

## **Education and Domiciliary Care of Disability. Family Caregivers of Persons with Accident Vascular Brain**

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**Received:** November 17, 2021; **Published:** July 27, 2022

### **Abstract**

**Objective:** To identify the knowledge of family caregivers on the management of patients with stroke disabilities who graduated from institutions providing health services.

**Materials and Methods:** Descriptive, cross-sectional sample of 37 family caregivers. Structured questionnaire was used, test of knowledge and PULSES profile.

**Results:** The most common strokes are ischemic (57%) and bleeding (38%). The most common motor disability (95%), sleep disorders (73%), aphasia (65%) and cognitive (30%) subjects showed more care for a disability (76%) with mild degrees of severity 57%, moderate 35%. Was evident in family caregivers better understanding for the management of motor disabilities, information on dysphagia, aphasia, sleep disorders, were excluded from the education provided to 9 out of ten cares, despite being offered it by staff health (92%) to 73% of caregivers, it was such incidental and therefore did not include care for disability present at discharge from the stroke.

**Conclusion:** Family caregivers face their role with low levels of knowledge about management of disabilities; recommended educational programs within institutions.

**Keywords:** Stroke; Disability; Knowledge

### **Introduction**

The importance of caregiver instruction that is faced with the home care of people who leave with a total or partial disability problem is permanent or not evident when analyzing the prevalence of stroke in the country that reports DANE [1]. This condition involves between 7.8% and 9.5% of the general population with a variability that depends on the regions; the same national body reports that the World Bank has reported that about 10% of the world's population lives in disability [2]. To estimate the importance of the topic under study, it is

necessary to estimate that about 10% of the world population assumes the role of family caregiver of people with stroke sequels, because for each person with a disability there is at least one person who plays the role of family caregiver.

In Dorotea Orem's theory of nursing, it is expressed that when, for reasons beyond his control, the person cannot satisfy his needs; the changes from being "an agent of his self-care to receiving care". In cases where the disability is part of the essence of the disease, it is necessary to focus the role of the caregiver which is assumed at the hospital level by the nursing professional, said function at the time of discharge of the patient extends to the instruction of the Family caregiver who will henceforth care for the disabled person in the place of residence; key aspect that was addressed in this study [3].

For nursing as a discipline, it is important to recognize the level of education, regarding the care of patients with disabilities, with which the family caregiver counts at the time of discharge, because these knowledge are conditioning factors that directly affect the quality of life of the Caregiver and caregiver [2,3] even more so if one considers the fact that in the Caribbean Coast, partly because of the low socioeconomic level and because of the lack of institutions dedicated to the home care of this type of patients, home management is in the hands of relatives, In most cases it does not have the training [4,5]. Professional and/or technical support to provide quality care.

Another factor to take into account is that half of the survivors to an acute episode of stroke leave with sequelae manifested in different degrees of disability; In the study on Care Ability of Caregivers of People with Chronic Illness Performed by Barrera, *et al.* (2004) it is demonstrated that the level of functionality of people with chronic disease (measured with the PULSES profile) is low level of functionality 16.67%, identical percentage had an average level and 66.67% had a high level of functionality [6]. These levels are enough for a person to need help to comply with daily activities, their participation in self-care is usually slow [7], progressive [8] and linked to the rehabilitation process. All of the above originated the descriptive research proposal, transversal with the objective of identifying the knowledge, about care practices, given to family caregivers of patients who leave public and private Health Services Institutions, with disabilities due to the sequelae of a Vascular Brain Accident.

### Material and Methods

Descriptive, cross-sectional study; for 10 months; caregivers of discharged or discharged patients with some type of disability were selected; the family caregivers located in the period were interviewed in different institutional spaces of the Health Service Provider Institutions; both the entity and the potential participant are duly informed about the study's fines and methods to obtain their informed consent and voluntary participation.

Given the lack of specific information due to the underreporting of cases of disability due to stroke, it was necessary to estimate the population susceptible to suffer the event under study, for this was based on the total number of people with disabilities (4,921 people) and prevalence of AVB of 1.4, according to the Bulletin of the Departmental Health Secretariat. With this information the base of population of people with AVB in 160 individuals was calculated.

