









## CARING FOR A FAMILY MEMBER WITH STROKE SEQUELAE: THE FIRST DAYS AT HOME AFTER HOSPITAL DISCHARGE

*CUIDANDO DE FAMILIAR COM SEQUELA DE ACIDENTE VASCULAR CEREBRAL: OS PRIMEIROS DIAS EM CASA APÓS ALTA HOSPITALAR*

*EL CUIDADO DE LA FAMILIA CON SECUELA DE ACCIDENTE CEREBROVASCULAR: LOS PRIMEROS DÍAS EN CASA DESPUÉS DEL ALTA HOSPITALARIA*

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### ABSTRACT

**Objective:** to apprehend the experiences of informal caregivers of people with stroke sequelae in the first days after hospital discharge. **Methodology:** descriptive exploratory study, with a qualitative approach, carried out in Maringá - Paraná, with eight family caregivers. Data were collected in May and June 2019, through audio-recorded semi-structured interviews, at the participants' homes and submitted to content analysis, thematic modality. **Results:** the category: experiences of caregivers in the first days at home emerged, consisting of three subcategories: caring after discharge: doubts and feelings; adaptations imposed on the family's daily life; facing difficulties in home care, which show already in the first days at home the repercussions of the presence of the family member with a stroke sequel in the lives of caregivers, who experienced negative feelings of insecurity in caring for the family member, fear of the worsening of the clinical condition, in addition to financial difficulties, decreased social relationships with family, friends and need for adaptations in the home's infrastructure. **Final considerations:** the nurse needs to consider the socioeconomic and cultural peculiarities of people with stroke sequelae in the home context and monitor and support the caregiver from the first days after hospital discharge, in order to minimize the impacts that this condition causes to the patient and caregiver.

**Keywords:** Stroke; Caregivers; Family; Home Health Nursing; Patient Discharge.

### RESUMO

**Objetivo:** apreender as experiências de cuidadoras informais de pessoas com sequelas de acidente vascular cerebral (AVC) nos primeiros dias após a alta hospitalar. **Metodologia:** estudo descritivo exploratório, com abordagem qualitativa, realizado em Maringá - Paraná, com oito cuidadoras familiares. Os dados foram coletados em maio e junho de 2019, mediante entrevistas semiestruturadas audiogravadas, no domicílio das participantes e submetidos à análise de conteúdo, modalidade temática. **Resultados:** emergiu a categoria: experiências de cuidadoras nos primeiros dias no domicílio, constituída por três subcategorias: cuidando após a alta: dúvidas e sentimentos; adaptações impostas no cotidiano familiar; enfrentando dificuldades no cuidado domiciliar, as quais mostram já nos primeiros dias em casa as repercussões da presença do familiar com sequela de AVC na vida das cuidadoras, que experienciaram sentimentos negativos de insegurança em cuidar do familiar, medo da piora do quadro clínico, além de dificuldades financeiras, diminuição das relações sociais com familiares, amigos e necessidade de adaptações na infraestrutura do domicílio. **Considerações finais:** o enfermeiro precisa considerar as peculiaridades socioeconômicas e culturais de pessoas com sequela de AVC no contexto domiciliar e acompanhar e apoiar o cuidador desde os primeiros dias após a alta hospitalar, de modo a minimizar os impactos que essa condição causa ao paciente e cuidador.

