



ORIGINALES

The Mother-caregiver of child/teenager with Cerebral Palsy: Taking care of herself

Mãe-cuidadora de criança/adolescente com Paralisia Cerebral: O cuidar de si

Madre-cuidadora de niño/adolescente con parálisis cerebral: El cuidado de sí misma

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ABSTRACT:

The care for oneself allows the person to add the various stages of life in a healthy way in the physical, emotional and spiritual aspects.

Objective: To understand how the woman-mother of child/teenager with Cerebral Palsy takes care of herself.

Method: A qualitative study with a phenomenological-hermeneutical approach held in the Association of Parents and Friends of Exceptional Children in a municipality located in the south of Rio Grande do Sul, Brazil, with ten mothers/caregivers of children/adolescents with cerebral palsy, between April and June 2015. For the collection of information there was used the participant observation and phenomenological interview, the interpretation by means of the hermeneutical approach. With regard to ethical considerations, the research was approved by the Ethics Committee of the Medical School of the Federal University of Pelotas, Opinion N 1,001,573. It was also presented, read and delivered the word of Informed Consent Form (ICF).

Results: The care for herself the woman-mother is tied to the care for the child/adolescent. It refers to taking care of herself, sometimes means taking care of the health, which may be related to the treatment of beauty, mention yet, not taking self-care unless at the time of the shower, and, even so, the son is next.

Conclusion: The study brings contributions to the practice of nurse to subsidize strategies for these women of taking care of themselves, to assist them in the process of adaptation to the new situation and in the process of taking care of the child.

Keywords: Care; Mother; Cerebral Palsy; Children with Special Needs; Nursing

RESUMO:

O cuidar de si possibilita a pessoa integrar as várias fases da vida de maneira saudável nos aspectos físicos, emocionais e espirituais.

Objetivo: Compreender como a mulher-mãe de criança/adolescente com Paralisia Cerebral cuida de si.

Método: Estudo qualitativo, com abordagem fenomenológica/hermenêutica, realizado na Associação de Pais e Amigos dos Excepcionais em um município ao sul do Rio Grande do Sul/Brasil, com dez mães/cuidadoras de crianças/adolescentes com paralisia cerebral, entre abril e junho de 2015. Para a coleta de informações utilizou-se observação participante e entrevista fenomenológica, a interpretação por meio da abordagem hermenêutica. Quanto às considerações éticas, a pesquisa foi aprovada pelo Comitê de Ética em Pesquisa da Faculdade de Medicina da Universidade Federal de Pelotas, Parecer nº 1.001.573. Também foi apresentado, lido e entregue o termo de Consentimento Livre e Esclarecido (TCLE).

Resultados: O cuidar de si da mulher-mãe está atrelado ao cuidado da criança/adolescente. Refere que cuidar de si, por vezes, significa cuidar da saúde, podendo estar relacionado ao tratamento da beleza, menciona ainda, não ter cuidado consigo a não ser no momento do banho, e, mesmo assim o filho está junto.

Conclusão: O estudo traz contribuições à prática da enfermeira ao subsidiar estratégias capazes de facilitar a estas mulheres o cuidar de si, ao auxiliá-las no processo de adaptação à nova situação e no processo de cuidar a criança/adolescente.

Palavras chave: Cuidado; Mãe; Paralisia Cerebral; Criança com Necessidades Especiais; Enfermagem

RESUMEN:

El cuidado de sí mismo permite a la persona integrar las diversas etapas de la vida de una manera saludable en los aspectos físicos, emocionales y espirituales.

Objetivo: Comprender cómo la mujer-madre de niño/adolescente con Parálisis Cerebral toma el cuidado de sí misma.

Método: Un estudio cualitativo con un enfoque fenomenológico/hermenéutico celebrado en la Asociación de Padres y Amigos de niños excepcionales en un municipio del sur del estado de Rio Grande do Sul/Brasil, con diez de las madres/cuidadoras de niños y adolescentes con parálisis cerebral, entre abril y junio de 2015. Para la recogida de información se utilizó la observación participante y la entrevista fenomenológica, la interpretación por medio del enfoque de la hermenéutica. Con respecto a las consideraciones éticas, la investigación fue aprobada por el Comité de Ética de la Facultad de Medicina de la Universidad Federal de Pelotas, Opinión N 1.001.573. También se presentó, leyó y se entregó el Formulario de Consentimiento Libre e Informado (ICF).

