing machine once again. It is just as if everything started from scratch”. (F6)

In those moments when the illness gets worse, when mothers, fathers and other family members sit helpless, faced with the deterioration in their children’s health, the lack of mechanisms to tackle, to deal with the situation, could lead to an experience marked by a significant physical and mental imbalance(17).

The experience of interpreting signals emitted by the child

For the mothers, the experience in interpretation of the signals issued by the child is related to the ability to identify the universe of needs that permeate the daily childcare routine. Considering the difficulty shown by the child in making verbal communication, the mothers learn to interpret their needs, trying to recognise what each expression of the child in fact represents; however, in some situations they show difficulty in knowing what to do.

> "There are some occasions when we do not know what to do. There are times where he gets so nervous, and we do not know what he has. If he has pain, or if not. We see if he has a fever, measure his blood glucose, five hundred other things, and is nothing like what we had imagined". (F1)

> "When I adopted him, he didn't even know how to cry, just tears. In addition, he was unable to smile [...] the first time he cried was when he had tummy ache, and I understood what he was feeling". (F7)

The family and the child develop strategies, based on interaction, that extend beyond the meaning of the words, for the construction of effective communication(18). The interaction between mothers and children with CP extends over the plane of physical communication, and the mother seeks other options to assign meanings to the feelings and desires that the child shows through the body language he transmits.

Through the oromotor changes present in the child with CP, the child makes use of non-verbal or psychobiological communication, which consists of gestures and of body and facial expressions, representing a way of transmitting their messages. The children communicate as according to their cognitive, sensorial and motor power; they can direct their vision or the part of the body that has better control and emits sounds, establishing different means of communication. Based on coexistence with the child, the family learns and understands the communication process, and then communication gets stronger, as there is closer interaction between child and family(16).

Some mothers also report on the consideration of the time frame as necessary for the understanding of the limits and potential of the child, making every effort to offer the best to their children, including specialized care for rehabilitation, and thus not placing any limit on the search, through guaranteed physical and emotional well-being for the child.

> "Ah, she has her own time, which we respect." Everything is controlled, like this. "Things went on, and improved [...]". (F2)

> "[...] Things are calmer now [...] as this is our first daughter and she was born with this condition, I have already got used to it. I don't see any problem". (F8)

> "[...], for example, if you come here and say that she needs something, I'll go right after her and I'll manage it". (F5)

> "We have talked a lot, sat and chatted, and then started to seek information and see how the treatment is". (F4)

> "I travel nearly 300 km every week. I leave the city of Rio Grande every Thursday for an appointment in Bagé. As I see it, I am doing my part. [...]". (F1)

The mothers spoke of their experiences, in search of guidance and information about the children's illness, and about how they could continue to offer the necessary support. Some mentioned the need to travel to another town to be able to get specialised support services. As time went by, and with the constant appraisals of health professionals, they seek treatment that promotes precocious motor and sensitive stimulation in their children, which could bring positive results in postural control and progressive improvements in the walking function(19, 20).

The mother's experience shows, in her speech, that there are no bounds when seeking the best for your child. Her attitudes when faced with the needs enforced by conditions of living with the child, characterised by a chronic disease, show absolute dedication, to do everything that is available, in order to give her child a future with better expectations.

> As I see it, I am doing my part. If tomorrow, or afterwards, I am making a mistake somewhere along the line, my child shall tell me. My child shall come to me and say: Oh, Mum, you are wrong there, you didn't take care of me. I think you are doing your best, and going that extra mile. I am doing my part. Let's see. (F1)

The experience in the interpretation of signals given by the children involved the identification of the difficulties they faced. The perseverant mothers sought to meet their needs, while respecting their own time, understanding their limitations, stimulating their potential and making every effort to ensure they have secure affection, well-being, growth, and development.

