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# Influence of family support in burden of caregivers of individuals with cerebrovascular accident sequelae

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## Influence of family support in burden of caregivers of individuals with brain vascular accident sequelae

**Objective.** Understand the existence of a relation between the caregiver's overload of a stroke sequel patient and the family support. **Methods.** Quantitative/Qualitative research, described by six caregivers registered in the Basic Health Network in Chapecó/SC – Brazil. For (data) information gathering, the Burden Interview scale of Zarit Burden and a semi structured interview were used. The scale analysis was described with percentage while the interviews was based on the Minayo reference. **Results.** Four participants were identified with moderate overload, all of them focused only in the caregiving without any family support and. Two participants didn't became overloaded, one had his familiar very independent and the other had family support, which can allow the caregiver to

work, to have a better social life and to be financial stable. **Conclusion.** The familiar's caregiver with family support feel more safe, reducing (easing) his load and being able to face the (care) daily challenges.

**Key words:** burden; family caregivers; family relationships.

## Influencia del apoyo familiar en la carga del cuidador de personas con secuelas de accidente cerebrovascular

**Objetivo.** Conocer la relación entre la sobrecarga de los cuidadores de individuos con secuelas de accidente vascular cerebral y el apoyo familiar. **Métodos.** Estudio descriptivo mixto (cuali-cuanti) realizado con seis cuidadores adscritos a la Red Básica de Salud del municipio de Chapecó/SC - Brasil. Se utilizó para la recolección de información la

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escala para evaluar la sobrecarga del cuidador de Zarit Burden y una entrevista semiestructurada. **Resultados.** Se identificó sobrecarga moderada en cuatro participantes; todos se dedicaban exclusivamente al cuidado, sin ayuda familiar. Dos cuidadores no presentaron sobrecarga, uno relacionado al bajo grado de dependencia familiar, y el otro asociado al apoyo brindado por sus familiares, lo que le permitió trabajar para mejorar la estabilidad económica de la familia y una mejor convivencia social. **Conclusión.** El cuidador familiar al tener el apoyo de otros miembros de la familia asume con más seguridad el cuidado; además, le reduce la carga, posibilitando el enfrentamiento de los desafíos impuestos por el cuidado.

**Palabras clave:** sobrecarga; cuidadores familiares; relaciones familiares.

### Influência do apoio familiar na sobrecarga do cuidador de indivíduos com sequelas de acidente vascular cerebral

**Objetivo.** Conhecer a existência de relação entre a sobrecarga de cuidadores de indivíduos com sequelas de

acidente vascular cerebral e o apoio familiar. **Métodos.** estudo quanti-qualitativo, descritivo realizado com seis cuidadores adscritos na Rede Básica de Saúde em Chapecó/SC - Brasil. Todos procedimentos éticos foram respeitados, projeto foi aprovado pelo Comitê de Ética da UFFS sob n. 817.161. Utilizou-se para coleta das informações escala Burden Interview e entrevista semiestructurada. A análise da escala foi descrita em porcentagens e da entrevista baseou-se referencial de Minayo. **Resultados.** identificou-se sobrecarga moderada em quatro participantes, todos dedicavam-se exclusivamente ao cuidado, não contando com ajuda familiar. Dois cuidadores não apresentaram sobrecarga, um relacionado ao baixo grau de dependência de seu familiar, o outro associado ao apoio dos familiares, possibilitando trabalhar melhorando o suporte financeiro potencializando o convívio social. **Conclusões.** O cuidador familiar ao contar com apoio dos demais membros da família assume o cuidado sentindo-se amparado, amenizando sua carga, possibilitando o enfrentamento dos desafios impostos pelo cotidiano de cuidado.

**Palavras chave:** sobrecarga; cuidadores familiares; relações familiares.

## Introduction

With the progress of the biotechnological sciences, there has been improvement in health care conditions, which promoted an increase in life expectancy, a fact realized by increasing longevity and the changing demographic and epidemiological profile of the Brazilian population. Associated with this condition, there has been an increase in chronic diseases, some of which are disabling and have no heal, leading to situations of incurable, progressive, and advanced disease.<sup>1</sup> This fact implies the increase of individuals dependent on their families and health services. In this context, home care arises, which is usually carried out by a member of the family, especially in low-income families.

The need to care for a family member at home requires a number of adjustments and reorganization of the whole family, with redefinition of roles and tasks, in order to adapt to the new reality. The family undergoes physical,

psychological, social and economic adjustments, causing changes in the natural context of family life.<sup>2</sup> In face of the new reality, the role of the family caregiver often arises, which is the person whose responsibility is to carry out the tasks that the individual with sequelae from a morbid episode cannot perform anymore.<sup>3</sup> In most situations, families have a family caregiver who becomes the primary caregiver, that is, the person responsible for the care and for most of the tasks developed at home in order to promote comfort and well-being to the loved one.