Resultados: El cuidado de sí misma de la mujer-madre está vinculado al cuidado del niño/adolescente. Refiere que el cuidar de sí misma, a veces significa tomar el cuidado de la salud, que puede estar relacionado con el tratamiento de belleza, menciona, sin embargo, no cuidar de sí misma a no ser en el momento del baño, y, aun así, el hijo está junto a ella.

Conclusión: El estudio aporta contribuciones a la práctica de la enfermera para subsidiar estrategias capaces de facilitar a estas mujeres el cuidado de sí mismas, al ayudarlas en el proceso de adaptación a la nueva situación, y en el proceso de cuidar del niño/adolescente.

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Palabras clave: Cuidado; Madre; Parálisis Cerebral; Necesidades Especiales; Enfermería.

INTRODUCTION

The woman, becoming a mother of a child with special needs goes to different stressor experiences in the process of being mother and primary caregiver. The new way of being and of being in the world makes the woman's family that more adjustments need to make in her everyday life to take care of the child. Sometimes, this woman-mother lives with and for her son, abdicating other roles played in her day to day⁽¹⁾.

Care given to children with special needs can cause social isolation to the main caregiver, because the child depends on a lot of care, in addition to the routine. Thus, social activities become reduced and or eliminated, because of the demands of care, workload that can cause physical, psychological or emotional distress⁽²⁾. Under this

view, depending on the workload, she doesn't have enough time to take care of herself.

The take care of oneself begins by self-awareness, self-criticism and self-analysis, what is not an easy task; however, both are necessary for whom to take care of the other⁽³⁾.

When discussing care with oneself, it becomes necessary to reflect about the viewpoint of care, since care cannot be considered only as an action that does something for someone; care is an action that constitutes the human being himself; thus, suffers influences of senses and meanings that give to his livings. It is care with oneself that the be-in-world unveils⁽⁴⁾.

Caregiving requires knowledge, dedication and concern with the other and with you. The ways to take care of you own, the other and us, when interconnected, happen in circularity, strengthening relationships in the caregiver's and feel yourself being cared, in a relationship of mutual exchange. Thus, the caretaker before exercising care of another, must exercise care to you, seeking the integration of physical, mental and spiritual dimensions to achieve harmony between caring of you own and the care with the other, taking care of yourself and feeling taken by the other⁽⁵⁾.

Research shows that women-mothers when main caregivers of children with cerebral palsy experience many stressors that affect their quality of life by dedicating most of their time to child care over the time of dedication to themselves^(6,7).

The woman-mother who cares for her child, that is, takes care of the other, also needs to live to take care with herself. Therefore, when discussing about care of her, it becomes important to state⁽⁸⁾ what defines her as being authentic. It adds that it can also be understood as the exercise of power-be in need of care, to take care of her.

In this sense, it sought to unveil the scientific literature regarding the woman-mother and caregiver of a child/adolescent with special needs resulting from cerebral palsy. It was observed in studies a concern with the quality of life of the mother as caregiver of the child, highlighting the level of stress and the workload faced by her. And, all at once, there is lack of support network, as well as existing public policies about the subject. This study wishes to recognize how mothers-caregivers of children with cerebral palsy take care of themselves, seeking a rapprochement with her lived world. Thus, faced with the shortage of national and international studies published about the subject, there is a need to expand and respond to a gap of knowledge, when it comes to take care of them, and so contribute to strategies of care to improve the quality of life of those mothers, justifying the relevance of this survey. In this sense, this study aims to understand how the woman-mother of child/adolescent with cerebral palsy will take care of her.

METHODOLOGY

This is a report of the dissertation entitled "Mother of child/adolescent with cerebral palsy: understandings about the care for herself as a woman"¹. It is a qualitative research in the light of a phenomenological-hermeneutical approach.