FINAL CONSIDERATIONS

The experiences of the family in caring for children with CP have been unique and challenging, and occurred exclusively through the mother; each one felt and faced adversities, and overcame difficulties, in a different manner. After all, the preparation for caring does not occur in advance, as no couple expects a baby with physical and cognitive challenges.

The families faced the challenges of caring for a child with CP, meaning that they needed to learn skills to meet the needs that CP shows. The mothers reported that the start of the learning process is beset with difficulties; however, with help from health professionals, the guidance was understood and put into practice. For some mothers, the fact that they were not prepared to care for their children helped to generate anxiety; they mentioned that they provided care in their own way and learnt through daily childcare activities. This aspect could be linked to difficulties in the assimilation of information and guidance passed on by the health team or the absence thereof. In addition, they develop the ability to interpret the signals emitted by the child, to identify the child's needs, this in the light of the child's difficulty in verbal communication.

Health professionals, especially those of the nursing field, need to consider the gaps that exist in the general guidance and preparation of families with regard to dealing with children with cerebral palsy (CP). It is also important that the team is able to transmit information and provide any relevant qualifications about the illness and the treatment with a view to programming actions that could meet their needs, and so these could continue with the care as required by the children, with security and autonomy.

As one of the gaps in this research, we mention the lack of interviews with health professionals, to identify just how these proceed with giving the mothers guidance regarding care of the child after being discharged from hospital.

A EXPERIÊNCIA DA FAMÍLIA DE CRIANÇAS COM PARALISIA CEREBRAL: SIGNIFICADOS E DESAFIOS DO CUIDADO

RESUMO

Objetivou-se conhecer a experiência da família no cuidado da criança com paralisia cerebral. Realizou-se uma pesquisa qualitativa no segundo semestre de 2014 com nove familiares de crianças internadas em uma Unidade de Pediatria. A coleta de dados foi realizada por meio de entrevista semiestruturada e os dados submetidos à análise de conteúdo, o que resultou na elaboração das categorias: Desafios na experiência do aprender a cuidar e A experiência de interpretar os sinais emitidos pela criança. Os resultados expressam os significados de mães protagonistas na experiência de cuidar do filho, permeada de desafios no aprender a cuidar, no interpretar as necessidades físicas e emocionais, nas dificuldades de receber apoio do pai ou familiares para o cuidado e na comunicação verbal pela ausência da fala da criança. Verificou-se a importância de os profissionais de saúde transmitirem às famílias informações e esclarecimentos pertinentes acerca da doença e do tratamento, capacitando-as a dar continuidade aos cuidados demandados pelas crianças com segurança e autonomia.

Palavras-chave: Cuidado da criança. Cuidadores. Enfermagem. Família.

LA EXPERIENCIA DE LA FAMILIA DE NIÑOS CON PARÁLISIS CEREBRAL: SIGNIFICADOS Y DESAFÍOS DEL CUIDADO

RESUMEN

Este estudio tuvo el objetivo de conocer la experiencia de la familia en el cuidado al niño con parálisis cerebral. Se realizó una investigación cualitativa en el segundo semestre de 2014 con nueve familiares de niños ingresados en una Unidad de Pediatría. La recolección de datos fue realizada por medio de entrevista semiestructurada y los datos sometidos al análisis de contenido, resultando en la elaboración de las categorías: Desafíos en la experiencia del aprender a cuidar; y La experiencia de interpretar las señales emitidas por el niño. Los resultados expresan los significados de madres protagonistas en la experiencia de cuidar al hijo, llena de desafíos en el aprender a cuidar, interpretar las necesidades físicas y emocionales, en las dificultades de recibir apoyo del padre o familiares para el cuidado y en la comunicación verbal por la ausencia del habla del niño. Se verificó la importancia de que los profesionales de salud transmitan a las familias informaciones y aclaraciones pertinentes acerca de la enfermedad y del tratamiento capacitándolas a dar continuidad a los cuidados exigidos por los niños, con seguridad y autonomía.

Palabras clave: Cuidado al niño. Cuidadores. Enfermería. Familia.

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