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## ORIGINAL ARTICLE

### CARE FOR THE FAMILY MEMBER AFTER A STROKE CUIDADO AO FAMILIAR APÓS ACIDENTE VASCULAR ENCEFÁLICO CUIDADO AL FAMILIAR DESPUÉS DE ACCIDENTE VASCULAR ENCEFÁLICO

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#### ABSTRACT

**Objective:** to understand the experience of family members in home care after hospital discharge from a family member affected by stroke. **Method:** qualitative, descriptive, convergent type study with four families. The study scenario was the household, with an average of 16 visits per family, once a week or when there was a need for assistance. For the analysis of the data, the technique of Content Analysis was used in the Thematic Analysis modality. **Results:** It was evidenced that the experience of caring at home led family members to deal with feelings such as fear, sadness, anguish and frailty, and the sick members reported anxiety, discouragement, frustration and revolt at being sick. **Conclusion:** the study allowed the understanding of the home care experience and the family life of the family members affected by stroke, allowing care practice and research to occur at the same time and, thus, provided the opportunity for interaction and bonding with study participants and the understanding of the experience and the repercussion of care at home among the family members. **Descritores:** Cerebrovascular Accident; Family; Home Care; Nursing Care; Nursing; Chronic Disease.

#### RESUMO

**Objetivo:** compreender a vivência dos familiares no cuidado domiciliar após a alta hospitalar de um familiar acometido por Acidente Vascular Encefálico. **Método:** estudo qualitativo, descritivo, do tipo convergente assistencial, com quatro famílias. O cenário do estudo foi o domicílio, com média de 16 visitas por família, uma vez por semana ou quando houvesse necessidade de assistência. Para a análise dos dados, utilizou-se a técnica de Análise de Conteúdo, na modalidade Análise Temática. **Resultados:** evidenciou-se que a experiência de cuidar no domicílio levou os membros da família a lidarem com sentimentos como o medo, a tristeza, a angústia e a fragilidade e os membros adoecidos relataram ansiedade, desânimo, frustração e revolta por estarem adoecidos. **Conclusão:** o estudo permitiu a compreensão da experiência de cuidar no domicílio e a vivência das famílias de familiar acometido por Acidente Vascular Encefálico oportunizando que a prática assistencial e a pesquisa ocorressem ao mesmo tempo e, assim, proporcionou a oportunidade de interação e criação de vínculo com os participantes do estudo e a compreensão da experiência e a repercussão do cuidado no domicílio entre os familiares. **Descritores:** Acidente Vascular Encefálico; Família; Assistência Domiciliar; Cuidados De Enfermagem; Enfermagem; Doenças Crônicas.

#### RESUMEN

**Objetivo:** comprender la vivencia de los familiares en el cuidado domiciliar después del alta hospitalaria de un familiar acometido por Accidente Vascular Encefálico. **Método:** estudio cualitativo, descriptivo, del tipo convergente asistencial, con cuatro familias. El escenario del estudio fue el domicilio, con promedio de 16 visitas por familia, una vez por semana o cuando hubiera necesidad de asistencia. Para el análisis de los datos, se utilizó la técnica de Análisis de Contenido, en la modalidad Análisis Temático. **Resultados:** se evidenció que la experiencia de cuidar en el domicilio llevó a los miembros de la familia a lidiar con sentimientos como el miedo, la tristeza, la angustia y la fragilidad y los miembros enfermos relataron ansiedad, desánimo, frustración y revuelta por estar enfermos. **Conclusión:** el estudio permitió la comprensión de la experiencia de cuidar en el domicilio y la vivencia de las familias de familiar acometido por Accidente Vascular Encefálico, posibilitando que la práctica asistencial y la investigación ocurrieran al mismo tiempo, y así, proporcionó la oportunidad de interacción y creación de vínculo con los participantes del estudio y la comprensión de la experiencia y la repercusión del cuidado en el domicilio entre los familiares. **Descritores:** Accidente Vascular Encefálico; Familia; Asistencia Domiciliar; Atención de Enfermería; Enfermería; Enfermedad Crónica.

