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Research Article

Overload in the Family Caregiver of the Older Adult with Sequela of Accident Vascular Brain

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Abstract

Objective: Describe, analyze and discuss overload in the older adult's family caregiver with aftermath of Vascular Brain Accident.

Methods: The project proposed, a qualitative study, with explanatory-interpretive design. results: Three categories emerged from the analysis; I: Delineating the overload, II: Acquiring caregiver skills and III: Family care vicissitudes.

Final Considerations: The overload experienced by the family caregiver brings variants in line with the time in which the family caregiver is dedicated to the care, family relationship, support of other family members and the conditions in which this care is provided, mainly home, implying a continuous process of acquiring skills and the ability to face the vicissitudes they present.

Keywords: *Family Caregiver; Older Adult; Nursing*

Introduction

Vascular brain accidents (ACV) is considered to be the second leading cause of death and the third largest of disability worldwide, affecting 15 million people each year, increasing their incidence in adults over the age of 65 who, after hospitalization for an episode of ACV, return home with both physical, cognitive and behavioral consequences that compromise their functional capacity, their independence and autonomy, leading them to require special care, which is usually provided by someone in the family [1,2].

By taking care of an older adult with aftermath of ACV, the family member will be part of an informal care system, related to the health system, because they are responsible for meeting the needs of dependents which implies a job without incentives and an increase in obligations, becoming a person of great importance to the elderly [2,3].

Caring for a person with ACV aftermath is facing unexpected goals, putting them in a vulnerable condition and physical, emotional and social illnesses can occur. Acceptance of this role brings numerous changes in the life of the caregiver, related to exercising the role, responsibilities with his family and supportive relationships [4-6]. All of this is reflected in states of disorganization, where feelings such as fear, longing, and problem-solving mechanisms disappear. When this state of discomfort and tension is not tolerated for a long period of time, the family caregiver tends to adopt other ways of responding to overcome the crisis, which can lead to an unhealthy adjustment with negative repercussions [2], being able to generate an overload.

Overloading from a care perspective has been conceptualized as health disturbances that can occur when care demands more of the resources available, it is a multidimensional concept with subjective and objective characteristics [7,8].

It has been proven that people are exposed to feeling overloaded when they assume the role of caregiver for a time that usually lasts longer than considered [9]. When talking about overload, the main element is the subjective impact of care in the daily life of family caregivers, that is, it understands how they perceive the performance of their new role, the decrease in their time, the impact on their health, the lack of privacy, problems with rest period and nutrition. Likewise, they are based on the skills of the caregiver, if they are able to care and connect with the desire they have to perform the role, they feel a great responsibility when providing care since they do not know if they are providing it in a correct way or not and this can contribute positively or negatively to the life of the person cared for [10,11].

Being a family caregiver has been perceived as an unforeseen occupation that differs from other jobs, because it occurs especially because of the development of the problems of the elderly and not because of the goals that each person proposes [12]. Caring is a difficult job where the caregiver to meet the needs of the elderly must know them first. Age, sex, marital status, educational level and relationship are relevant characteristics that can produce a risk of suffering overload, since according to these, experience, dedication, maturity, persistence and the skills to make any decision that is appropriate are determined. timely to resolve elderly care events [13,14].

In Chiclayo there is a single service that concentrates patients with stroke sequelae, offered by EsSalud through the Home Care Program (PADOMI), which provides home care to patients who do not have the ability to travel to the 7 hospitals; aimed at older adults with temporary or permanent functional dependence. Currently, PADOMI of the Naylamp I Hospital, registers around 25 to 30 cases of registered patients identified with sequelae of stroke.

In this context, a reality similar to the one described is observed, the family member who assumes informal care at home, becomes committed due to the blood and affective bond that he has with the elderly, rarely questioning his own ability to care and disposition to be awarded this assignment. The family caregiver contributes to the health system in the care of dependent older adults; When trying to respond as much as possible to their needs, however, they often suddenly accept this role, so they do not reflect or acknowledge what they know or not, or the possible consequences that they will have in their life, and even if they really want to assume this role, because many times, faced with this reality, there is no other option [15].

Materials and Methods

The results of the research were aimed at seeking the benefit of family caregivers and nursing discipline. It was important to state to participants that the benefit is not immediate in them, but that the results will contribute to a greater understanding of the phenomenon of overload in the family caregiver.