Based on the population estimates, the finite population formula was used with 95% confidence, 5% tolerable error and p value of 0.14. The sample size was 37 patients with disabilities due to a Vascular Brain Accident and 37 main family caregivers.

Non-probabilistic sampling was used, for convenience, in which the patient and his caregiver were placed in two domains: at the institutional level, at the time of patient's discharge and at home. For the selection of study subjects in the homes, the Emergency Medical Care Centers (EMCC) of eight neighborhoods were visited in search of information on cases of users who had previous hospital discharge due to this cause; Community leaders were also interviewed. As inclusion criteria for applying the survey, the following conditions were investigated for family caregivers:

- Be a caregiver of a disabled person due to a Stroke.
- The Vascular Brain Accident of the subject of care should have happened in less than seven years.

Exclusion criteria: The patient was not included in the study to the family caregiver when he/she presented one of the following criteria:

- That the hospital care should have been carried out at an IPS located outside the city.
- Denial of consent by the family member or the patient.

To identify the knowledge that caregivers have about the management of patients with disabilities due to the Vascular Brain Accident, an interview was conducted for the elaboration of the "Survey of Characterization of Home Caregivers" of the care group of the National University of Colombia [4].

To measure the patient's degree of functionality, the PULSES scale was used, which has five components that evaluate: P: stability of the pathology. U: use of upper limbs, L: locomotion or transferability, S: sensory capacity, E: elimination and S: Social activity as expected. This scale has a minimum score of six and a maximum of 24, the higher the total score obtained the more dependent the person is and the lower the score is more functional [9].

According to Resolution 008430 of October 4, 1993 of the National Health Council, which regulates research ethics, this study was classified as "minimal ethical risk"; being the main ethical risk identified to find deficiencies or errors regarding the way of caring for the patient at home; Through educational strategies, specific education was provided for the needs of each type of disability (according to the case of the patient), and informed consent was requested from the potential participant, indicating that participation was voluntary and they could refuse to participate [10].

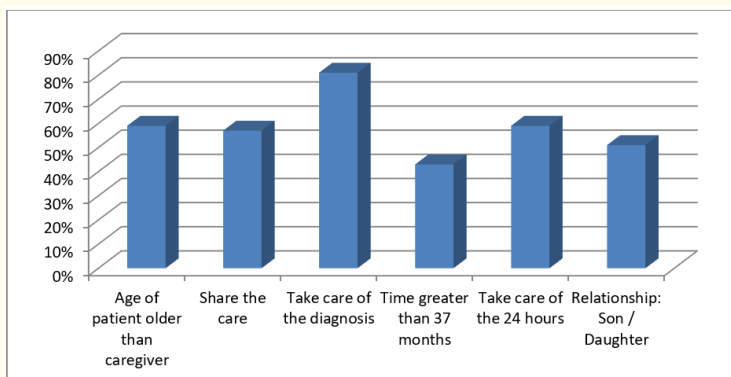
The information was analyzed using descriptive statistics methods, the results were processed using the Microsoft Office Excel operating system and presented in tables and graphs.

## Results

A total of 37 family caregivers were interviewed and the functionality of the same number of people with disabilities due to stroke was evaluated, of which 84% were located at home and the remaining 16% were located at the time of hospital discharge. The results are of interest to the institutions that provide health services, with the sole purpose of developing activities for the educational interventions of the health team that are relevant to the clinical situations of the patients.

**Socio-demographic characterization of caregivers:** With regard to the socio-demographic characteristics of family caregivers, 76% of the women were aged between 36 and 59 years (46%), with an educational level of 27%, married (43%), Household "(54%) and caring for their family, and belong to low socioeconomic strata (73% Stratum 1).