The intentional sample consisted of ten mothers-caregivers of preschoolers last year, 5-12 years old and adolescents of 13-19 years old, according to the Statute of the Child and Adolescent (ECA) with special needs resulting from Cerebral Palsy.

Inclusion criteria were: being the mother and caregiver of the child/adolescent with special needs resulting from Cerebral Palsy; the child is between the ages of 5 to 19; the child go to school; not be traveling or away from the institution during the period of data collection; the mother being of an age less than 18 years old. And as exclusion criteria: to present difficulty of verbal communication.

The survey participants were identified by the letter M, which means Mother, and the numbers 1 to 10 respectively, according to the order of the interview.

After project approval by the Research Ethics Committee of the Medical School of the Federal University of Pelotas, Opinion N 1,001,573, from 26th March, 2015, there was made the invitation to the survey participants through the letter of invitation, presenting the voluntary purpose to participate and the possibility to withdraw from the research at any time. To those who agreed participate and that fit the criteria of inclusion and exclusion, there was introduced, read and given an Informed Consent (TFCC).

The data collection took place in the period from April to June 2015, using the techniques of participant observation and the phenomenological interview, what happened at APAE and domicile of participants.

The phenomenological interview was adopted by the fact this kind of interview values each movement, expressions, gestures⁽⁹⁾, aiming the self-care of the woman-mother and caregiver of the child with special needs resulting from cerebral palsy.

The researcher had at least two meetings with each participant before the phenomenological interview. In all, 35 meetings were added with the mothers, and 7 hours of interviews and 80 hours of participant observation.

Considering the complexity of the ontological interpretation of being, there was used the hermeneutic interpretation of Paul Ricoeur; adding other philosophers, such as Gadamer, Heidegger and nursing researchers: Motta (1997)⁽¹⁰⁾ and Milbrath (2013)⁽¹⁾, who used hermeneutics for the interpretation of the information.

Hermeneutic phenomenology is widely used as a model to perform the interpretation under the existential point of view, seeking to understand the directions, in addition to addressing the meanings of subjective feelings, attributes and intentions^(10, 11).

The archives of the transcripts of the interviews in their entirety were stored under the responsibility of the researcher and research counselor at the Center for Research and Studies with Children, Adolescents, Women and Family (NUPECAMPF), in room 202 of the UFPel, for a period of five years; from the end of the survey. After it, it will be incinerated, as advocates the Resolution 466/12⁽¹²⁾.

MEANINGS

The category: Taking care of you own, the woman-mother of child/adolescent with cerebral palsy that emerged from the interpretation of information.

The woman-mother of child/adolescent with cerebral palsy taking care of herself

Taking care of you is to make your own knowledge about the concerns inside of your own life story.

It is understood that caring of one own-self, as it is not prescriptive, but something to be conquered by search for inner knowledge is particularly an individual pursuit, but that happens in the encounter with the other, highlighting the human being as being of relationships⁽¹³⁾.

The human being, as a released being in the world, is open to endless possibilities, opened under the power to learn the meanings of what he experiences⁽¹⁴⁾. In this way, the human being is able to question, reflect about his existence to realize such a need^(14, 15).

The human being, as a thinking being, reflective, has decision making ability, regarding his existence, this does not mean that he doesn't experience facticities. Only that he is responsible for the choices he makes, and has the ability to decide about how he will handle with the situations that appear.

Taking someone care of his own is to make his own knowledge about the concerns in his life story. Under this perspective, to have concern with your own is not to be selfish, neither selfishness, but what is significant is to give value to your own. This understanding of your own harmony of taking care of yourself does well between you and the world⁽¹⁶⁾.

With the dialogue with the participants in respect of their understanding about the care for themselves, it was possible to realize in some testimonials of women-mothers that take care of themselves is associated with care with aesthetic issues; however, even when carrying out these actions cause the child's questionings:

For me it's just when I'm going to do hair highlighted, to make myself beautiful, for me to feel better, stay about three months, I get nauseous, and I make it again, but it's the only thing I do for myself, to take care of (M1).

I don't get without fixing the hair [...] when I go to the hairdresser, also to do the nails, it is so, I hold him with one hand and with another I do the nails; then the girls from the beauty salon entertain him to keep him busy (M5).