Participants were free to decide their participation, which they recorded with the signing of informed consent. They had every right to decide freely when to withdraw from the investigation.

This research, when considering "overload in the family caregiver", needed to be introduced into a topic involving phenomena within a context, so the methodology that was raised is qualitative with an explanatory-interpretative approach.

The scenario was the homes of family caregivers and the eldest adult. Most of the houses were located in the center of the town of Chiclayo, 8 houses are in urbanizations, and 4 in certain young villages at a maximum distance of 15 minutes from the hospital. The homes are of noble material, with adequate ventilation and lighting, and have all the basic services. Some homes have 2 floors and others with 3 floors, have a living room, dining room, kitchen, bathrooms and bedrooms. Some of the homes are typical of the eldest adult, so the caregiver had to move out of his own home even with his family, in order to assist the dependent older adult.

The sample size was determined non-probabilistically and during project execution progressively. Theoretical sampling was used, which served to be able to collect the different meanings of the study phenomenon and to be able to explain the facts; this was achieved with 12 speeches.

Data collection took place between January and May 2019 once each participant's addresses were obtained. Those who accepted signed the informed consent application, which specifies in detail what the study consists of. Once signed, they were informed that they will be recorded during the course of the interview that lasted approximately 20 minutes and then filled the "Zarit Scale" which takes approximately 8 minutes. Interview speeches were correctly transcribed without any manipulation as referred to by the participants in the recordings; some subjects were introduced to read and confirm whether it is indeed what they have stated, or if they want to add or change something, this served to give greater validity and credibility to the results. Likewise, in some cases it was necessary to return to the participant's home for further deepening of the responses they provided.

The research analyzed the directly expressed content and interpreted its meaning, so the thematic content analysis [16] was used. It began with the preparatory phase, where the literal and thorough transcription of all the information obtained in the speeches was carried out. Codes (E1, E2, E3...) were used for greater confidentiality of the subjects' personal data. Then the information was grouped together for reading.

In the pre-analysis phase, a list of the interpretations and ideas that according to the literature explain what the participating subjects have wanted to convey.

In the analysis phase, the answers to each question were considered as text fragments and were divided into textual units that explain something about the study phenomenon. Once a textual unit was obtained, they were encoded, these codes emerged according to the same discourses and the conceptual framework. When interpreting the fragments some refer to the same thing, so some were labeled with the same code, so that for code consolidation they can be grouped. When grouping the codes, the categories were formed to define them according to their degree of interpretation. When the categorization process was completed, it was analyzed, interpreted and discussed to finally generate an explanatory or meaningful framework.

Finally, in the phase of relativization, verification and contrast of the findings and creation of the definitive explanatory framework, it was verified that the theoretical framework explained the discourses used in the results.

Results and Discussion

With regard to the subjects these were characterized by being 10 women and 2 males who come from the province of Chiclayo, whose kinship found was: daughter (o), sister, granddaughters and wives who have been caring for the eldest adult from 4 months to 15 years, in an average of 12 hours a day 7 days a week. There are ages ranging from 40 to 80 years old, have a secondary and higher educational level. Some were found to be married, widowed and single and 9 of them have children. Many of them live with the older adult and even with other relatives.

As a result of the data analysis and processing described above, three categories were reached that allow a naturalistic understanding of the overload in the family caregiver.

In relation to the first category called Delineating Overload, it was found that the question of caring for a sick and/or disabled elderly person, the result of a vascular brain accident, involves a series of changes initiating at the family level [17].

"My mind is always thinking and thinking about my mother, so I have completely isolated myself from the family... Everything. I don't go out, out of here I don't visit anyone or go anywhere" (E1).

"I have a 22-year-old girl; she's a little nervous, she doesn't like to go out, she doesn't want to have friends and with her and my sister we always went to mass. Now she says to me, "Mom for my aunt, you can't take me anywhere anymore," now we don't go out much anymore" (E3).

"I've taken all the responsibility from Monday to Sunday, and they want me to give them space, my kids, they want me to go out on the street, go for a walk, but I don't have that life now" (E6).

Another aspect expressed by caregivers is, who lose their freedom and even stop interacting with other relatives the more the older adult needs care or is lonely, the caregiver tends to stay "isolated" in the home to take care of it and, consequently, the further away it is from the social context.