**Palavras-chave:** Acidente Vascular Cerebral; Alta do Paciente; Cuidadores; Enfermagem Domiciliar; Família.

### RESUMEN

**Objetivo:** conocer las vivencias de los cuidadores informales de personas con secuelas de accidente cerebrovascular (ACV) en los primeros días tras el alta hospitalaria. **Metodología:** estudio descriptivo exploratorio, con abordaje cualitativo, realizado en Maringá - Paraná, con ocho cuidadores familiares. Los datos fueron recolectados en mayo y junio de 2019, mediante entrevistas semiestruturadas grabadas en audio, en los hogares de los participantes y sometidas a análisis de contenido, modalidad temática. **Resultados:** surgió la categoría: vivencias de los cuidadores en los primeros días en el hogar, que consta de tres subcategorías: cuidado tras el alta: dudas y sentimientos; adaptaciones impuestas a la vida diaria de la familia; enfrentando dificultades en el cuidado domiciliar, que evidencian ya en los primeros días en el hogar las repercusiones de la presencia del familiar con secuela de AVC en la vida de los cuidadores, quienes experimentaron sentimientos negativos de inseguridad en el cuidado del familiar; miedo al empeoramiento de la situación clínica, además de dificultades económicas, disminución de las relaciones sociales con familiares, amigos y necesidad de adaptaciones en la infraestructura del hogar. **Consideraciones finales:** el enfermero debe considerar las peculiaridades socioeconómicas y culturales de las personas con secuelas de AVC en el contexto del hogar y monitorear y apoyar al cuidador desde los primeros días después del alta hospitalaria, con el fin de minimizar los impactos que esta condición ocasiona al paciente y cuidador.

**Palabras clave:** Accidente Cerebrovascular; Alta del Paciente; Cuidadores; Cuidados de Enfermería en el Hogar; Familia.

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## INTRODUCTION

Stroke is a public health problem in Brazil and in the world, representing the second leading cause of death and the third of functional disability.<sup>1</sup> In Brazil, in 2019, 1,102,486 hospitalizations were registered due to health problems. circulatory system, of which about 20% are related to stroke. And of the 1,316,719 deaths registered in 2018, approximately 357,770 were from this cause.<sup>2</sup>

Although most individuals survive a stroke, the sequelae resulting from this injury significantly affect the functional capacity and quality of life of those affected and their families, impacting health and social security systems.<sup>3</sup> Care demands after discharge hospital require the presence of a caregiver, usually informal, represented by spouses, children, and other family members, who plays a fundamental role in meeting basic human needs and in the rehabilitation process.<sup>4</sup>

However, by assuming this responsibility, people fail to fulfill other roles they had previously played, which is a challenge to be faced.<sup>5</sup> This is because many are inserted in the labor market and/or have family and personal obligations that, added together to the role of caregiver, lead to an imbalance between their capacities and demands.<sup>6</sup>

The challenge is increased, above all, when the person assumes the task of caring without the necessary knowledge and support, generating feelings of overload, anxiety, stress, physical problems, and decreased quality of life.<sup>7</sup> Thus, the performance of long-term care period to a family member with stroke sequelae, especially severe ones, implies multiple consequences for caregivers.<sup>8</sup>

Considering this context, during the care of patients with stroke in the hospital environment, it is important to be concerned with the continuity of care that includes these individuals and their families at home.<sup>9</sup> This is because the psychosocial and assistance interventions available, such as individual psychotherapy and home visits by professionals working in primary care are limited and usually occur when symptoms are already chronic and the problem is already installed, as a result of late home care.<sup>10</sup>

Thus, it is believed that knowing aspects of daily care in the first days after hospital discharge can help identify the most elementary demands of families while adapting to the new routine of life and care. In this sense, the results of this study may encourage and support an action with emphasis on the preparation of the caregiver even during hospitalization, in addition to highlighting the importance of monitoring and early implementation of educational activities and support for family members

in the home environment. These strategies can favor the realization of care at home and also minimize the impacts of this condition for patients and caregivers.

Given the above, the aim of this study was to apprehend the experiences of informal caregivers of people with stroke in the first days after hospital discharge.

## METHODOLOGY

Descriptive research with a qualitative approach was conducted in accordance with the guidelines of the Consolidated Criteria for Reporting Qualitative Research (COREQ). The research was carried out with family caregivers of people with stroke sequelae residing in Maringá-PR and two municipalities belonging to the main population arrangement (MPA) of its metropolitan region. It is noteworthy that, at the time of the study, none of the municipalities had a home care/hospitalization service, although most of their populations were covered by teams from the Family Health Strategy.

Data collection was carried out in May and June 2019, through interviews at the homes of eight caregivers of family members with stroke sequelae, located during the period of hospitalization in two hospitals in the city of *Maringá*, one philanthropic and the other public. All interviews were conducted by the first author, a nurse with specialization and experience in the emergency and urgency area.