In this sense, the primary caregiver has often been object of study by being in a relationship of exclusive accountability for their dependent family member, which puts them in a vulnerable condition for the onset of physical, emotional, social and financial diseases. The burden of this individual is a major problem, which has arisen interest not only of researches but also of assessment tools such as Zarit Burden Interview, which was adapted and validated in Brazil.<sup>4</sup> This

instrument consists of 22 items that evaluate and classify the caregiver's burden in different levels. Individuals with sequelae of cerebrovascular accident (CVA/stroke) have different levels of dependence related to the severity of the morbid episode. The higher the degree of dependence, the greater the involvement of the caregiver and the greater the overload assigned to them. This experience of caring for someone with stroke sequelae at home has become increasingly common in the daily lives of families.<sup>5</sup> The caregiver has to deal not only with the difficulties of mobility, self-care and communication, but also with the possible cognitive impairment, depression and personality change. There is a wide variety of responses to these changes, which differ from individual to individual and also in the same individual over time. Some people are able to deal more appropriately with the adversities of care, while others react less appropriately, often in situations where stress overrides.<sup>6</sup>

Because it is a complex and often lengthy process, the ideal is that caregivers are not alone in this context. Thus, it is indispensable to form a support network that is able to minimize the negative aspects caused by the function of caring. Therefore, the aid from other family members in the development of care provides indispensable support and protection, which helps easing the burden attributed to a single individual, helping to face the challenges imposed by the daily routine. Thus, from these considerations, this study aims to evaluate the existence of relationship between the burden of caregivers of individuals with stroke sequelae and family support.

## Methods

This is a descriptive study with quantitative and qualitative approach, carried out with six caregivers registered in two Primary Health Care Units of the Municipality of Chapeco, located in the west of the State of Santa Catarina - Brazil, between July and September 2014. As for the inclusion criteria to participate in the study, the primary caregiver needed to have family ties with the user; not receive remuneration for the care

provided; live in Chapeco and be registered in one of the Family Health Centers of that municipality, and provide care to a family member with stroke sequela. To collect the information, initially, the coordinator nurse of the selected Family Health Centers for research was contacted and informed about the purpose of the study and its relevance, so that she could contribute in the survey of study participants. After a survey on the unit, home visits were scheduled in the selected families. Caregivers who met the requirements were invited to participate. As a tool for data collection, authors used the Zarit Burden Interview scale, adapted and validated in Brazil,<sup>4</sup> in order to identify the burden of family caregivers. This instrument consists of 22 questions that are complementary, and once compiled, show the existence (or not) of family burden – i.e., this study included the entire instrument. Each item is scored based on the following scores: never (0) rarely (1) sometimes (2) often (3) always (4). In the last question, the scores are: not at all (0), a little (1), moderately (2), quite a bit (3), extremely (4). The total score ranges between 0 and 88, and the higher the score, the higher the perception of burden. The classification is based on the following scores: severe burden (scores between 61 and 88), moderate to severe burden (scores between 41 and 60), moderate to mild burden (scores between 21 and 40) and no burden (scores lower than 21), and then a semi-structured interview was performed in order to identify family support in caring, which was recorded, transcribed and analyzed. The guiding questions which refer directly to the object of study were: do you receive some kind of help from your family in the care of your family member? What kind of help? What does this help mean you? How does this help interfere with your day-to-day of care?

The analysis of information coming from the Zarit Burden Interview<sup>4</sup> were described in percentages. In order to analyze the information, researchers used the Minayo proposal,<sup>7</sup> which is characterized by two operating times. The first includes the fundamental determinations of the study, which is mapped in the exploratory phase of the investigation. And the second time is called

interpretive, as it is the starting point and end point of any investigation, which is the encounter with empirical facts. The interpretative phase has two steps: data ordering and classification of data, including horizontal and comprehensive reading of the texts, cross-reading, final analysis and the construction of the report with the presentation of results.<sup>7</sup> The ethical aspects of research involving human beings were respected, in accordance with Resolution 466/12 of the National Health Council. Participants signed the Informed Consent Form. The project was approved by the Ethics Committee of the Universidade Federal da Fronteira Sul under the number 817,161 and CAAE 34968014.5.0000.5564.

