THE CHALLENGE OF CARING FOR A FAMILY MEMBER WITH DISABILITIES RESULTING FROM CEREBROVASCULAR DISEASES

O DESAFIO DE CUIDAR DE UM MEMBRO FAMILIAR COM INCAPACIDADES DECORRENTES DE DOENÇAS CEREBROVASCULARES

EL DESAFÍO DE UN MIEMBRO FAMILIAR CON INCAPACIDADES DECURRENTES DE ENFERMEDADES CEREBROVASCULARES

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ABSTRACT

Objective: to raise the difficulties and to evaluate the level of overloads of family caregivers of individuals with disabilities resulting from cerebrovascular diseases. Method: descriptive study of qualitative approach, conducted with five caregivers. The data were collected at home from June to September of 2013, through interview with semi-structured script. Then, the interviews were transcribed and subjected to the analysis of thematic content. The research was approved by the Ethics Committee in Research, CAAE nº 16398713000004.

Results: three categories emerged which demonstrated that the caregiver provides social isolation, self-care deficit, financial difficulties and physical exhaustion, being the spirituality and religiosity the main ways of coping and emotional support for them. Conclusion: home care was cited by caregivers as an arduous and stressful task and they often forget their own needs, letting them with self-care deficit. Descriptors: Chronic Disease; Caregivers; Home Care.

RESUMO

Objetivo: levantar as dificuldades e avaliar o nível de sobrecarga dos cuidadores familiares de indivíduos com incapacidades decorrentes de doenças cerebrovasculares. Método: estudo descritivo, de abordagem qualitativa, realizado junto a cinco cuidadores. Os dados foram coletados no domicílio nos meses de junho a setembro de 2013, por meio de entrevista, com roteiro semiestruturado. Em seguida, as entrevistas foram transcritas e submetidas à análise de conteúdo temático. A pesquisa foi aprovada pelo Comitê de Ética em Pesquisa, CAAE nº 16398713000004. Resultados: emergiram três categorias as quais demonstraram que o cuidador apresenta isolamento social, déficit de autocuidado, dificuldades financeiras e esgotamento físico, sendo a espiritualidade e religiosidade as principais formas de enfrentamento e apoio emocional para este. Conclusão: o cuidado domiciliar foi citado pelos cuidadores como uma tarefa árdua e estressante e que muitas vezes se esquecem de suas próprias necessidades, levando-os ao déficit de autocuidado. Descritores: Doença crônica; Cuidadores; Assistência domiciliar.

RESUMEN

Objetivo: levantar las dificultades y evaluar el nivel de sobrecarga de los cuidadores familiares de individuos con incapacidades decorrentes de enfermedades cerebrovasculares. Método: estudio descriptivo, de enfoque cualitativo, realizado junto a cinco cuidadores. Los datos fueron recogidos en el domicilio en los meses de junio a septiembre de 2013, por medio de entrevista, con guía semi-estructurada. En seguida, las entrevistas fueron transcritas y sometidas al análisis de contenido temático. La investigación fue aprobada por el Comité de Ética en Investigación, CAAE nº 16398713000004. Resultados: surgieron tres categorías las cuales demostraron que el cuidador presenta separación social, déficit de autocuidado, dificultades financieras y agotamiento físico, siendo la espiritualidad y religiosidad las principales formas de enfrentamiento y apoyo emocional para este. Conclusión: el cuidado domiciliario fue citado por los cuidadores como una tarea ardua y estresante y que muchas veces se olvidan de sus propias necesidades, llevándolos al déficit de autocuidado. Descriptores: Enfermedad Crónica; Cuidadores; Asistencia Domiciliaria.

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INTRODUCTION

Currently, the Chronic Non-communicable Diseases (NCD) became one of the biggest public health problems. The World Health Organization (WHO) estimates that they are responsible for 63% of all 36 million deaths in the world in 2008. In Brazil, this reality is even worse, because they are responsible for 72% of total deaths in 2007.

It is known that the presence of chronic disease can contribute over the years with the emergence of the called diseases of the circulatory system, in particular the cerebrovascular disease (DCBV). WHO estimative indicate a trend of gradual increase in the number of deaths attributed to cerebrovascular disease that probably will reach a global mortality of approximately 12.1% in 2030.

Cerebrovascular diseases are responsible not only for a great part of deaths worldwide but also for large number of disabilities. After an episode of Cerebrovascular Accident (CVA), it could be a series of neurological deficits that make the person need help in his daily activities, even the most basic ones.