The inclusion criteria were being 18 years old or more, being the main caregiver of a person with stroke sequelae and moderately severe dependence identified with the application of the Modified Rankin Scale (MRS), that is, with a score equal to or greater than four.<sup>11</sup> In turn, the only exclusion criterion applied was to reside in municipalities not belonging to the MPA.

Semi-structured interviews were carried out between seven and 10 days after hospital discharge, in a private place, inside the home, without the presence of the family member being cared for. They lasted an average of 35 minutes, were audio-recorded after consent on a smartphone device in the recorder function, and guided by the following guiding question: “How has it been for you to take care of your family member after the stroke?”

A total of six hours and 45 minutes of interviews was obtained, which resulted in 60 pages typed in Word® with 1.5 spacing between lines. All content was submitted to content analysis, thematic modality, following the three basic steps: pre-analysis, analytical description, and inferential interpretation.<sup>12</sup> Thus, the transcribed material was initially organized, followed by “floating reading”

and, then a thorough reading with identification of common and specific aspects. After this step, clippings, classifications, categorization of the statements were carried out with identification of 20 units of meaning, grouped into six units of record, which finally resulted in a category called: “experiences of caregivers in the first days at home”, constituted by three subcategories: “caring after discharge: doubts and feelings”, “adaptations imposed in the family’s daily life”, and “facing difficulties in home care”.

The study was approved by the Standing Committee on Ethics in Research Involving Human Beings of the *Universidade Estadual de Maringá* and in its development all the ethical precepts regulated by Resolution 466/12 of the National Health Council (*Conselho Nacional de Saúde-CNS*) were considered. The caregivers who agreed to participate in the study signed the Informed Consent Form (ICF) in two copies. To guarantee their anonymity, in the presentation of the results, extracts from their reports are identified with the letter “C” referring to caregiver, followed by an Arabic number corresponding to the sequence of inclusion in the research (C1, C2 ... C8), followed by the degree of kinship (mother, daughter...sister-in-law).

## RESULTS

The eight caregivers participating in the study were aged between 32 and 75 years, being six married and two widows. Regarding kinship, four were daughters, one daughter-in-law, one mother, one wife and one sister-in-law. With regard to education, five had incomplete primary or secondary education, two were illiterate and one had incomplete higher education.

### Experiences of caregivers in the first days at home

The study participants accompanied the family member during the hospitalization period, which ranged from 15 to 60 days and, despite that, when they arrived at home, they faced different experiences, difficulties and feelings that gave rise to three subcategories that will be described in follow:

#### *Caring after hospital discharge: doubts and feelings*

The caregivers reported that, when arriving at home and faced with the first care to be provided, they experienced feelings of despair, sadness, anxiety, and helplessness.

This is because they did not feel prepared to carry out home care alone, nor did they have a support network to help them:

*We went to shower later and wet the entire sofa bed. I did not know what to do. An immeasurable despair hit me, how was I going to be able to do all this alone? It was time to eat, and she had to eat pasty food as she was not able to swallow. I made some soup, hit the blender, and tried to give it to her, but she was not holding her neck sitting up, my aunt was already gone, and I could not get her into the chair by myself, too heavy. At that moment in the kitchen, I broke down crying (C4, Daughter).*

*My sister was desperate because she could not change her diaper on her own, as my mother is obese and very weak, she does not even have the strength to lift her leg. She had feces up her back, and we did not know how to change the diaper, I felt helpless. At that moment I started to cry and think about how we were going to do it [...] (C1, Daughter).*

Caregivers showed insecurity to perform simple care such as bathing, feeding, and changing position. They even mentioned that, for fear of making a mistake and worsening the family member’s clinical condition, they failed to provide some basic care.