"Three years ago, I could go to Túcume, where my wife is from... I could go for a weekend to relax, but from 2 years ago I'm not going here anymore" (E2).

"I have set aside quite a bit, for example... there's a lunch between colleagues and I for coming quickly to see my mom I don't share with them; there's a party and I don't go at 4 or 5 in the afternoon there are engagements, and I don't go for my mom, for taking care of her" (E6).

"I don't go out like I used to, I don't have that freedom anymore, sometimes I go out and I have to come back fast... my activities have changed by 50% for example my community, I wouldn't leave her for anything, but I left her for this same situation and now I've come back because my husband is already "a little recovered", he's improved, but not quite so I can't go out all the time" (E11).

It is perhaps because of this, that several family caregivers are forced to reduce their time, their working day or simply leave their work away from home, since they attend not only to the dependent older adult if they do not also attend to the needs of their family (children, husbands, grandchildren) and it is not always known how long it is that this situation is going to prolong [18].

"I've been a saleswoman and I've been in charge of a group of people, but now I can't do it, I'm dedicated to my mom. It was in August that she fell and no longer walked, from that moment she needed more of my help... Now I don't sell because to do that you have to go out and time doesn't give me honestly" (E5).

"You couldn't anymore because I needed more time for them... I used to sew, and I was going to sew myself where my cousin and from there I came back here, but the time you need to sew, I don't have it, that's sitting quiet, but with them you can't because you have to see them, serve them their breakfast, give them their pill and look at them that they won't fall off" (E8).

Care not only brings changes at the interpersonal level, the demands of care of the eldest adult are accompanied by physically and emotionally adverse changes, and the resulting burden could develop irreversible tensions and conditions [19].

"There are times when my spine hurts, I can't walk normal, it starts to hurt my leg, but then I forget, I do my activities and it happens to me, I don't listen to it because it's worse, besides that I no longer have time for that" (E4).

"I have my appointment to have surgery, but I haven't been able to operate for the reason that I have it to her and I can't leave her, I can't" (E5).

"Well, I'm tired, aren't I? as I tell you when there's enough clear work, I get more tired and when it's not normal" (E7).

The second category called: Acquiring caregiver skills, shows that the family member is the first resource that dependent older adults have, and their care skills should be potentialized in such a way that they can take care when they are appropriate to do so in the domestic space.

"When I started taking care of her, I had no idea about this, I had no knowledge, but after she was hospitalized, we received talk about how to provide care for her, they recommended us, they explained, so I learned how to take care of her at home" (E5).

"Most of the skills we learned the second time it was, at the hospital the nurses told us that we have to see it every day; that was explained to us by the nurse, as she already knows that this disease is not cured, is not reversible or can attack again" (E7).

The discourses show that the caregivers themselves gradually learned ways to care. It is time, constancy and commitment that determines the acquisition of skills, emphasizing that the time of care for the eldest adult has also allowed them to gain meaningful experiences.

"I've learned with my parents how to put insulin, measure glucose, measure pressure, give injections, change the tube" (E2).

"Right now for the same situation one has to learn and give above all affection, and for example now I am an expert in changing the diaper, yes, in two minutes I clean it, I change it quickly; already with practice one learns" (E6).

There is no doubt that the family caregiver is a priority in the recovery process of the eldest adult, constituting a complex process, since being in charge of all tasks can frighten and overwhelm them intensely. That is where the preparation and capacity of the caregiver plays a key role. In the face of this, caregivers are looking for their own strategies to carry out care [20].

"It has not affected me; I organize myself, I work in the morning, I do school mobility, and at noon during that lapse there is the technique she waits for me to arrive, she changes it, she puts her pajamas and I stay with him" (E4).

"If I go to work, I have to get up at 5 because sometimes I leave before 8, in the morning I am changing his diaper, I give him his pills and then I go to work; when I'm not there my brothers see it too" (E7).

By considering family caregivers as an essential element in the health system as support, this requires accepting their strengths and limitations. Once the family caregiver has developed his personal skills, he tends to see the positive side of the situation. Essential care skills are knowledge, courage, and patience, which are evident in them [19].

"Skills... patience, quite patience because if I could not; If I didn't have it, I'd leave her, right? But no, I have a gift of patience that God has given me" (E10).