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## INTRODUCTION

Chronic Non-Communicable Diseases (CNCD) evidence the role of the family in caring for their involvement in all stages of illness, providing support and support in care for the family.<sup>1</sup> However, caring for a family member with chronic illness can generate stress and produce disorders for both the family and the sick person.<sup>2</sup>

Nevertheless, complications resulting from the chronic nature of CNCD, such as Stroke, generate care dependence in the person affected by morbidity, resulting in restrictions on the activities of daily living, cognition and decision-making capacity and, consequently, loss of autonomy, leading to changes in family dynamics.<sup>5</sup> For this, it is necessary for the family to adopt strategies to adapt to the new reality and reorganize to provide care to their family member on their return home taking into account complexity of care required in care.

In order to confront this process of readaptation to a new day-to-day life, it is essential the participation of health professionals, in order to orient and support them, promoting the family potential for a good adaptation and, consequently, improving the quality of life of these people. In this perspective, dialogue, listening and welcoming are important aspects of this process.<sup>3</sup> It is also essential to recognize that the family is an essential part of the process of care and recovery of the family member who is ill and that the need for guidelines for the practice of care is constant and needs to be performed.<sup>4</sup>

## OBJECTIVE

- To understand the family members' experience in home care after the hospital discharge of their relative affected by a Stroke.

## METHOD

Manuscript extracted from the dissertation << Family life: home care for the family with disabilities due to stroke >> presented to the Graduate Program in Nursing of the State University of Maringá - SUM. Maringá (PR), Brazil, 2015.

Qualitative, descriptive study of convergent care type (CC). The choice of the CC was made because this method allows the assistance actions to be incorporated into the research process and the research processes are incorporated into the care actions, thus providing the introduction of new Nursing care practice.<sup>6-7</sup>

The study participants were the members of four families. The first approach for the selection of the participants occurred during the hospitalization of the sick family member and the participation in the research was based on the following inclusion criteria: to have a family member, over 18 years of age, affected by the EVA for the first time; to present a moderate, severe or very severe degree of dependency identified from the application of the Mini Dependence Assessment (MDA). For the selection, 22 families were approached and of these, 17 were excluded because they did not meet the inclusion criteria. After the participants were defined and the patient was discharged from hospital, data were collected.

The setting of the study was the family home. The first visit occurred one week after discharge from hospital, and the other visits were agreed and performed according to the needs of each family, through home visits, with a minimum frequency of one visit per week. In total, at least 16 home visits per family were carried out. The care offered was determined by the needs emerged at each meeting held covering activities such as care guidance, disease evolution and complications, clarification of doubts for all family members, as well as demonstration and conduct of direct care and entertainment activities such as music therapy and didactic games. The care offered was based on the researcher's professional experience, national and international protocols and theoretical studies on the subject.

After each meeting with the families, the key points were immediately noted in the field diary as facial expressions and demonstration of positive or negative feelings. For completeness, audio recording was used whenever authorized by the participants. As recommended by the CC, the information assistance, collection and analysis processes occurred simultaneously, which allows the application of a variety of methods for the analysis of collected data. Thus, for this study, we opted for the use of Content Analysis<sup>8</sup>, in the Thematic Analysis modality.

The project was approved by the Standing Committee on Ethics in Research Involving Human Beings of the State University of Maringá (opinion no. 502.185 / 2013; CAAE: 22059013.4.0000.0104). Family members who agreed to participate in the study signed the Free and Informed Consent Term (FICT) in two ways. The FICT of the person who was ill was signed by the family member who accompanied him during the hospitalization period due to motor alterations that

prevented him from writing, but in three families visits to the home were also consented to by the family member who was ill with verbal authorization.

To ensure anonymity, families were identified with the four seasons of the year. The seasons of the year were used as an analogy thinking about the very "seasons" of life, since all experience different phases in the course of the walk. Each family member was named with the name of a flower being this specific of each season of the year.

## RESULTS

Four families of people with care dependency due to stroke participated in this study. After analyzing the data, the following categories emerged: "Fear of the unexpected: the abrupt illness of the family member affected by stroke" and "Reorganization of family dynamics: possibilities for care".