From this issue, it is necessary to the family get involved and be organized to provide the care that the people require. However, the difficulty of the assistance practice and great concern for the welfare of the sick family causes the caregivers involved in the task of taking care, many times forget themselves and their needs. In this way, it is necessary to support the caregivers, which justifies the development of studies on the difficulties faced by family caregivers, the conditions in which occurs this confrontation and the health needs of this population.

OBJECTIVE

- To raise the difficulties faced and to evaluate the level of overload of family caregivers in the home care process to the individual with disabilities resulting from cerebrovascular diseases.

METHOD

Descriptive study of qualitative approach, carried out with five family caregivers with disabilities resulting from cerebrovascular diseases, selected through the technique of “snowball”. According to this search strategy, the first respondent indicates that, in turn, indicate another one, and so on.

Data collection took place at home from June to September of 2013, through interviews. They had an average duration of one hour, and then transcribed in full and subjected to content analysis thematic mode. This is a set of analytical techniques of communication which aims to understand the contents and/or hidden manifests when organizing the data into meaningful words or classes of data defined by a word or expression.

To evaluate the level of overload of caregivers, the Zarit Burden Interview scale was used, evaluating the impact of caregiving on physical, psychological and social spheres. It is composed of 22 questions with answers of Likert type with four points ranging from never (0); almost never (1); sometimes (2); almost always (3); always (4). The total score could range from 0 to 88 points, being that the higher the score, the greater the overload.

There are no standards or cut-off points established. However, it can be considered indicative of “the absence of overload” a score of less than 46, “moderate overload” from 46 to 56 points and “intense overload” a score higher than 56. The level of dependence of patients was also evaluated through the quick and global dependency evaluation scale - Mini Dependence Assessment (MDA) which consists in the evaluation of four activities: bodily, locomotor, sensory and mental. In each of these activities three items with scores ranging from 0 to 2 are evaluated, being zero (0) corresponding to the independence or normal, one (1) to partial dependence and two (2) to the total dependence of human help. Total dependency evaluation may vary from 0 to 24, which provides 5 levels of dependency: null (0), slight (1-8), moderate (9-14), severe (15-19), and very severe (20-24).

The development of the study was according to the national and international standards of ethics in research involving human beings, and occurred in accordance with the ethical principles governed by Resolution 466/96 of the National Health Council. Its project has been approved by the Permanent Committee on Ethics in Research with Human Beings (COPEP) of the State University of Maringá (opinion 297,227). For the identification of participants, fictitious name of birds were used.

RESULTS

People assisted by family members had an average age of 63 years old. Four were male and one female. Regarding the level of dependency of family members sick, two showed slight dependence, one moderate...
dependence and two severe dependency (Figure 1).

The caregivers surveyed had an average age of 48 years old, all were female, and resided in the same house of the family member sick. Regarding the kinship with the sick member, one was a sister, two were daughters and two were wives. The main health problems mentioned by caregivers were arthritis and bursitis, which demonstrates that people who care also need to be cared for and therefore should be the subject of actions and attentions of nursing.

In the overload of caregivers evaluation, the average score was 32 points, being a maximum of 57 points and a minimum of 5 points, which indicates that caregivers generally did not show overload, however, when analyzed separately, a caregiver showed intense overload, two moderate and two, the absence of it.

<table>
<thead>
<tr>
<th>Sick Caregiver</th>
<th>Caregiver</th>
<th>Kinship with the caregiver</th>
<th>Time cared</th>
<th>Level of overload</th>
<th>Level of dependency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eagle</td>
<td>64</td>
<td>Wife</td>
<td>03 anos</td>
<td>Absence</td>
<td>66</td>
</tr>
<tr>
<td>Hummingbird</td>
<td>46</td>
<td>Sister</td>
<td>10 meses</td>
<td>Intense</td>
<td>62</td>
</tr>
<tr>
<td>Canary</td>
<td>37</td>
<td>Wife</td>
<td>01 ano</td>
<td>Moderate</td>
<td>40</td>
</tr>
<tr>
<td>Swallow</td>
<td>60</td>
<td>Daughter</td>
<td>07 meses</td>
<td>Absence</td>
<td>90</td>
</tr>
<tr>
<td></td>
<td>34</td>
<td>Daughter</td>
<td>06 meses</td>
<td>moderate</td>
<td>58</td>
</tr>
</tbody>
</table>

Figure 1. Presentation of level of overload of the caregivers, according to Zarit Burden Interview and the level of dependency of the sick caregivers according to the Mini Dependence Assessment.