*I did not even know how to give the medicine because he coughed when he swallowed. I was afraid he would choke. About three days I did not give the medicine because I was afraid [...] (C2, Daughter).*

*That pipe that enters the food clogged twice. I did not know how to do it; I was terrified of thinking it might come out. When he returned from the hospital, he went four days without eating, because I could not get the food down, until a neighbor came to visit and explained to me, because she had already taken care of her mother-in-law (C3, Daughter).*

By becoming protagonists of home care, the participants revealed that they felt unprepared for this role. They attributed this unpreparedness to the fact that during the hospitalization period they were not included in the care, although they observed them when they were performed by the hospital professionals.

*The first time I had to change the diaper, I did not know where to start, because the nurses did this at the hospital. We were hospitalized for a month, and I never had to do it (C5, Daughter-in-law).*

*When she got home with my husband, it hit me, how am I going to be able to aspirate this tube [tracheostomy]. We got the vacuum device, because I had to vacuum the same way in the hospital, but I never did that, I just saw the nurses doing it (C7, Wife).*

*I did not know how to dilute the medicines to put in this pipe [nasogastric tube], after all, it is almost 10 per turn, three days later it clogged, then we learned that I had to rinse after the medicine, but no one had ever told me that, they only told me when we got back to the hospital to change the catheter [...]. (C8, Sister-in-law).*

*There at the hospital, they dressed, bathed... And I looked, but when I got home, I seem to have forgotten everything [...]. (C2, Daughter).*

Caregivers also reported the difficulty in getting home care from the basic health unit after hospital discharge.

*We've been home for ten days and no one from the health unit came here, I call there and I am never able to reach them (C1, Daughter).*

*[...] I'm tired of calling there and no one answers [...]. (C4, Daughter).*

*The girl from health unit came here because my neighbor went to the health center and talked about the event. But she said the nurse and doctor would come on Friday. It has been eight days, and no one showed up (C6, Mother).*

In the absence of professional help and lack of knowledge about how to act in relation to home care, caregivers chose to seek information on the internet.

*[...] After three days at home, a wound started to appear with red blisters on her buttocks. So, I started looking on the internet for what it could be and saw that it was not to turn over in bed, I started watching videos on how to do this, that is what helped me until you arrived [...]. (C3, Daughter).*

*I decided to look for videos on the internet about dressings and aspiration, I was always very scared, but this was encouraging me and showing that was not a seven-headed beast (C7, Wife).*

The reports in this subcategory show that the caregivers had doubts and experienced negative feelings about the care they were performing in the first days at home.

### *Adaptations imposed in the family's daily life*

The testimonies showed that bringing home a family member with a sequel of stroke exposes other weaknesses in the family environment, including the inadequacy of the home infrastructure for care.

*I bathed him on this couch, because there was no hospital bed, I did not think I would need it (C2, Daughter).*

*I put her to sleep on the sofa bed in my living room, how was I going to go upstairs with her? [Crying] (C4, Daughter).*

*Our bathroom does not fit the chair, I made an adaptation, I put a basin under the chair, I heat the water and I shower with a mug right here in the room. I would have to break the wall, but now I am not able to do it [...]. (C3, Daughter).*

The caregivers explained that changes in infrastructure were necessary in order to enable/facilitate daily care:

*As you can see, I took my daughter out of the room, she is sleeping with my husband, and I made a room for my mother with this bed for me to sleep next to her (C1, Daughter).*

*My living room became this hospital room you are seeing, I removed my furniture, put it in the room she slept in, I left only the television, because they said it stimulated her [...]. There is no luxury, but that is where the hospital bed we got would fit (C4, Daughter).*

The changes in view of the needs of the family member with stroke also affected economic and relational aspects of family life. The new demand required unexpected adaptations and even resignations on the part of caregivers and their families.

*[...] I had to get by because I still lived on the farm, my father lived alone, and when it happened, I had to run to rent a house in the city to be closer to the doctors. My husband was unemployed, and we had no money, a brother from the church helped us (C1, Daughter).*

*When I talked to my husband, he did not accept it well, because he thought about the expenses, we do not have money, I am a teacher and I earn just to survive, I pay rent, my daughter goes to college and my husband is a construction worker. Even though my husband did not like it and was not in favor of it, I kept my decision to take my mother to my house (C3, Daughter).*

The report by C7, for example, demonstrates how the presence of a family member with stroke sequelae at home had implications for their working life.