Usually once a month I go to the salon, cut the hair, make a moisturizing, do the nail. These things all weekend I paint the nails, during the week I'm always makeup. I like makeuiping me, use earring (M6).

Take care of myself little actually [...], my hair I cut, I cut these days; now it is half curled up again, did highlights once, after I've not done it so, the eyebrow I do it myself, I don't have time to go to the salon and no money, we do nails at home there is time, we like painting, but we own (referring to her and her daughter) (M7).

The statements show that women-mothers have a concern with their appearance, although each of them does it according to their particularities, be they financial or

because they feel well to carry out these activities. However, do take care of them with the son.

Taking care of the beauty to these women can contribute to raise self-esteem, encouraging the development of a positive feeling for them. It could be a way for unveiling a moment of search for feelings and self-esteem promotion.

A Brazilian survey aimed to understand the female vanity and its relationship with self-esteem. It was performed with 210 women who answered a questionnaire about vanity and involvement. Found that, the higher the vanity, the greater the self-esteem of women. Vanity also influences positively the use of cosmetics and treatment⁽¹⁷⁾.

These women-mothers became able to (re) organize their way of being in the world combining child care with needs and take care of themselves. For Mayeroff⁽¹⁸⁾ the human being can decide by void, becoming a real weird to yourself, or you can choose to suit your own needs and this is the date when puts the other in your life. In this perspective, these women-mothers decided to suit their needs and also the needs of the children.

Care of the beauty is associated with an integral conception of health, since physical care even considering emotional aspects like self-esteem and happiness, feel beautiful is a condition to be happy⁽¹⁹⁾.

The caregiver who takes care of herself also has better living conditions and will have better conditions to take care of the other; it will promote improvement in her quality of life and existence; thereby improving the care provided for the other, valuing her human condition and of the other to exist in the world⁽²⁰⁾. In Heidegger's philosophy, to take care of oneself, is to take care of being and being, and, being responsible for this being⁽²¹⁾.

For other women-mothers take care of themselves is restricted to get perspective when they lack health care.

I worry, even look up sometimes [...], always go, do some test, when I need to, I will and make the appointment, because have to worry a bit with us, is the health of the people (M3).

This week, made me do; I couldn't stand pain from the injection in my back; desperation. (M4).

The statements show that for the M3 and M4 participants, to take care for themselves is to re-establish health. Gadamer⁽²²⁾, when discussing health concerns that draws attention by its presence; however, often it is forgotten, because the human being only after him when he lacks.

A child/adolescent with cerebral palsy depending on the special needs that has, in many cases, demand physical effort of who performs the care. Thus, backaches are not uncommon, for this mother get decrease the pain besides being a care for her, it is a care for the child, if it does not improve, and it will not be able to provide care that the child/adolescent demands.

A study ⁽²³⁾, whose goal was to assess the algic prevalence, physical and mental burden, and the quality of life of the caregiver of the child with cerebral palsy, concluded that mothers showed a significant index of burden and of algic regions, due to care for them provided. In this context, pain is the reflection of the daily activities carried out, since they are dedicated full-time to children who have different kinds of needs, what can make it difficult to care of themselves of these mothers.

In this sense, it becomes important that the caregiver perform preventive activities such as physical activity, preventive examinations, and healthy nutrition, among others. The life of the mother depends on frequent caregiver self-assessment, to recognize what is important to her and the better way to take care of her. Attitudes like that can lessen the impact of the care with the child with cerebral palsy in the lives of these women-mothers.

Thus, take care of you is to take care of what are ⁽²⁴⁾. It is to exercise the power of being in any everyday situation. The be-in-world that is essentially care-care-of-yourself-and-being-with-others ⁽²⁵⁾. In the mode of coexistence, human beings need to worry about the care of the other and with the care of the women-mothers need to care about the care for themselves, in addition to the primary caregivers. The burden of everyday life has consequences for these mothers, because while the children grow more demand physical exertion, which can compromise the health of these caregivers:

I feel pretty back pain knows; it is to force to change, to get down to load (M2).