The analysis of the interviews allowed the identification of three categories: introducing changes arising from home care, care as a task of great physical and emotional requirement and the faith and religiosity as a way of coping.

Introducing changes arising from home care

One of the changes that have occurred in the lives of caregivers was social isolation as they are deprived of their work and leisure activities outside their home leading to a break in their social conviviality. Changes in social life were identified because of the impossibility of leaving home, by the time that is spent in care and also of concern for the welfare of the patient during his absence.

We can't go out, for example, I can't go out and stay all day out [...] then you're worried, you don't know if you're going to get home and how will find [...] if I go out he can't go out, that neither travel nor think. (Hummingbird)

A caregiver revealed that the spouse has become very introspective and refused to go to certain places, and not to leave him alone she also ended up not leaving home:

Oh, it's not like before, there are places that I can't take him, because he doesn't want to go, then I won't either. (Eagle)

Another change reported by caregivers were the losses on physical health and self-care deficit.

Oh, I'm very bad, I need to take better care of my health [...] and if we also gets sick, I need to make two surgeries and I won't, it is impossible. (Hummingbird)

These reports reveal that the concern with the welfare of their sick family makes caregivers involved in direct care, often they forget about themselves and their needs.

I don't have much time to take care of me [...] the walks that I did I do not do anymore. (Eagle)

Another big change is the difficulty in reconciling family care to work outside the home, many of them need to abandon it or reduce the workday.

It has changed everything, I had to stop working at the office, I started to sew, because what I would be doing at home? Even today, I cannot sew anymore because every time he calls me. (Hummingbird)

At first, I stopped working, I stopped everything [...] because before I did my nails in the houses, then I started doing at home anyway. (Canary)

I left the job because who was going to take care of my father? (Swallow)

It was also evidenced in the reports the difficulty of the sick family member to exercise a gainful activity that will contribute to the family income, which shall receive a retirement or illness that is not always equivalent to what was received previously, contributing to the decrease in family income.

The financial has also changed, because he's not working anymore, he was and now he's getting the help disease, until when the government wants [...] sometimes a relative or other one helps, but not always, my daughter sells candy, I do nails and so on. (Canary)

The difficulty of the caregivers to exercise their work outside home, impossibility of the sick family member in maintaining a remunerated activity, as well as increased spending on treatment and hospitalizations, are factors that may contribute to these families to experience a period of financial difficulties.

And we have a lot of expenses with him because the SUS (Unified Health System)
Faith and religiosity as a way of coping.

The lines evidenced the importance of spirituality to support the disease of the person cared:

- Oh we search strength in God [...] The people pray, I do my work in the Church [...] we have to have faith in God if you understand? (Hummingbird)
- My only distraction is going to church [...] the Pastor of the Church that fills us with hope and faith. (Bem-te-vi)
- The Church also helps a lot, is the main thing, for me is above my family, not the Church, but what I seek in the Church. (Canary)
- Praying helps me cope with this situation, we need to be with God. (Swallow)

All caregivers at some point in the interview resorted to religious figures, showing devotion and referred to these deities as a source of support to keep them alive and willing to win this battle together with the family member, as reported Hummingbird:

- When I'm not supporting it anymore I speak thus: “God will get rid of,” it's not like he's going to get rid of, he's going to take his pain, understood? (Hummingbird)

The reports have shown that spirituality acts in the lives of these people as a base to support the hard times and also influences how they conceive care.

- I try not to complain, I view this as an opportunity for spiritual growth, I know that God will give me strength. (Eagle)
- My husband has a lot of pain, he thinks so, I can almost go out and when I go out I have to go back soon [...] my aunts help a little because I can't handle it [...] it’s not easy, I even lost weight. (Swallow)
- My only distraction is going to church [...] my aunts help a lot because we need to be with God. (Canary)

Thus, care for these caregivers, assumes a charitable role, since they believe in a God that rewards every man for his good works and, for some, an opportunity of personal and spiritual growth.