*[...] I left my job without even notifying because it was like that suddenly. I called my boss, but he said I am going to have to ask for my own resignation because he cannot settle with me. I have been with the company for 12 years and now that I needed it, I feel helpless. I cannot leave my husband for my work, even if we need this income. Now we only have his retirement, and expenses will increase, but I have to take care of him (C7, Wife).*

Thus, financial burden was another problem frequently experienced by caregivers.

*Half of my salary this month was spent on electricity that increased here at home, help with food, diapers that we have to buy, medicines that the doctor prescribed that are not available at the health unit (C1, Daughter).*

*The retirement is blocked, because she had to prove she is alive, I am the only one to look for it, and I have no one to take care of her. I need this money to buy diapers and food, because they have not released it yet through the SUS, my sister-in-law lent me some money, but it is only for this month, I will have to solve it (C5, Daughter-in-law).*

The reports in this subcategory highlighted the changes that took place in the caregivers' personal lives and the adaptations that were necessary in the physical environment to enable the provision of care.

### **Facing difficulties in home care**

By exposing the difficulties experienced soon after arriving at home, the caregivers showed a lot of emotion, accompanied by crying and a feeling of acceptance. But, at the same time, they revealed an important need to express these feelings, as if this helped alleviate suffering:

*I think I am developing a certain depression because I feel helpless, sad, and tired. It has been 10 days since we got back from the hospital and I do not sleep well, I do not eat, and I just think about how to help her. Do you understand my situation? I have insomnia, I was taking medicine to sleep, and now I cannot take it for fear of not waking up, I have a whacked head and about to have a nervous breakdown (C4, Daughter).*

*After three days he was discharged, came back home, but he did not walk, did not speak, and did not eat, since the day he returned home and saw my son like this, I cry, but I hang on so as not to show my despair. It is very difficult for a mother to see her hardworking son come home from the hospital in a wheelchair, without speaking. But I have to be strong to help him (C6, Mother).*

The referred burdens were not only physical, but also psychological and highlighted the dimension and importance of the suffering experienced in care in the first few days at home. The visible face of this suffering was identified based on frequent crying and reports of difficulty sleeping, weight loss and a feeling of impotence, despair, and discouragement.

*I am afraid my dad will choke since he got back from the hospital I have not slept. I have already become a zombie. I am afraid he will be sick, fall, I do not know if another stroke can happen (C2, Daughter).*

*It is very difficult to see your mother in a situation like this and feel powerless for not knowing how to take care of it, I do not feel like doing anything anymore, and I do not have the courage to live (C1, Daughter).*

*I have a lot of pain in my legs and arms, and I do not even have the strength to do my homework that I used to do. Now my father like this, how am I going to help? This broke me inside; I cried and saw no solution. My dad, who took care of me so much, helped me so much throughout my life and now he needs me, and I cannot help (C3, Daughter).*

*The first few days we got home; I cried every day. I have lost five kilos since he had this disease, because I do not even have time to eat (C4, Daughter).*

*In the first three days we arrived, I did not take a shower, because I did not have the courage to leave his side for a minute, due to insecurity (C5, Nora).*

The absence or even deficiency of family/social support reflected in self-care with their own health, including in cases where the caregiver was already living with a chronic condition.

*The diabetes and blood pressure medicine is over, and I cannot go out to get it, how can I leave him here with this pipe [chest drain]? He is not able to go with me, because it is three blocks,*

*I could go, but how do I do it? I am waiting for the neighbor to have some time and come here to stay with him, so I can go [...] (C6, mother).*

In addition, it is necessary to consider that the lack of family and social support compromises the quality of care that is provided to the family:

*When the catheter came out, I had to call the ambulance, my brothers do not come to help, I stay there every day, she is at my house, and no one is available. I was waiting for more than two hours, because no one could take her to the hospital with me (C4, Daughter).*

*I need dressing material, a tube to aspirate, oil to apply on his skin and I cannot get it. How do I leave him alone? I do not have anyone to stay here (C1, Daughter).*

