

Needs of caregivers of stroke patients after hospital discharge*

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ABSTRACT

The aim of this study was to describe the needs of family caregivers of stroke victims after discharge. This is a qualitative study based on convergent-care research conducted with four families and carried out through home visits according to the needs of each family. Data were collected using open-ended interviews and participant observation, and were transcribed and subjected to thematic content analysis. The findings were organized into two thematic categories, namely: Discovering the need to continue treatment of family members at home and The social support of families for coping with illness. Based on the observations, it was possible to identify the difficulties of these families and provide guidelines at home to help them adapt quickly after discharge, thus promoting the recovery of patients and quality of life of family caregivers.

Descriptors: Stroke; Family Relations; Home Nursing; Humanization of Assistance; Nursing Care.

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INTRODUCTION

The cerebrovascular accident (CVA) is considered the second most common cause of death in the world, and survivors can suffer crippling after effects⁽¹⁻²⁾. Even after discharge, most sufferer functional disabilities, such as problems seeing, feeling, walking and speaking, and rely on the fundamental care of their families. Moreover, CVA has a socioeconomic impact on family life and the healthcare system⁽³⁻⁶⁾.

Today, extensive discussions are being held on the advancements needed to promote effective strategies for the rehabilitation of people with CVA, especially regarding their return home^(1-2,5,7). These discussions address social support networks as valuable resources to compensate some of the demands placed on the healthcare systems⁽⁷⁻⁸⁾.

When returning home, the perspective of care differs from the care provided in hospitals, given the absence of health workers at home⁽⁹⁾. This care, however, must be continued to rehabilitate patients, improve their quality of life, and prevent potentially avoidable readmission^(2,5,10).

This moment generates apprehension and fear in the families, especially in cases that require more complex care⁽⁷⁾. Consequently, tasks such as sponge baths, scheduled medicine administration, changing positions to prevent pressure injuries, and others, must be taught to the family members during hospitalization, so they can carry them out properly and with confidence at home^(2,10).

In addition to the training and guidance during hospitalization, the families must be supervised in the discharge transition period to identify any difficulties they experience in this process and build strategies to mitigate and/or minimize the family's suffering^(1-2,11). In this perspective, convergent-care research (CCR) has proved to be a consistent methodology to identify difficulties, promote support for these families, and produce data for research⁽¹²⁻¹⁴⁾.

Therefore, the aim of this study was to describe the needs of family caregivers of stroke victims after discharge.

METHOD

This is an exploratory, descriptive, qualitative study based on convergent care research (CCR), conducted with caregivers of stroke survivors after hospital discharge. The main justification for selecting CCR was the possibility of articulating this methodology with the nursing practice, introducing innovations in care and formulating the research topics according to the needs identified in the current context of the practice⁽¹³⁻¹⁴⁾.

Two institutions were selected to search for and approach the families, with the approval of these institutions. One institution is a public hospital with 123 beds, accredited by the unified health system (SUS), that gives priority to services, teaching and research. The other institution has 192 beds and provides services for the SUS, health insurance, and private patients.

The inclusion criteria for the families were living with a sick family member in the city of Maringá and/or the metropolitan region and being family members the main caregivers, with no financial gratification. The main caregiver concept used in this study refers to the person responsible for providing the daily care and support to the sick family member at home⁽⁸⁾.

For the CVA survivors, the inclusion criteria were patients admitted to hospital through the SUS during the researchers' observation period and having a moderate, severe or very severe level of dependency, according to the Mini Dependence Assessment (MDA)⁽¹⁵⁾.

The criteria for exclusion were people with CVA under 18 and patients whose families had hired a healthcare professional or caregiver for the home care.

The families were approached from February to May 2014, initially during the patient's hospitalization in the clinic and ERs of the two institutions. Twenty-two families were approached and 17 of these families did not meet the inclusion criteria because they did not live in Maringá or the metropolitan region (9); they did not reach the minimum degree of dependence, according to the MDA(3); the family member who had suffered a CVA had not survived; they had hired a health worker for the home care (1); the family member was institutionalized at a long-stay inpatient facility (1). The five families who meet all the inclusion criteria were informed on how the research would be conducted and asked to schedule the first home visit after discharge. One family declined after the second visit, resulting in four families participating in the research.

Data were collected during the home visits at least once a week for an average of 70 minutes, totaling 16 visits. The main caregivers and the CVA survivor were present in all the visits. Four CVA survivors and six family caregivers participated in the study. The family members read and signed two copies of an informed consent statement. The informed consent statements of the CVA survivors were signed by the main caregivers, that is, the people accountable for the daily care of the patient. Furthermore, in three families the home visits were also verbally approved by the patient, while in one family consent was not possible due to the severity of the CVA sequelae.