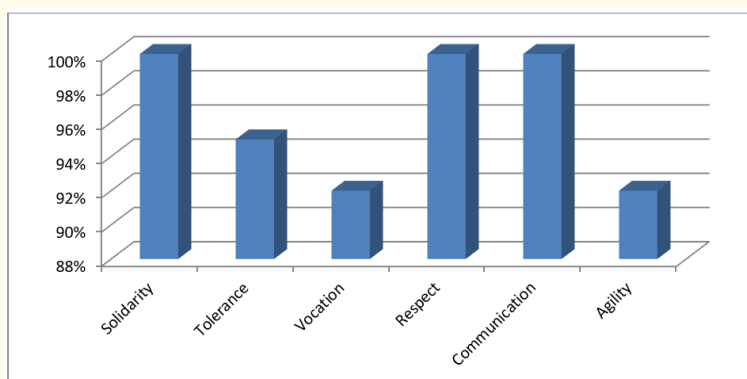
The characteristics that make it possible to identify that the people who exercise the role of primary caregiver of patients with stroke in Monteria, would be relatives of first degree of consanguinity in particular the children and the parents, among them eight out of ten exercise this role from the AVB the subject of care, in long hours because of the demands of care originated by the different sequels presented by them, as seen in figure 1.



**Figure 1:** Sociodemographic characteristics of caregivers.

The most frequently identified types of vascular accident were ischemic (57%) and haemorrhagic (38%). Patients had a disability in more than one of the four groups studied. The most frequent motor area (95%). The severity of this disability according to the PULSES profile was mild (57%), moderate (35%), and severe 8%.

**Personal characteristics of the family caregiver:** The personal characteristics of the family caregiver and that favor home care for patients with disabilities were those that are required for an adequate coexistence and interaction; Situation that reflects the personal commitment of the caregiver with his sick relative and the demonstration of the capacities for the care inside the family, as seen in figure 2.



**Figure 2:** Caregiver personal characteristics.

**Characteristics of the education received by the caregiver:** Regarding the caregiver’s opinion about the knowledge the has for the care of the sequelae of disability by AVB, 73% of respondents were identified as having this knowledge and 27% believed that they did not have the information for the Provision of care.

**Knowledge about care for motor disabilities:** Motor disabilities were the most frequently identified. Regarding the knowledge that the caregiver has about the care of motor disabilities related to the upper and lower limbs, as a whole they obey aspects of general, cultural

knowledge about habits and activities to be carried out by people with motor disabilities; indicative that caregivers of patients with this type of disability have not received specific education about the care needs of each case (See figure 3).

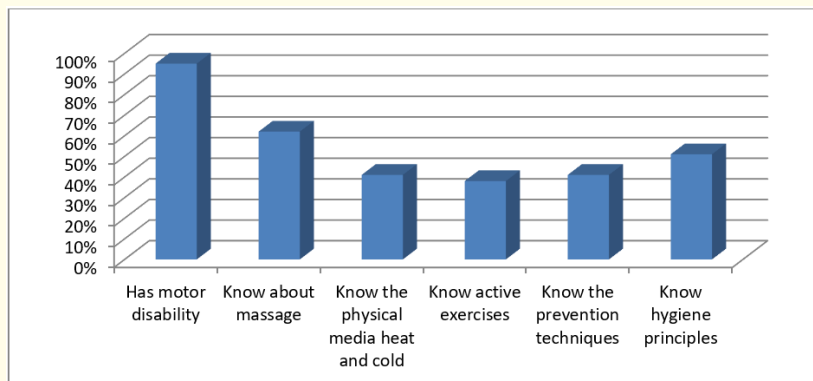


Figure 3: Knowledge about caring for motor disability.

**Regarding dysphagia:** It has been identified that it was present in half of the studied sample; however, in the sample of participants, ignorance prevailed about the maneuvers that caregivers must apply to face this symptom at home, which by its very nature makes it difficult to satisfy oral hydration and nutrition needs. It is important to note that only in one of the six dysphagia care maneuvers did a third of the caregivers surveyed achieve the appropriate response; however, when reviewing the meaning or content of the maneuver, it was possible to identify that this learning is typical of general knowledge about eating habits (See figure 4).