"People who are with this disease... you have to be patient, faith, and above all be with them until God determines. Take care of them, don't you? be patient especially because such a sick person is very problematic" (E12).

The third category called: Vicissitudes of family care, analyzes the experiences of caregivers since it is in the family environment where relationships are constituted, which contributes to older adults and family members feeling valued, because, regardless of age, we all have affective needs. It is believed that the establishment of affective bonds arises when relationships become more intimate and proximal [21].

"The good thing is that my wife helps me and supports me by taking care of my dad when I'm working, that's why there's no problem the same here in the house live more people and also help to take care of contribute a little of their time" (E2).

"I have the help of my children, my grandchildren; they take care of my husband when I have to do other things. My daughters support me, we've always been in proximity, that's the good thing they support me a lot because it's their father too, even my son sees it" (E12).

For caregivers, their family is considered their first support network. They are identified as "secondary caregivers". But as in different circumstances, not all major caregivers have this kind of "lucky".

“Sometimes I feel lonely, because I’m alone, because they don’t support me, but what can you do about this, force them? I can’t, I sometimes call them and sometimes my mom also feels that way because apart from having so many children, she has so many grandchildren who don’t come, one also needs the support of them” (E5).

“I have no help from my other brothers, they do not want to take care of her; we are 4 brothers, but of the 4 we take care of two; look one of them lives at the front of the house and doesn’t want to take this responsibility, she just comes to say hello and leaves, imagine what daughter does that?” (E6).

“I stop alone, I’m not with anyone here, today Sunday they sometimes come to see her, but I take care of her alone, with no one, everyone goes to work, they all go out the only thing I stay with my two children and she” (E10).

Some people may deal more appropriately with adversity of care, while others react less appropriately, often in situations where stress prevails [22].

“I got to such a stress level that I wanted to run and crash into the wall, so stressed was me, so choose to talk to the family to start taking turns why stress is terrible…” (E2).

“I am suffering a lot of headache and the doctor has told me that it is stress, stress from the same problems as in every home that there are some and other things, but I also told him about my mom, the doctor says that I have to ask for help to support me in the question of my mom cannot leave all the burden for me alone” (E5).

The meaning of being a caregiver is influenced by numerous feelings that permeate care.

“Some time I got well depressed, I was sad, because it feels, there’s no one to talk to, with whom to talk” (E1).

“I have a lot of worry, depression, even if my children help me in caring. I’m sick because I don’t take my pills in time, my medications I leave them I don’t remember” (E11).

“Sometimes I feel sorry for myself, it makes me sad to see my husband like this, but what can I do I have to take care of him and draw strength to where I don’t have until God determines, right?” (E12).

The question of caring for a sick and/or disabled elderly person, the product of a vascular brain accident, involves a series of transformations, not only in the domestic environment that will house him, but also in the lives of those who will take care of him. Evidence confirms that while the older adult is hospitalized, the nursing team provides care and more often than the time, the family assumes the role of mere spectator, wasting the opportunity to prepare them for the time of the patient’s hospital discharge; then the transition of attention occurs, that is, some family member assumes responsibility, creating a sense of overload, even if they often do not recognize it that way [17].

The dedication of the family caregiver can be so great that they are completely isolated from their own family. This study has identified that 83% of caregivers are women and 75% are over the age of 40, who are in a dispersed family life cycle, i.e. married, with children and even grandchildren, but no longer fully dependent on them. However, the older adult’s own situation of dependence with sequel makes the older adult fully dependent on them, tending to abandon his life routines and compromises his family dynamics.

Caregivers offer their time and effort to help their family member; change in their lives produces a high cost, changing according to each other’s needs. Regardless of whether the caregiver is a young person or an adult, their activities will be altered giving the feeling of having no choice but to manage their own lives. Silva [23] showed that these types of roles, need the abandonment of professional activity in favor of this responsibility assumed and that affects the financial situation in the face of the impact of the exit from work.

Time is an important factor influencing and related to the demand for care; of the twelve participants, eleven care for an older adult with total dependence, this means that there is a total loss of autonomy and, consequently, the caregiver becomes indispensable and perennial.