Only the higher it gets, it's harder because I lack strength. Last week, made me do, I couldn't take the pain in the column; [...] I believe it is to get him out of bed (M4).

A child diagnosed with cerebral palsy brings significant changes to the parents, especially the mother caregiver ⁽²⁶⁾. These are exposed to situations that require a big commitment of time and physical effort, which affects different aspects of health. Mothers are frequent back pain, due to the transport of the child from one side to another, surpassing, in many times, their limits ⁽²⁷⁾. Overcoming that takes the authenticity of your so-to-be.

In contrast to the importance of caring for the child and at the same time take care of themselves, some of the participants claim not having care of themselves:

There's not! Doesn't have that. Let's put it this way, take a little time for me, half an hour of the day, there's no! If I talk to you I lie. The only time that I take for me is the baths and even sometimes yelling at me [...] life is like that, it's a heavy business (M4).

Don't make-up. I give thanks to God when I take a shower; it is taking care of me. He's quite bashful (referring to the child with cerebral palsy), there's no time for much of anything. I'm not very vain, before having him after he was born, I think more him than me, so doesn't leave much time. [...] When you have a special child, you think of him and stop thinking about you. I just forgot that I also need to take care of myself (M9).

In terms of getting ready, haven't taken the time to get ready, just take a shower, put on some clothes and so. Don't have, [...] does not have a time (M10).

These women-mothers live a care routine that does not allow time for them, or they don't allow time for them, since maternal care is socio-culturally. That bath time is the only time I have for me, because the rest is dedicated to the child with special needs. In this sense, study published in Brazil ⁽²⁸⁾ concludes that the mother, primary caregiver, which previously took care of the family as a whole; when it becomes the mother of a child with special needs as a result of cerebral palsy, change your focus of care, centering it in the son.

Britto ⁽²⁹⁾ full stating that the mother-child/caregiver teenager with cerebral palsy leaves aside the woman, that is forgotten, fact that negatively affects your self-esteem, since they don't allow themselves to prioritize, at some point, the care with the appearance or with the health. Mothers reported lack of support, moreover, it is difficult for them to give up the child to work, becomes unacceptable to devote some time to pamper yourself.

Care performed by mothers of children/teens with special needs demand and complex actions, continuous and intensive care. The mother forgets to dispense care to you, don't take your consciousness existence while being separated from the life of her son, taking upon himself all responsibility with the care of the child, a relationship of mutual dependence between the binomial mother/son. Therefore, he believes, too, that be fulfilling your mission to be mother and take care of the child. Attitudes like this become a big challenge for these mothers, who, in many times, do not want to share it with other family members.

In this sense, it is important to reflect on the support network that can assist health teams in the construction/acceptance of family support networks. Considering that sometimes mothers, waive or render the networks of support offered to them, because they want their presence constant in the life of the child and you can't trust your everyday demands other people, a fact that leads to overload of work. The action of caring, second Rosseló ⁽³⁰⁾, is the moment when the beings transcend the barrier that separates them and transform into one building and me in us. Taking care of someone is open to the prospect of the US.

One of the participants mentioned that takes care only of his son, couldn't say how to take care of them, as referred to in the first place is the son:

I don't know what to say, because I care. I had meningitis, hence I was dropping beforehand was different. That's pretty good today, the first place he (referring to the child with cerebral palsy), because I'm so afraid of losing it. The doctor scared me, I left the Office, I will never forget what he told me, and I got that fear. He said the Brother each year could lose him. So each year the Brother does (pause) I am afraid of that age. That I'm really scared. He has 17 years, it's 18. The doctor died of cancer, he is doctor ended up going (M2).

In this sense, it is important to reflect on the way the pros talk about the child with cerebral palsy because the mother captures and live what was said. When the doctor told his mother: "What the brother each year could lose it", interrupts the hope of mother who may have difficulty in adapting to this being, for anguish with the possible

finiteness of the son. The sense of finiteness is very strong, not to be told as a speak any, you need to be true, but you never can take hope. According to Gadamer ⁽³¹⁾, there's no way to live without the prospect of a future.