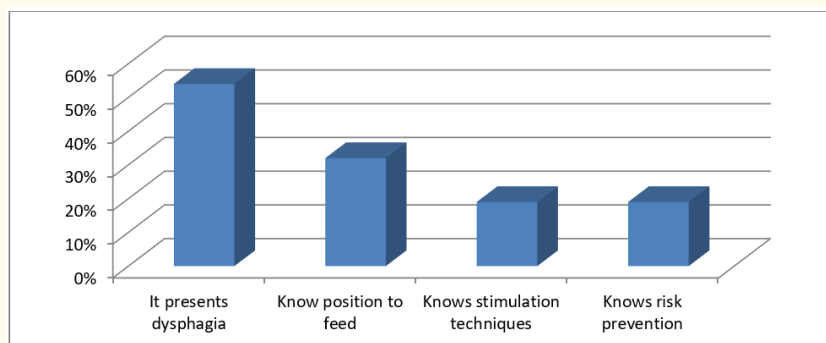


Figure 4: Knowledge about care of dysphagia.

Two-thirds of the patients who are cared for by relatives have speech and/or aphasia disabilities; despite the prevalence of this disability, it was observed in the sample that nine out of ten caregivers of language disabled patients had no knowledge of appropriate techniques to keep communication active or to improve speech, only one of each Three caregivers surveyed had been educated about how the temporo-maxillary exercises are performed (See figure 5).

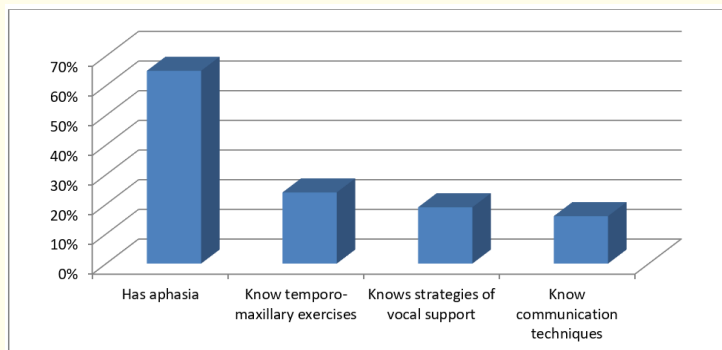


Figure 5: Knowledge about aphasia care.

In the sample, a 76% of little or no control was identified on the urinary and fecal sphincter musculature. The information that the caregiver has to deal with the patient with incontinence problems is fractional and incomplete (35%); in general it is related to the hygiene of the patient, 22% with bladder exercises and 11% with the environment that should surround the person to favor elimination); The three elements of knowledge would be comprehensive, but as can be seen, marked differences were identified in terms of the availability of knowledge by the family caregiver.

**Knowledge about care to regulate the pattern of sleep and need to conserve memory skills:** It was identified that seven out of ten patients have problems with sleep. About the management of this symptom was identified as a common pattern that family caregivers are unaware of the importance of avoiding daily naps to promote nighttime sleep, the importance of using handrails in the patient’s bed and maintaining a calm environment (See figure 6).

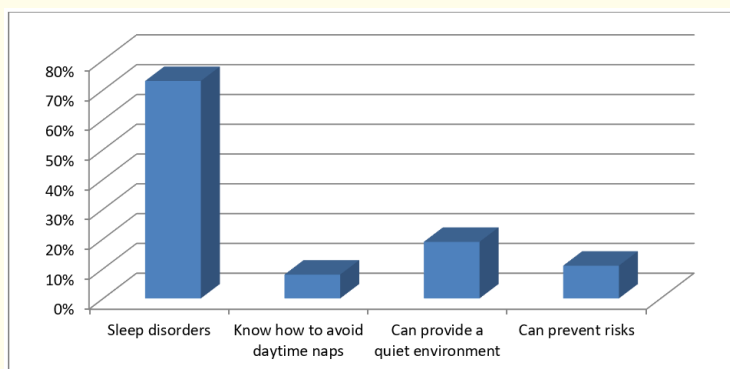


Figure 6: Knowledge related to the improvement of the sleep pattern.

Memory problems were identified in five out of ten patients; 27% of caregivers have some kind of information to achieve improvement or stability of memory deficits, and to preserve the abilities that have not been lost in the patient. In particular their knowledge is related to the importance of using short messages and in 22% use of simple instructions.

**Mechanisms of obtaining knowledge about disability:** The group of family caregivers who reported having knowledge about the management of patients with stroke (n: 27) reported that they received this information from the health professional (89%), 8% received it from a relative and 3% from friends or neighbors.