The nursing care was determined according to the needs detected in each visit, and covered activities such as providing guidelines about home care, evolution and complications of the disease, and answering questions of the family members. It also involved direct care practices and demonstrations, such as sponge bath and spraying, oral hygiene, dressing and meal supervision, medicine administration schedules, change in decubitus, and entertainment activities, with educational songs and games.

The nursing care was based on the professional experience of the nurses in the research group, the home care protocol⁽¹⁶⁾, the systematization of nursing care ("SAE"), the NANDA, and theoretical studies on the subject.

A field journal was used to record the performed activities, doubts and needs of the families, informal interviews, and other data from participant observation. As of the second visit, and after proper authorization, the visits were recorded on a digital device and, subsequently, transcribed in full. At the end of the visits, the nurse researchers provided feedback to the participants.

The transcribed statements and the journal formed the body of data, which was subjected to content analysis. The analysis followed the three steps required for this method, namely, pre-analysis, exploration of the material, and processing of obtained and interpreted results⁽¹⁷⁾.

This analysis led to the following two categories: Discovering the need to continue treatment of family members at home and The social support of families for coping with illness. To ensure the anonymity of the families, they were identified with the names of the four seasons and each member was identified with the name of a specific seasonal flower.

The project was approved by the Standing Committee on Ethics in Research Involving Humans of the State University of Maringá (Case No. 297.227/2013, CAAE: 16398713.0.0000.0104), in accordance with all the provisions of Resolution 466/12 of the National Health Council.

RESULTS

Table 1, below, shows the characteristics of each family, followed by the results discussed in both categories.

Table 1: Characteristics of the participating families Maringá, PR, Brazil, 2015.

Family	Description
Family Summer	Amaryllis, 79 years old, a retired teacher, living with her eldest daughter, Dahlia (caregiver), 42, public employee, her son-in-law, Geranium, 37, pastor and businessman, and her two grandchildren, Vinca (10) and Coleus (1 year and 7 months). Amaryllis has systemic arterial hypertension (SAH) and cardiac arrhythmia. After the CVA, she has difficulties speaking, swallowing, and walking. The family has a harmonious relationship and a stable financial status.
Family Autumn	Snapdragon, 58 years old, master builder, his wife, Rose, 53, housewife, and their two children and granddaughter. After CVA, Snapdragon has difficulties walking and speaking and suffers from short-term memory loss. He smokes, has SAH, and stage 5 polycystic kidney disease, waiting to start dialysis treatment. Rose, the main caregiver, also smokes and suffers from SAH and hypothyroidism. The family is having difficulties because of relationship problems between their two children. The son, Mayflower, is 26 and a multiple drug user. Orchid, 29, the eldest daughter, is a widow and suffers from SAH and panic attacks. She has a 6-year-old daughter and they live at the back of their parents' house.
Family Winter	Formed by Azaleia, 92, retired, her daughter, Cherry tree, 58, and her son, Jasmin, 50, both working as general services assistants. Hydrangea (Azaleia's eldest daughter) and her family live in the same backyard. Azalea has SAH and Alzheimer's disease. Before the CVA, she could not walk but she could speak and eat normally. After the event, she became totally dependent on care. Jasmin is elitist and Hydrangea has type II diabetes, SAH, cataracts and special needs (leg amputated due to diabetes complications). The greatest difficulty mentioned by the family was the limited social support network.
Family Spring	Consists of Carnation, 79, and his wife, Gerbera, 73 years, both retired. The couple lives alone and has seven children. The eldest daughter, Calla, 50, lives with her husband and daughter in a house on the same plot as her parents. The early CVA sequelae left Carnation with difficulties walking, talking, swallowing, and movements on the left side of his body. After four follow-up weeks, his speech improved and he started using walking sticks. Gerbera has a venous ulcer in her lower right leg that requires weekly dressings. Their main difficulties were related to the caregiver's burden, given her age and circulatory problems, which impair the performance of her daily care and, consequently, her husband's care.

Discovering the need to continue treatment of family members at home

When asked about the guidelines and training of healthcare professionals at discharge, the family members said they had received little information, leading to a series of questions during appointments, mostly regarding their concerns with rehabilitating the patient's lost communicative and motor functions.

Will she stay that way or will improve with time? (Cherry tree – family winter) I think he's going to start walking again, right? You have to be patient, right [...]. (Rose – family autumn).