## Results

The study was carried out with six caregivers of family members with stroke, aged between 20 and 79 years; two caregivers were less than 30 years and a caregiver was over 70 years of age. Women were majority, with a quantity of four. As for the degree of kinship, two caregivers were daughters, two were spouses, one was father and one was daughter-in-law. With respect to education, four caregivers have completed elementary school, one is illiterate and one has not completed high school. In relation to labor activity, three participants have never had a paid activity and referred themselves as housewives, two are retired and one caregiver works at home and has a remunerated activity. Regarding gross monthly income, three caregivers receive from one to three minimum wages, two caregivers receive less than a minimum wage and one caregiver receives from three to five.

Regarding overload in the care process, it is observed that the care in the domestic sphere is mainly unpaid and performed by women; although involving family ties, it can be understood as the social devaluation of women's labor. The task of caring is hard as it relates to a chronic disease and becomes more difficult by the poor financial conditions of those involved in the care process, as exemplified by the following report: (...) *sometimes we almost kill each other here, because there is no money, I ask and no one*

*helps me, but later we make peace, because there is no use in fighting (C4).*

Regarding the burden assessed by Scale Burden Interview, a moderate burden was identified in four participants, all of which were devoted exclusively to the care, not relying on family help. Two caregivers showed no burden, one related to the low degree of dependence of the family member, and the other associated with the support of family.

Among the six caregivers, two showed no burden. One of the caregivers live with the aphasic wife, and the care is limited to communication. This data can be an indicator that the burden is different in each individual and the degree of dependence directly influences the burden. This assertion is demonstrated in the following speech: ... *the greatest suffering is having to help her in everything; as she cannot walk, I have to help her, get her up, make her sit (...) if she starts to walk, it will ease half of the suffering (C1).*

Regarding the changes in family relations resulting from the care process, it could be observed that care is not an easy task and requires a drastic change in the lives of those who perform it and also requires the fulfillment of certain tasks taken as delicate, stressful and complex, and, often, the caregiver is also a fragile person who is already aging stage or in the process of becoming ill. Another caregiver showed no burden even though experiencing a situation of dependence of her family member.

Other relevant information was that some caregivers, when informed about the result of the burden scale, felt frustrated by having overload, understanding it as lack of love for their family member, however, researchers had the opportunity to show that the burden is not proof of failure but a result that arises from the continuous care and exposure to stressful situations. It was evident that the lack of support, whether it is formal or informal, has become a reason for overload and generation of feelings of loneliness in the care process: *Now they come less frequently here at*

*home because they are afraid that I ask them to take care; they should come here to help me (...)* No one stays with him for more than two days (C6). Another caregiver also emphasizes that: *when she stays in the hospital, I have to do it all by myself, because the other siblings do not want to help, they say they cannot (...)* I even left my job to take care of her (C3).

Living with the lack of understanding and insensitivity of other family members generates feelings of abandonment, which is another aggravating factor, since these caregivers are immersed in care tasks often full-time, not having time to relate to other people, to talk and share their suffering, which is evident in another speech: *I no longer do what I want (...)* I now have imitations to go out, I am always in a rush (...) when I wake up in the morning I have to dress him up, give food; so he is always in first place, then my other to-do things; even to my work in the beauty salon has to wait, it is always after, when it is possible (C6). It is evident that the caregiver develops skills and abilities to deal with difficult situations in daily life and experiences wear, which is evidenced by the difficulty to organize their routine and perform all the tasks for which they are responsible.

An essential condition to be considered is that sometimes the caregiver, due to the level of involvement in care, fails to pay attention to their personal needs, and thus, physical problems arise, as a consequence of the lack of self-care. When they take on role of primary caregiver, a new scenario emerges in the life of each of them, and their needs and desires is put in a secondary place, while the dependent family member's demands are highlighted. The fact of not having support of secondary and tertiary caregivers was a new barrier, making it impossible, sometimes, that this caregiver could take care of his own health needs. This feeling is evident in the speeches: *when I get sick, I cannot do what I would like to do, such as staying quiet, sleeping (...)* it is only me to provide care, I must handle things, because I know she needs me (C2). Experiencing change in lifestyle is a difficult

situation faced by caregivers because they fail to live their own life to live other's life. This selfless relationship sometimes causes suffering, decreased self-esteem, loss of freedom and stress. This fact is aggravated when the caregiver does not have the support of other family members, becoming as dependent on other people as the sick family member, which is clearly described in the following statement: *as I cannot count on my brothers, I have to ask my neighbors, when the neighbors can (...) they take her and take to their home to look after her there, so I can get out a bit, trying to distract myself* (C3).

The family caregiver shares the pain and suffering of the person of whom they take care and although unpleasant feelings permeate their daily routine, there are moments when they feel happy and fulfilled, as in situations where they can count on the support of family: *when they come here and stay with her for me it is a sign that they still love us (...)* they have not abandoned us (C1). *Oh, I feel good! Even happy, because I know if I need I can call them and they will be here, they share this with me* (C5).