Education was incidental to 86% of the respondents (only 3% received the planned education that merits the case); As far as the place in which it was educated it is observed that 86% received the information in the hospital or clinic and 16% in the home. The opinion of the family caregiver on the education received seems to have an influence on what the family believes it should know; In this sense, 54% of family caregivers surveyed rated it as appropriate and complete (41%); 16% believed language was simple, and 3% said that information received in education was "practical".

**Expectations of the caregiver:** The expectations of family caregivers for their abilities to help their caregivers and related care practices generally show low frequencies that may be a product of family caregivers' knowledge about the potential for help and activities Capable of performing the person with disability by AVB in their care. The expressed expectations were classified considering the caretaker's will or feeling and not based on what he expects of his relative in the condition of disability.

### Discussion

The social and demographic characteristics of the family caregivers of patients with stroke are perhaps due to the world tendency and the context of Cordoba to assign to women the responsibility for the care of vulnerable subjects, it was possible to observe that the relationship between men and women in the role of family caregiver tends to be superior to studies carried out in other regions [2] a result probably influenced by the high unemployment rates in the male population.

The care of disabled individuals is entrusted to the elderly population [3], perhaps in consideration of their experience, levels of patience and tolerance or because potential junior caregivers are studying or working. It is necessary to emphasize the social meaning that represents the exercise of the role of family caregiver for the group formed by the over 60s, many of whom are able to need for themselves a caregiver.

When analyzing the relationship "caregiver's age - patient's age", it was observed that in cases of stroke, the age of the patient is greater than the age of the caregiver; that is, the family caregivers of patients with stroke are younger than their care subjects. In this respect differences were evidenced with the studies consulted, according to the findings can be deduced in the contrast seems to correspond to the type of event being studied; and that the older age of the care subject in relation to the age of the family caregiver is possibly due to the type of morbidity characteristic of the older adult and old age [11].

The data show a predominance of the low socioeconomic stratum, these findings may be due to the tendency of the researchers to work with this type of population, where the home care is in greater proportion in the hands of family caregivers, without professional training for it.

Communication is a feature of great importance in the act of care, since it implies the exchange of ideas or thoughts between the caregiver and the subject of care and also covers the manifestations of feelings, emotions and needs between these [12] in the results it was observed that the communication between this binomial occurs naturally, without the specifications that can and should be given by the cognitive and language disabilities that usually accompany or be part of the sequels of stroke.

The role of the health professional, as a transmitter of knowledge to the family caregiver of the patient with stroke sequelae, was identified. However, education focuses on aspects such as habits, medications and gross motor behavior, and neglected others such as management of the subject with deficit in sphincter control, with aphasia and sleep disorders [14].

This fact, although of interest, is not done in a programmed or formal way, it must be remembered that the type of predominant education received was incidental [15]; in this type of transmission the knowledge that is offered occurs without planning, it does not establish follow-up to the recipients, however and despite the "improvisation" and incompleteness identified in the education to the familiar care-takers they considered it appropriate perhaps by the degree confidence that inspires the educator.

The importance of the attempt to provide education as a fundamental component of the rehabilitation and the use of the opportunity for the family caregiver to learn about the pathology, its causes and prevention should be emphasized [16]; as well as the meaning of the comprehensive care trial that would be achieved by including the family in the rehabilitation process; However for this to be achieved the information must be adequate and sufficient to all present and potential needs [11] of the disabled by AVB [6].

In this regard, it is noteworthy that more than half of the respondents said they did not have knowledge about the prevention of possible complications related to motor deficit, such as pressure ulcers and neurovascular complications, with a high probability of occurrence due to that the skin and tissues are broken by the wear, since the sensitivity changes, being able to happen incapacity to respond to the pressure and the discomfort for lack of the change of position and of movement [17].

Complications caused by dysphagia may also be avoidable to the extent that what is expressed by Paixao [8] who affirms that the patient's sitting position when eating, carrying out postural maneuvers with the head, promoting oral sensory stimulation, training food control in the mouth (offering in small quantity, verifying the presence or absence of food accumulated at the sides of the oral cavity if not ingested before offering more food) and keep the person seated at least half an hour after eating for the prevention of pulmonary complications caused by vomiting or regurgitation [18].