Moreover, the families reported they felt insecure about the schedules, doses, adverse reactions, and care in administering the prescribed medication.

Is her pressure high? So can I give her the medication now? Or should I wait for the right time? (Cherry tree – family winter);

My husband has a terrible itch, could it be a reaction to the new pressure medication the doctor prescribed? (Rose – family autumn);

The caregivers were also concerned and afraid of some CVA sequelae, such as dysphagia.

I mash the food really well, she does not like it, but the speech therapist told me to do it, I keep an eye open because I'm terrified she'll choke because she still can't swallow properly. (Dahlia – family summer).

You have to mash it all up, doctor's orders, if not, he can choke and it all goes to the lungs like it did in the hospital. (Gerbera – family spring).

The family members also feared the risk of falls, especially during bath time.

My children come every night to give dad a bath, and they are scared to death of him slipping, can you imagine that? God forbid if this man falls in the bathroom and something happens! (Gerbera – family spring).

Skin care was addressed by the families, especially family winter since Azaleia is bedridden and fully depends on care. In view of Azaleia's pressure injuries, the caregiver's anguish and feelings of powerlessness are quite apparent.

It saddens me to see my mother like that, when she didn't have these wounds... It was OK, but now it's difficult and I did everything I could to prevent it [cries]. (Cherry tree – family winter)

In light of the doubts, anxieties, and difficulties of the families, the nurse researchers provided information on adverse reactions to the medication, wrote down the scheduled times on planners and/or sticky notes in visible places, demonstrated sponge bath and spraying techniques, and supervised the first baths until the caregivers felt confident enough to do them alone. With regard to food, the families were advised to remain calm and patient during meals and offer food to their family members according to their needs and speed of chewing and swallowing. At times, the sick family members were encouraged to feed themselves.

In relation to the ongoing treatment for the pressure injuries, they were encouraged to continue with hydrocolloid dressings in the calcaneal and sacral regions exhibiting hyperemia to maintain skin integrity in those regions. They were given instructions on how to apply soothing massages with body oils after the bath.

Moreover, the nurse researchers provided oral hygiene guidelines with support and demonstrations of oral cleaning techniques. They also conducted recreational activities to stimulate cognition.

The social support of families for coping with illness.

Most families had some family or social support that helped them with the rehabilitation and care of the sick family member.

Look, it is not easy at all, working and taking care of her [...] it is chaotic. I have to give her a bath alone, then I give her dinner and all the medication, luckily my bosses are good and let me out early to come see her, where else could I do that? [...] they support me with everything I need, it's like a family. (Cherry tree – family winter)

Social isolation was identified in some families due to the caregiver's lack of time to leave home for leisure purposes or even the fear of friends and relatives of interfering with the care. All the caregivers stated they felt isolated because of the care demands of their family member.

*We never go out much, either, and as we are new in this city, we do not get many visitors. (Dahlia – family summer).
I do not have anyone to leave her with so I do not go out with friends. (Cherry tree – family winter)*

The families had financial difficulties due to the sharp increase in spending and reduced family income after the caregiver stopped working. The caregivers, however, received financial support and food supplies from social actors directly involved with the families, such as church and business friends, in addition to extra income from self-employed relatives who were not directly involved with the daily care.

*He has not gotten his retirement, yet, and we have no income, the children help a little, my siblings, and we get basic food supplies from the church, but I am tired of depending on others, it is horrible! (Rose – family autumn).
The spending has increased, luckily we get help from lots of people [...], but still, I need to get some things to pay later at the pharmacy, I find a way and always get the things she needs. (Cherry tree – family winter)*

DISCUSSION

Many families, when forced to cope with a chronic health situation, are confronted with the choice of assuming an important and preponderant role for the recovery of their sick family members: being a caregiver. Public health policymakers in Brazil are gradually considering home care provided by family members as a powerful resource for deinstitutionalization⁽¹⁶⁾. When patients return home after being hospitalized, their families feel fragile and must choose a caregiver to ensure the continuity of care⁽¹⁸⁻¹⁹⁾.

This care is often performed intuitively and may lead to errors due to the lack of guidelines during hospitalization or the provision of guidelines that do not address the real needs of caregivers. Furthermore, family members do not always have time to assimilate and master the guidelines provided during hospitalization⁽²⁰⁾.

It is important to continue care after discharge for positive results in treatment and a better adaptation and recovery of the limitations caused by CVA, thus preventing co-morbidities and potentially avoidable hospitalizations⁽²¹⁾.