It can be affirmed that changes in the life of the caregiver can lead to a strong tendency to neglect their own health, which contribute to the process of overload and therefore to a poor quality of life. Most of the caregivers in the present study reported at least one health problem, such as tiredness, headache, back pain. In this regard, Giraldo18 reported that people who act as caregivers do not monitor their health, since the task is considerable, and although warning signs such as pain, restlessness, fatigue are shown, they continue to care without paying attention. These ailments are the beginning of a bad state of health, so you have to know how to recognize these symptoms and give them their due importance so as not to increase your own suffering or that of the sick older adult.

These family members now have a duty to learn to care for in their day-to-day life, based on experience or what they see or have seen from people who have long cared for older adults with similar characteristics so that they can expand their knowledge of care. But there is a mishap in most family caregivers; according to their peculiarities and the way they took on the role of caring, they face situations that do not know how to solve [24].

Caregivers say that at the beginning of this activity they did not know what to do because they had no information or did not know the disease, nor how it would evolve in their family member. Knowledge about the disease or the procedures to be performed with the older adult is a factor that increases the feeling of overload in the person as it generates concern, insecurity, anxiety, and nervousness; they come to consider that instead of helping they are doing "a bad job." This result is consistent with other studies, which reveal that the disrecognisement of care and the fear of aggravating the health of the eldest adult deprive the family caregiver to carry out more activities [24].

The family caregivers who participated in the research belong to the PADOMI program, which they say is definitely the best of insurance because all the health equipment (doctor, nurses, therapist, psychologist) go to each enrolled patient's home, evaluate them, and see how it is developing, according to which they leave indications for the older adult. Relatives highlight the work of nurses by mentioning that they advise them, give them recommendations for them to learn and improve in care, explain what happens to the older adult, and clear up their doubts and fear that something worse might happen. While it is true careers receive recommendations on how to care for their family member, but do not express that they receive self-care teachings, this is why many research indicates that caregivers are a group forgotten by the health system [25].

By the fact of the situation there is often more rapprochement as some family members support in care. This is essential to counteract overload as family caregivers can take time for themselves and clear their minds of the activity that makes them dependent on the sick older adult. According to Lopes, Nogueira, Aparecida, Carreira, Aparecida [26] show that, at the beginning of the disease, the family is fragmented in terms of the division of care; however, in the face of the difficulties and needs of the day to day, it was eventually organized in an integrated way, and all participate, to a lesser or greater degree, in this activity.

Care often creates union between family members, but dependence on elder care can threaten the balance of family dynamics, leading to disorganization that normally interfere with family functionality.

Among the reasons that led family members to assume the role of caregiver, the most common was the absence of others who could perform this task. Care, therefore, has emerged as an "obligation", not as an option of life. The emotional burden involved in the family relationship (parents-children) directly influences this function that ranges from obligation to gratitude [27].

Exhaustion, coupled with the symptomatology of those who feel overloaded, can be the result of perennial dedication and effort in the task of caring. This usually leads the caregiver to ignore their own needs, and they experience stressful and overloading situations [22].

Family caregivers feel attachment to the older adult, so seeing them in this new condition, not being the same person as before, makes them sad in remembering past moments; they feel sorry for the fact that by communicating with them they are not even recognized by their own relative. But caregivers also tend to be irritated and despair of the elderly person's disability, which sometimes leads them to feel angry or upset with the older adult [28].

It is necessary for nursing to prepare to intervene in the management of the overload of the family caregiver who after internment will support the older adult with sequelae of the disease, considering that it also needs support and attention as well as the eldest adult. Improvement actions can be determined in the nursing care process, including in nurse-led home care programs, so that you can have better evidence and focus on providing ongoing care not only to the dependent older adult, but also by providing strategies to improve the caregiver's quality of life.

Conclusion

The family caregiver, during the hospitalization of the eldest adult with ACV and the transition from hospital to home, goes through a difficult situation, not only because of the condition of his family member but because of the unexpected change they undergo from that moment, since continuity of care is required after hospital discharge where all possible teachings provided by the nursing team are brought home and must be applied to improve the quality of life of the older adult; for many of them because of their different personal characteristics this process is difficult to deal with. In this context the family caregiver is experiencing an overload, which is valued according to the degree to which he perceives that care has impacted different aspects of his life, so it is considered as a multidimensional phenomenon and is characterized by encompassing subjective elements and objectives that relate to each other. In other words, caregiver overload depends on the impact of caring, focusing on the impact it has on both the physical and mental health of the caregiver.

Conflict of Interest

The authors declare that there is no conflict of interest.

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