However, this absence was reflected, above all, in the manifestation of physical and emotional overload of the caregivers:

*I am very tired because I have to think about everything: the medicines, the day the doctors return, preparing the food, taking care of him, I still have my little son who was sick, cleaning my house, I have six brothers, but everything remains for me (C2, Daughter).*

*As we do not have a child, I am alone to take care of him. As you can see, I have not been to the market for more than months, I live off donations, and from a brother in the church who goes to the market for me, but it is hard to depend on strangers. No one in the family comes to help me. He has brothers, sisters-in-law, nephews, but they only come to visit and look there (C7, Wife).*

It was possible to verify that the burdens appeared soon after hospital discharge and manifested themselves in different ways, according to the reality of each caregiver and each family.

## DISCUSSION

The caregivers participating in this study experienced, in the first days of care at home, several feelings, which were related to the insecurity in caring for the family, the fear of worsening in the clinical condition, financial difficulties, the need for adaptations in the infrastructure of the home and the lack of social relationships with other family and friends.

These feelings have been frequently identified in the national literature. For example, a qualitative study carried out in the state of Minas Gerais that investigated the meanings of living with elderly people with stroke sequelae found frustration, frailty, and fear of care. It also showed that taking on the role of family caregiver has physical, psychological, social and, above all, implications for family dynamics.<sup>13</sup>

In this sense, a study on the functioning of families with care-dependent elderly people in Cuiabá, Mato Grosso, revealed that the dependence of one of its members causes significant changes in several areas of family life, such as finances, affection, and the caregiver's health, in addition to causing loss of freedom for family members who live with the dependent person.<sup>14</sup>

The experience of taking care of a family member with stroke sequelae is configured as a task that causes stress and exhaustion, due to the affective involvement and changes in a relationship that used to be reciprocity, to a relationship that is now dependent. As a result, the individual who assumes this role starts to have important restrictions in their own life.<sup>15</sup>

A study carried out with informal caregivers of patients with stroke sequelae in Australia found a decline in the mental and physical health of the participants, as well as the experience of feelings of isolation, abandonment and lack of support from family and friends, and the fact that few have strategies to manage their own health.<sup>16</sup> In the same direction, in North Carolina, research highlighted that the absence of support, resources and knowledge about care after a stroke generated social isolation and feelings of depression in caregivers, compromising the patient's recovery process. This is because the caregiver's performance is affected, so that he becomes less likely to guarantee the necessary resources for the rehabilitation of the family member.<sup>17</sup>

In Brazil, working time as an informal caregiver is generally not considered in studies that assess burden. One of them, however, only included people who had been caring for at least 30 days and at least five times a week,<sup>9</sup> while another defined a minimum of six months of activity after the injury.<sup>18</sup> Therefore, the differential of this study is the fact that data collection took place seven to 10 days after hospital discharge, and during this period the caregivers are already experiencing overload and negative feelings about the care. This allows us to infer that the suffering resulting from unpreparedness for continued home care arises in the first days of home care.

Thus, it is important to consider that nurses working in hospital units should start preparing the family for the moment of discharge early. Thus, it is essential to teach basic care related to, for example, the administration of medication, bathing, dressings, changing positions, handling tubes and drains, clinical signs of deterioration, among others. In this sense, it is important to encourage and enable family members to help with care during hospitalization, as with supervised practice, doubts can be resolved, favoring the development of skills and security among caregivers, and reducing anxiety about having to take care.