According to literature, the CVA causes apprehension in the families with respect to the continuity of care, especially when the family caregivers are not appropriately prepared^(5,7,18). Families must be trained and empowered at the institution before discharge to ensure greater safety in home care^(1,21-22).

The rehabilitation of CVA survivors aims to restore their independence for self-care and self-management at home and avoid complications arising from the impaired body movements and immunity. Healthcare actions must involve guidelines to ensure rehabilitation in all aspects —physical, mental, spiritual, and social— and restore the dignity, respect, and independence of survivors^(18,22).

In this study, the sick family members were encouraged to perform tasks, such as washing their teeth and eating alone, according to their cognitive and motor level. This autonomy, even in simple, everyday activities, boosts their self-esteem and confidence, provides well being, and relieves the burden of caregivers^(5, 7,19).

Guidelines on medication were also provided, such as mechanisms of action, schedules, doses, and adverse reactions. When necessary, the medication was administered by the nurse researchers. According to the statements, the families were very uncertain about this subject and these doubts were attributed to the lack of basic guidance on home care provided by the healthcare workers during hospitalization. This absence of guidelines leads to inadequate knowledge, mainly caused by the complexity of medication and concerns regarding the required care⁽¹⁰⁾.

After CVA, 30% to 40% of the survivors need some type of help to eat due to dysphagia. The most frequent complications of dysphagia patients are aspiration pneumonia and malnutrition, resulting from lack of synergy in the swallowing mechanism. Dysphagia is usually associated with coughing after swallowing, difficulty breathing, and lung infection, and compromises both the respiratory portion and nutrition^(5,21).

The caregivers of families with this difficulty were advised to ensure they remained calm and conveyed tranquility to the sick person when swallowing. In every visit, every question made by the family members regarding care revealed that most difficulties faced by caregivers were directly related to lack of information on the disease, treatment, and complications.

Concerns about the risk of falling were also observed in the four families. According to a study⁽²⁰⁾, the major risk factors for falling are impaired balance, being over 65 years of age, proprioceptive deficit, diminished strength in the lower extremities, difficulty walking, impaired mental state, visual difficulties, and use of antihypertensive drugs. Guidelines to reduce the risk of falls should be part of the care plan for CVA survivors, and the protection and prevention measures should be practicable by the family caregivers.

Despite all the precautions of the caregivers, it was not possible to prevent pressure injuries, possibly related to diminished perception, blood circulation, and impaired mobility^(7,20). Specific guidelines such as change of position, massages with essential fatty acids, use of special mattresses to reduce pressure, encouraging patients to leave the bed, and adequate nutrition, were provided to improve skin health and prevent other injuries or the contamination of existing ones.

In addition to the important role of professionals in the provision of guidelines and training, the families need social support, often defined as a web of relationships surrounding a subject, whether people, institutions or social movements^(11,19). The inability of the sick family members to return to work is highly relevant, since it is both a source of financial resources and a support for social relations. The illness of a family member is recognized as a process that could impoverish the social network and expose the sick person to a situation of social vulnerability^(18,20).

Moreover, the sick person's inability to go back to work can reduce the quality of life of these patients and of their families. In this sense, financial difficulties are a major problem for sick people and their families since disease directly increases expenditure on medication, supplies, and services⁽¹⁹⁾.

Finally, the weaknesses caused by a chronic condition were also identified. It is necessary to formulate and implement policies that promote greater family support for care after discharge. Investments during this recovery period can help reduce the rate of readmission, often considered preventable, with the availability of quality home care.

CONCLUSION

By entering the family homes, it was possible to observe that chronic disease causes a number of changes in the family routine and forces family members to cope and adapt to the new situation. Understanding the families and experiencing the return home of survivors after discharge provided valuable insight into the difficulties they must face. These difficulties include doubts about administering medication and the pathology of CVA itself, and insecurities regarding daily care, such as bathing and feeding.

Based on observations and application of the CCR method, the nurse researchers could provide support for these families during the adaptation period, thus promoting the rehabilitation of the sick family members and quality of life of the family caregivers.

The use of CCR helped create a bond with the families and identify their needs in the first months of home care, while promoting a convergent care constructed according to the socioeconomic, cultural, and contextual characteristics of each family.

Although the sample size does not allow generalization, and is, therefore, considered a study limitation, the results are reliable since the main objective was to gain greater insight into the needs of caregivers of CVA survivors when practicing home care. Moreover, it reveals the need to conduct further studies with different methodological approaches involving this subject, especially with the families of care-dependent patients.

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