Study that sought to discuss the process of communication between the health team and the family of a child with cerebral palsy, warns that the words spoken by health professionals should be thought to have a dialogue. The language of health professionals has a weight, a power over the family of child/adolescent with special needs ⁽³²⁾.

The mother, while caretaker par excellence, for the most part, is overwhelmed due to the need for special and continuous care related to the monitoring of the treatment of child/adolescent. Health workers accompanying the child/adolescent conduct charges in relation to the care, without realizing that the mother also needs to be taken care of, because they are women with desires, aspirations, dreams and needs that are not always related to the son ⁽²⁹⁾.

One of the participants, it was observed that only one organizes your time so that you can perform take care of themselves, and take care of the child:

Now I'm able to take care of myself a little more, but before it's not like I didn't have the time. I was feeling a bit stifled, because you're there, it seems that only in that direction. Then you leave you aside. Not today, today I'm able to separate, a time for me and one for him (referring to the child with special needs) and a time for the activities that I have to do on a daily basis. I'm feeling today with my self-esteem better than before because I'm getting a little time to get ready, a time for small, just for me, for me to enjoy as a woman, dating (laughs) (M8).

It can be observed by the report that mother she divides the time, a time for the son and a time for you, and you feel better and with a high self-esteem. Fits reflect on this model of care, it would be interesting that mothers could take care of the child, taking care of you, but for that it is necessary to be aware of themselves, and of the son, in the sense that they are two lives and that she can exercise the care without neglecting to one and other.

Through the Heideggerian perspective, this mother gives existential possibilities she and son, stimulates her authenticity. It is worth mentioning that the time, whether or not if there is always time ⁽²¹⁾, it is the responsibility to choose it.

The care dispensed to the son by this mother is perceived as authentic, that is care, care for autonomy. Authentic care enables the other take their own steps, perform their own life, aiding in the construction of existential children and build them ⁽³⁰⁾.

Know care involves learning how to take care of themselves and each other, having always reality, possibilities, limitations. Take care of you is to be able to create a synthesis in which the contradictions don't cancel each other out, but the bright side predominates. Take care of yourself is to love, welcome, recognizing your vulnerability, could cry, forgive and develop the ability to overcome obstacles and adapt to changes, to bounce back and learn from the mistakes and contradictions ⁽²⁴⁾.

Most mothers reports take care of you through the beauty care, other health care, other referred to do not be careful yourself. It was observed that the life of the mother is strongly rooted to the son, justified by moments in which they say take care of himself, his son is together, even this not realizing the presence, as if it were a person. One of the Moms can separate the time, and pamper yourself, live a moment your, perceiving themselves as being-in-world. The live this way made this woman-mother raise your self-esteem, live better, so it is important that all mothers were able to book a time to pamper yourself. In this sense, health professionals may act, helping those woman-mothers to develop the care of them, so that they can take care of them, taking care of the children and feeling cared for.

CONCLUSION

To get to understand the look after her, the woman-mother of child with special needs resulting from cerebral palsy was unable to perform an approximation with the daily lives of these women, emerging from the reflection on the vulnerability to exist as a human being exposed to several existential facticidades and the resourcefulness of the human being to adopt an authentic attitude and dedication to each other.

It was noted that the become the mother of a child with special needs, to experience the existential condition of the son, puts in the background to take care of the own-self, moreover, lack of social support networks.

The care for them, for some of these mothers, is related to beauty, health and, for others, taking care of them own is non-existent. For those women-mothers referring to perform care, this is related to the aesthetic intervention that make along with the child/adolescent, showing not an exclusive time for them.

The study has scientific and social relevance, since it encourages reflection of health professionals, especially nurses, in relation to the care of the mother of child/adolescent with cerebral palsy, and consequently the improvement of practice, thus contributing to the improvement of society and understanding the world. The study has scientific and social relevance, since it encourages reflection of health professionals, especially nurses, in relation to the care of the mother of child/adolescent with cerebral palsy, and consequently the improvement of practice, thus contributing to the improvement of society and understanding the world.

Such contribution shall be ensured by the usefulness of the work to researchers and readers, because it adds to the set of scientific knowledge about the subject, by the originality of the approach and the contribution to overcoming gaps in knowledge.

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