## Discussion

The association between unpaid housework and women can be explained by the tradition in a recent past where women did not play roles outside the home. It is evident also in this study, with regard to the female universe, that some caregivers add to the care of the family member, household chores and the roles as mother, grandmother and wife, which may generate an accumulation of work with consequent overload in different areas of life, such as social, emotional, physical, spiritual, contributing to the neglect of themselves and their own health.<sup>8</sup>

The total average burden of family caregivers in this study was similar to other studies that had the purpose of evaluating this phenomenon among caregivers.<sup>9</sup> Some studies have shown that caregivers with a high degree of overload are more easily affected by diseases such as depression, with an average frequency of 30%



of observed caregivers.<sup>10</sup> Family members who take on the role of caregivers can get into a crisis situation, and may feel tension, stress, frustration, fatigue, embarrassment, depression and impaired self-esteem, resulting in physical, psychological, emotional, social and financial problems, which in turn affect the well-being of the patient and the caregiver.<sup>11</sup>

The stress experienced by caregivers increases the risk of cardiovascular diseases and its risk of mortality by 23% and 63%, respectively, compared to non-caregivers.<sup>12</sup> These negative impacts on the caregivers' well-being may result in the breakdown of care and institutionalization of stroke survivors, which imposes a substantial cost on health systems. However, in the Brazilian context, the caregiver has been devalued both at the government level, because of lack of strategies and infrastructure to intervene systematically in the context of a situation of dependency, as in non-governmental level, which includes the very family and health professionals. Therefore, caregivers are challenged by numerous demands and start to have restrictions in relation to their own life, which contributes to the appearance of burden.<sup>13</sup> In this sense, researchers believe that when caregivers receive support from other family members and the care is shared, there is a relief in the tasks and time to take care of themselves, thus reducing the experienced overload, especially when the situation of dependence is greater.

Studies have demonstrated that the degree of dependence directly influences care, determining how much time the caregiver will have to spend to assist in the activities of daily living.<sup>11</sup> The difficulties encountered by caregivers in this study arise from the physical effort made in the daily task of caring, leading to exhaustion and the desire of changes in this reality. The activities that require physical exertion are certainly those that cause more difficulty, since, to care for a dependent adult, it becomes necessary to have a good physical capacity to perform heavy tasks such as locomotion, and the need to quickly recover from a sleepless night.<sup>5</sup>

For the caregiver who showed no burden even experiencing a situation of dependence of her family member, this may be associated with her professional activity, as she performs remunerated activities at her house, which suggests the possibility of maintaining financial autonomy and interaction with others in the community, which can minimize the damage of chronic care by a family caregiver. Social relations, that is, socializing with others can be a form of relief to the pressures experienced in the everyday routine of care. Numerous studies support the idea that people who have good social networks adapt more easily to their situation. In the same way, studies consider that these nets protect individuals against stress caused by the disease and by the fact of becoming caregivers, allowing re-evaluating the situation and adapting better to it, helping to develop positive coping responses.<sup>13</sup>

In the family, the person that engages in the role of caregiver makes it by a movement of "slipping into it", parallel to the occurrence of another movement triggered by the other members of the system, which is "slipping out of it". This means that the more the caregiver is involved in the care, the more the non-caregivers disengage from this role.<sup>14</sup> This situation can lead the caregiver to loneliness in the care process.

The family care is a complex phenomenon, which generates different feelings. Receiving support from family members to go through this time means that there is love in the family and the sense of abandonment is minimized in face an adverse situation. The fact of having someone to turn to in difficult times makes that the caregiver feel supported. The family, whether nuclear, formed by parents and children, or expanded, which includes people considered members of the same family, regardless of consanguineous or parental ties, constitutes as a primary source of aid and care to its members.<sup>3</sup> The basic natural social network is the nuclear family; however, relatives, neighbors, friends and health services also constitute the extensive social support network.<sup>15</sup>

In conclusion, this study allowed knowing the existence of a relationship between the burden of caregivers of individuals with stroke sequelae and family support. In this perspective, there is evidence of overload of caregivers associated with significant changes in family ties, demonstrating greater burden on caregivers who do not have family support. The burden related to care is a readily apparent phenomenon and, when persistent, can lead to caregiver illness. However, when care is shared, suffering is minimized and the existing family relationships are strengthened, making them more solid and loving by the involvement established between those involved. It should be noted that in a society that has undergone changes in the family structure, there is need of development of public policies with a view to the establishment of formal support for patients and their families in situations of dependency is necessary.

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