### ● Fear of the unexpected: the abrupt illness of the family member affected by the EVA

During home follow-up, a link between the researcher and the researcher was created, which made it possible to perceive, through the reports and expressions, several negative feelings of the family, such as fear about the care process and the family's revolt, suffering from experiencing illness, according to their narratives:

*I was scared, I was not ready for this (tears), I did not know what to do when he (husband) came home (Rosa - fall family).*

*I was very scared when my son said, "Daddy had a stroke." It happened every thing in my head, I thought, "He (husband) will need me." [...] My son came from the hospital crying, saying: "Mother, I'm going to be without my father! What will become of me without my father? "These boys, if they lose their father, I do not know, I think they die (Gerbera - spring family).*

*I was a good person, whenever I saw a person needing something on the street I helped, I do not understand why God let this happen to me! (Voice of weeping) (Mouth-dandelion - fall family).*

*When he came home, I was scared, but at least he was going to be here with us because staying in the hospital is not easy (Rosa - fall family).*

In the winter family, Boca-de-Leão also made reference to the feeling of frustration and incapacity, besides facing change in their work activity, because, due to the sequelae of the disease, it was not possible to resume their work having to seek retirement and depend on the help of the children, relatives and institutions to maintain the house.

The loss of the work force and the forced removal of the disease had repercussions on his life and the feeling of frustration led him to increase the consumption of cigarettes even with all the orientations made by the researcher and other health professionals, as can be observed by wife's report:

*He is smoking more than before the stroke, I think it is anxiety because he is not working (Rosa - fall family).*

Feelings of gratitude on the part of the family caregiver were also observed, however difficult and tiresome it may be. According to the participants, care was an opportunity to give mothers the care they received throughout their lives:

*Poor thing, she suffered so much to take care of us! [...] My father married another and left my mother and she never abandoned us, so everything I can do for her I will do! (Cherry tree - winter family).*

*The mother took care of us alone because she separated from my father, now, it's me who takes care of her [...] we sometimes fight, but she knows I love her! (Dahlia - family summer).*

On the other hand, the presence of feelings of escape and indifference was observed, which resulted in a separation from the family member with the sick person. It is known that the way families deal with situations after illness depends very much on how this relationship was established prior to the event. It is observed, in the statements of the deponents, the attitude of indifference on the part of some familiar members, however, the posture was in agreement with the level of relation that the patient had with this relative.

*She (daughter) comes in here, goes to her house ... Sometimes I say, "Come here to stay with your father ...". She disguises ... Speech: "Oh, mother!" And does not come ... she is more independent, right? [...] (Rosa - fall family).*

*My brother does not help care, he drinks, you know? [...] Sometimes he enters the room (of the mother), but only when I call him (Cerejeira - winter family).*

In taking care without the help of other family members, caregivers suffer from this mixture of feelings:

*But I was so desperate because I have to take care of her alone. Alone and God, right? (Cherry tree - winter family).*

*I take care of him. Because you see, everyone works, who would care? (Gerbera - spring family).*



### ◆ Reorganization of family dynamics: possibilities for care

Faced with the illness situation of a family member, especially when the disabilities become chronic, most of the people involved in this process get organized into the new routine. Within this organization, many family members relinquish activities of personal interest to collaborate in the care:

*Yesterday, she (daughter) came and did a general cleaning; tomorrow, she comes again, my daughter is my daughter, she helps me a lot! [...] She is moving to another house, she is running because they are building, but she does not stop coming here [...] my children come every day at night to bathe in the father, there is not a day, when is not one, is another (Gerbera - spring family).*

*When he's off he helps his father a lot, drives him, takes him up and down [...] on the weekends, he does not even leave the house because the father may need something (Rosa - fall family).*

For the family reorganization, there was also the change of roles, as the children started to have more financial control and care. In the winter family, for example, the daughter began to administer the retirement of Azaleia and to take care of her as if she were a "daughter", as happened in the families fall and spring in which the children began to collaborate with the sustenance of the house.