**DISCUSSION**

On the results achieved, it was possible to observe that the sick family member took the caretakers to social isolation. Other studies have shown that this isolation can be due to a number of factors such as the inability to leave home, because of the time that they spend in care, and the absence of another person to oversee the patient while the caregiver is out, changes in family relationships and friendships, the abandonment of working activities and the non-participation of other relatives in care.
Although the caregiver be deprived of contact of their social network as a result of the care provided to his family member, the inner circle of relationships can be strengthened or overlap the outer circle or intermediary who is harmed, i.e. taking care of a loved one can become more meaningful and rewarding than social losses generated by the overload and confinement that care causes to the caregiver. This was evidenced in the testimonials of caregivers, being possible to realize that despite the difficulties and challenges, they found meaning in the act of caring, which is configured as an act of love and personal growth.14

The testimonies also revealed that the major concern with the sick family member took caregivers the self-care deficits, which corroborate another study in which it was identified that caregivers often do not meet their basic human needs, and these are often affected and that such reality finds overshadowed by evidence of the sequels of the patient, that demand attention and continuous care and that lead to an intense physical and psychological overload at the caregiver.15

The self-care deficit identified in this study was also checked in others, which demonstrated that the caregiver strives both in care to his family member that ends up giving up time to take care of his own health and also moments of leisure and social coexistence been presenting self-care deficit and social isolation. These data show that the person in charge must also be target of the actions of public health and health professionals.16-18

With regard to factors that led families of the study the changes and financial difficulties, another survey found that families investigated showed the same factors reported by the caregivers of our study and that were related to the difficulty of caregivers in reconciling the care when with work outside home. Many of them had to abandon or reduce the workday, contributing to the reduction in family income and the increase in expenses related to the care of the patient, in addition, the family's difficulty in exercising a gainful activity because of disabilities can accentuate even more this situation.19

The caregivers also reported that the family care sometimes is a task of great physical and emotional requirements. Studies have shown that the experience of taking care of a patient dependent has been pointed to by family caregivers as a very stressful and exhausting task, due to the affective involvement, as well as the transformation of a relationship of reciprocity by another of dependency. In addition, generally the care is usually assumed by only one person, which ends up accumulating this activity to other of their personal routine, generating a physical and emotional overload.20,21

In this study, generally, caregivers showed moderate overload of care. Other studies that evaluated the overload of caregivers of dependent patients also found this finding, and caregivers showed moderate overload when analyzed together. However, in two studies, to be analyzed separately, caregivers have submitted divergent Zarit scale scores, as well as in the present study. This divergence may be due to a number of factors such as the level of dependence of the family member, anxiety and nervousness by the family member, lack of knowledge with regard to activities he may exercise alone, while care and support networks exist.22,23

These data reinforce the need for planning and implementation of nursing actions guiding the caregivers to carry out leisure activities and social interaction in order to minimize the overload experienced by them.

Most caregivers cited the faith and religion as coping strategies. How each person understands the spirituality is, in general, the associated with the search of a support and comfort. When the person gets ill or experience the illness of a family member, he coexists with situations of suffering, imbalance and is at this moment that the spirituality emerges, leaning upon the subject in the context of instability.24

Several studies with home caregivers pointed out the importance of faith and religion as a means of emotional support and relieve internal conflicts, favoring an acceptance by the situation experienced by the caregiver. In this case, religion and religiosity will act as a buffer from the harmful impacts to health. The Church, cults, masses and meetings that the family member participates, would work, then, as a source of relief and emotional comfort.22,25,26

In other research that dealt with the religion and spirituality as important sources of support for the fight against chronic disease by relatives, the results showed that those resources generated in caregivers feelings of hope and acceptance in the face of the difficulties of dealing with chronic diseases.27

The nurse must recognize the spirituality as coping strategy and identify the spiritual needs of the patient so that they can plan and...
The challenge of caring for a family member... offer the most possible comprehensive assistance.

CONCLUSION

The results of our study allowed to meet the realities of family caregivers of patients with cerebrovascular disease and thus to raise their difficulties and the factors that lead to overload and diseases.

Home care was cited by caregivers as an arduous and stressful task and that they often forget their own needs, leading them to the self-care deficit. Other difficulties reported by caregivers were social isolation, financial changes and the great physical effort and concern that care to a family member dependent on demand, being that the faith and religiousness were pointed out as an important source of confrontation and emotional support.

This study comes to contribute for the unveiling of the home care needs, generating data that support the practice of the nurse, since this is important on the instrumentalization of the family for the care and also for public health strategies aimed at this population. The nurse must develop monitoring giving attention to the caregiver, interacting with family, understanding the impact suffered by it and thus obtaining valuable information for the establishment of contacts with the patient and family, since it is the family continue the care until a full recovery or remaining capacity building by the sick family member.

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The challenge of caring for a family member...