A study carried out with relatives of stroke patients admitted to an intensive care unit (ICU) of a hospital in Massachusetts, United States, found that they had anxiety, panic and symptoms of post-traumatic stress, because they knew they would take care of them. at home.<sup>10</sup> As identified in a study with Australian family caregivers, it is very important to offer services that complement the hospital's information, through training, education and community support, as demands are not cumulatively met, due to lack of knowledge about their implementation, for example, generally lead to adverse results on the health of the family member and on the quality of life of caregivers.<sup>19</sup>

In this regard, a survey carried out in three hospitals in Taiwan one year after being discharged from a first stroke showed a relationship between the level of education of family caregivers and their own health care. In view of the results, the authors recommended that health services, through discharge plans, support groups, consider not only the patients' conditions, but also the health status of their caregivers, to avoid overloading in the first days at home, and that provide easy-to-follow instructions, personalized consultations, and free courses for training in the necessary care.<sup>20</sup>

Some participants reported that they look for information on the internet about preparation for care. Although this approach is not the most appropriate, since much of the information provided may not have scientific proof, it cannot be overlooked that it was through this means that some caregivers got the help they needed to carry out the care. The use of this strategy, therefore, shows the difficulty of access and the distance that still exists between caregivers and health professionals. In this sense, users of a mobile application developed at the *Universidade Estadual do Rio de Janeiro* with the aim of facilitating communication between family members and health professionals stated that this application gave them the feeling of being connected to the health team and that this, consequently, improved home care.<sup>21</sup>

Thus, it is inferred that the use of different technologies can be a viable alternative in the search for strategies that favor the access of users to services and communication with health professionals. This is particularly important in the case of chronic conditions when there is stability of the condition, but follow-up is still necessary, especially in the first days after hospital discharge, since in this period a new world unfolds, with doubts and insecurity being common.

The results of the present study demonstrate the need for and importance of preparing the caregiver to carry out care at home, even during hospitalization, so that he or she is seen as an integral part of care. It is also up to health professionals to consider the caregiver as an important element of support and a fundamental link between the patient and the institution, making the care environment safer and more welcoming.<sup>22</sup> From this it is possible that the arrival at home is less traumatic and cause less suffering for the caregiver and family member.

However, professionals need to reflect on the transition from hospital care to home care. In this regard, a study carried out in Florida with 40 caregivers revealed that the rehabilitation team can help the caregiver and the patient to prepare for the challenges of being discharged home, even during the hospitalization period. This can be done by identifying gaps as family members assume responsibility for providing care.<sup>23</sup>

Considering this scenario, interventions to favor this process can and should be carried out before, during and after hospital discharge. However, to minimize caregiver burden and improve outcomes for stroke patients and their family caregivers, the family unit and the importance of individualized care plans that value specific needs and characteristics should be considered.<sup>23</sup>

Inpatient unit nurses can propose, together with their companions, a care plan to organize discharge and care upon arrival at home. The importance of the care plan being constructed during the hospitalization period is highlighted, in order to provide subsidies for the nurse to guide the patient, family member and/or caregiver, in addition to favoring the transfer of care from the hospital to the home, facilitating and helping to develop the role of the caregiver after hospital discharge.<sup>24</sup>

It is considered that well-informed, oriented, and more experienced caregivers are less anxious and safer in providing care, which reflects in more capacity and availability to care for the patient.<sup>25</sup> Therefore, it is essential to include and encourage the presence and participation of family members in care during hospitalization, not as labor, but as a form of training and preparation of the caregiver for the care that will necessarily have to be performed at home.

## FINAL CONSIDERATIONS

The involvement of a family member by stroke sequelae has repercussions on the way of life and on the family's duties, especially on the person who takes care of them after hospital discharge. It is common that when faced with the need to take care of the family member, this person feels insecure and distressed during the first few days at home and away from health professionals.

Taking care of the dependent family member requires strength and courage from the caregiver to overcome insecurities arising from the hospitalization period and the fragility found after hospital discharge. Understanding the feelings and difficulties in care is essential so that the health team can better equip the family member for care and, in this way, minimize the suffering and burden at the beginning of this journey.

It is noteworthy that, in the first week after hospital discharge, the caregivers have already reported physical and psychological overload, which demonstrates that it is essential that the community has early involvement and joint work from different sectors, in addition to looking at the caregiver-patient binomial.

The fact that only female caregivers participated is highlighted as a limitation of the present study, as men can have another experience during the first days of adaptation and home care. Thus, it is suggested that future studies include, in addition to the condition of transition from hospital to home, male caregivers, in order to deepen the understanding of this phenomenon.

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