Despite the importance of communication in the human life and relationship scheme, it was found that caregivers of stroke disabled people with language disorders show that most of them did not receive professional tools to treat. This type of disability derived from stroke. Being that there is a range of possibilities to improve with care techniques care-subject communication as are repeating sounds of the alphabet, it is also significant to speak slowly, use paper and pencil, and promote the form of nonverbal communication, ie through Gestures, affirmation and denial, indicate with the index, use figures; all of the above combined with the patient's patience to understand the patient's frustration with the inability to communicate will contribute to their prompt recovery [19].

More than half of the caregivers surveyed do not have knowledge about specific care when there are alterations in the sleep pattern, the main knowledge of family caregivers is the need to maintain or promote a quiet environment for rest. Information about keeping the person involved in activities (reading, drawing, music) during the day and the first hour of the evening has been overlooked, can lead to physical and mental satisfaction that causes the sleep period to be received with liking [10] in the majority, because these patients may have tendency to continuous sleep.

Cognitive deficits predominate amnesic disorder, which the person experiences after a stroke, this condition can make the person who suffers from it does not recognize the surroundings or people, does not correctly interpret the use of equipment or objects, and that is not capable of reasoning clearly or employing a correct judgment. For this reason the disabled person is exposed to risk situations such as "wandering", "getting lost" or having difficulties with the management of space and time, it was identified that family caregivers have not received education or information about the possibilities of presentation of these types of symptoms include among others disorientation, forgetfulness and the like.



The family caregiver of Monteria generates a series of expectations related to the improvement of the clinical situation of the person cared for, in this sense expects "recovery" of the losses and also has fears about its efficiency in the performance of the role of family caregiver; Do not feel prepared or are not sure of their knowledge, in their opinion they do not have the skills and abilities to carry out the care activities that demand the situation of their relative disabled by AVB and by those who respond to the extended family. Results that are similar to those obtained for Torres [12] who described the main expectations of family caregivers among them "do not leave me alone" "are more patient pending" "receive education and support, help us to understand the whole family, collaborate and participate in the situation".

With the findings, it can be deduced that the caregivers interviewed for this study have a false expectation of patient cure, which makes it necessary to raise awareness among these caregivers about the evolution and the progressive recovery that implies the disabilities caused.

### Conclusion

The family caregivers of patients with stroke share the general characteristics and characteristics of this type of caregivers. The specifications of the person whom the family delegates or chooses for the role apparently contemplate the age range, emotional stability and the formation of a home, religious beliefs and family principles. Among the values that people who perform the home care of patients with some degree of disability by stroke can be described the solidarity, respect, ease of communication, tolerance, agility and dexterity.

Although the results show a low training of the family caregiver in terms of how to meet the patient's care needs, it is of interest to analyze that the family caregiver reports that the education he has was provided by health professionals who work within the institution. where the patient was hospitalized, through incidental (i.e. unplanned) education. In general, it is appreciated that the knowledge that caregivers of people with disabilities or with a functional disability have is incomplete and fractional, which prevents correct or appropriate care at home; however, more than half of the caregivers considered the education received from health professionals adequate and/or complete.

The study identified that the knowledge that family caregivers have on the management of patients with disabilities due to stroke, are related to assistance in basic daily activities and to specific care for pathology, educational components for rehabilitation Are not incorporated into the education offered to the family member. Knowledge regarding the management of pathology presented a low level of knowledge, perhaps because they depend directly on the education offered by the health professional taking into account the type of disability in each case which would explain the false expectation of recovery Total of the patient who has the family.

### Recommendations

To promote in the Health Service Provider Institutions, the creation of an educational program printed through brochures addressed to the family caregiver of the patient with Vascular Brain Accident, with theoretical and practical content, integral that can be adapted to the specific disabilities of the patient.

Territorial health entities should carry out statistical studies to determine the incidence and prevalence of stroke in the region, as well as to determine the main types of disability that this causes to the population; In order to propose strategies of health promotion and prevention of the disease tending to reduce the morbidity associated with the pathology.

Encourage partnerships between the University of Cordoba, Health Services Provider Institutions and community support networks (community elders, community action councils, NGOs, churches) to offer family caregivers advice and help in home care.

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**Volume 4 Issue 8 August 2022**

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