*She (daughter) helps, she pays the bills here from home, it's such a help! (Rose - fall family).*

*We are both retired, but when we need it, the children pay for it (Gerbera - spring family).*

According to the deponents, other social organizations were predominant in the aid of the expenses that, due to the disease, tend to increase:

*The only income I have is my carpets, although I can not do it right, my daughter helps, pays for things here from home, the church helps, the pastoral, my brothers, but it's hard, right? [...] he (husband) is going to do the skill Friday, he already made one and was denied, now the Santa Casa gave me a certificate that he is renal, let's see if he can [...] get it because we're living without income, right? (Rose - fall family).*

*I take care, huh, I do not leave her without things at all, even if I have to buy 'spun' at the pharmacy I'll find a way [...] I did not buy tape for dressing, then I went to the post office and they they gave me that from here ... the expenses were very much raised here from home, even though she earns things [...] (Cerejeira - winter family).*

The financial alteration of the families was related to a number of factors, among them, the family member's illness, which resulted in the inability to return to their occupation, the removal of the work of the main caregiver, having to dedicate themselves to the care, and lack of time to engage in paid activity. The financial imbalance generated contradictory feelings in the families accompanied at the same time that, in the fall family, it reverberated in discouragement to come to depend on the help of other people.

In this sense, social support networks are important in the moment of adapting to the new reality, generating feelings of gratitude on the part of the relatives, since they feel welcomed and supported in having their support network:

*We are living with practically no income, I can not live with the help of others, you know? (Rose - fall family).*

*But I have a lot of friendship, I like everyone there, more than thirteen years I'm there, right? [...] they help me a lot, sometimes I need money, they give me and do not even charge me later (Cerejeira - winter family).*

In the process of reorganization of the family dynamics, even the physical space of the home needed to be altered in order to better accommodate the familiar and facilitate the care:

*Here at home, she has a room for herself, to be more at ease (Dahlia - summer family).*

*For now, he is sleeping in the living room and I here on the side on the mattress because it is closer to the bathroom and I am afraid he will get up at night and want to go alone (Rosa - family autumn).*

Despite all the changes and efforts made by family members to adapt the home and better accommodation for their family member, there was a report that shows the desire to return to life in the same way that it was before illness, lamenting for not having autonomy to do what it wishes:

*She (mother) said that she wanted to live alone, to have her things, in her way, but I can not leave her alone, I'm afraid that something will happen, God forbid, right? (Dahlia - family summer).*

## DISCUSSION

Illness due to stroke occurs suddenly and unexpectedly in people's lives. The impact of the disease generates great incapacities, mainly in the physical mobility, causing abrupt changes in the daily life of the sick person and his family. The event of the stroke requires a modification of social and labor activities and

entails a kind of biographical rupture, which means changes in the identity, structure of meanings, relationships and concrete organization of life, directly interfering in the physical dimensions, social and cultural life of people.<sup>9,11</sup>

Generally, after confirming the diagnosis of a serious illness, relatives and the sick person bring to mind all the knowledge they have about the disease, think about the seriousness of the situation and are taken by negative feelings.<sup>12</sup>

The EVA leads the person affected to dependence and limitations to the development of simple daily activities such as self-care. This situation is conducive to the development of feelings such as anxiety, depression, discouragement and revolt. For the rehabilitation after the event, it is necessary that the person with illness has a good ability to overcome and change to face the new life and rehabilitation of their functions.<sup>13</sup> In this phase of emotional vulnerability, it is essential the action of the Nursing team for the strengthening the capacities of the subjects and the family to help them in this moment of readaptation promoting a better quality of life for these people.

The impossibility of carrying out the daily activities of life causes great frustration and decline in well-being in the affected person.<sup>14</sup> In addition, with illness, feelings of anxiety and anguish are intensifying and some people unconsciously seek mechanisms of to confront them. Each person needs a different time to learn how to deal with the new situation. Therefore, the nurse needs to be attentive by encouraging the family to respect the period of adaptation of the disease by the family member who is ill.<sup>15</sup> In short, this period of adaptation is not an easy moment to be lived by the patient, being relevant the role of the family in supporting the family member and the health team in support of the family.

In this aspect, we highlight the return to the home after a stroke event as a phenomenon that generates a mixture of feelings for relatives between hope and happiness, to see their family member alive, recoverable, and fear and concern. The sick person, while being happy to return home, is also bitter about the disabilities that the event has caused. In this sense, it is important that the family receive guidance and support from the health team so that it can conduct their conflicts and fears in a more serene way.<sup>16</sup>

This feeling can be justified by the intergenerational care that relates the need

for retribution to the theory of gift, which has the sense of creating a term obligation, and the meanings attributed to care relate to gift and debt. Therefore, the care given to the family member is a retribution to what was done. In human care, the circulation occurs between giving, receiving and giving back. Care is an inherent and fundamental endless cycle of people's survival.<sup>17</sup>

Each family responds in a way to illness. Some seek solutions addressing the problem situation and others adopt strategy in an attempt to deny the present situation, being directly related in how the relationships were constructed prior to illness.<sup>19</sup>

In a study that sought to understand the feelings involved in caring for the family member affected by stroke,<sup>21</sup> it was understood that family members suffer from feelings of compassion for otherness because they see the family member suffering from it and also because they feel powerless to not be able to get rid of it, of this pain. Added to the feeling of alterity and compassion, solitude was observed.

Lack of participation of other family members in care is a factor that may accentuate the caregiver's overload. The absence of family support generates feelings of loneliness and suffering that can increase the vulnerability of caregivers to physical and emotional illness.<sup>20-21</sup> Therefore, the active participation of health professionals, especially nurses, as support at this time of return to the home and readaptation to the new routine, is of extreme importance in promoting the quality of life of people and the family.

It is known that the family is the place of mutual support and has fundamental importance to those family members who are sick. It can be seen that the suffering caused by illness also interferes with the lives of those who are directly involved in care and are affected by the suffering of the other<sup>22</sup> and, through this fact, the family rearrangements are necessary, thus enabling care to the needs revealed.

Faced with illness, the family system as a whole reorganizes itself, often requiring internal negotiations, seeking new definitions, such as the exchange of roles in the hierarchical organization of its nucleus, with the aim of guaranteeing care, maintenance and its structural functionality.<sup>23</sup> Therefore, the family can be considered a space where complementarity happens with the other, because what an individual can not assume alone, a group assumes it in a dynamic

movement according to the needs arising from the context.

For this, in the process of family reorganization, it is necessary to adapt to several problems that emerge with illness. Among them, the financial life. Financial changes have also been reported in other studies<sup>24-25</sup> and have shown that the financial imbalance is a common repercussion in the daily lives of caregivers. The importance of support by social support networks, be they institutions, public and private services and a network of friends is stressed, since this support facilitates the control of difficult and problematic situations.<sup>25</sup>

The impairment of functional capacity after stroke has important implications for the family, the health system and, especially, the life of the affected person. It should be noted that these families are in a situation of vulnerability since the loss of autonomy to perform daily activities and make their own decisions contributes to a significant decrease in their quality of life.<sup>26</sup>

The illness of a family member causes (re) arrangements between the people who participate in the care to provide support and support to those who become ill. It is important to remember that family relationships provide the majority of the necessary support for the sick person, since it is in family everyday that illness occurs and it is there that can be experienced by approaching the relationships among their members.<sup>27</sup> Therefore, the importance of strategies that promote the quality of life and autonomy of the people.

## CONCLUSION

The study allowed an understanding of the experience of caring at home and the experience of families of family members affected by stroke, allowing care practice and research to occur at the same time and, thus, provided the opportunity for interaction and creation of a link with the participants of the study. The contributions acquired from the lived feelings, the changes and reorganization in the family dynamics, the repercussions on the life of the caregivers and other family members involved in the care of the family point out the fundamental need for the presence of Nursing and the health team at home so that can help the family to identify their strengths and weaknesses and thus, together, choose priorities in the planning of care.

In this sense, CC proved to be useful because its versatility enabled families to support both direct care and to subsidize

them through health education and to identify that the care exercised in these families already existed prior to the family member's illness and that is in care family members are usually instrumented for illness situations. Even though this care is considered empirical by health professionals, however, it is real and important for the protection of its members and especially in face of illness.

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