

## Learning-doing of the elderly caregiver at home

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### ABSTRACT

This study aimed to know how elderly caregivers learn to care for family members at home. A qualitative study was carried out with six elderly caregivers of dependent relatives in the Brazilian northeast. Data collection took place from March to June 2017 through a semi-structured interview, and we employed content analysis in order to organize and systematize the data. The research showed that the learning of elderly caregivers develops through the observation of professional practice through professional guidance and experience in care. The findings point to management that emphasizes strategies in education and health that contribute to the learning of caregivers.

*Keywords:* Caregivers, Elderly, Learning, Homecare

### INTRODUCTION

In the context of caring for dependents, it is possible to notice the predominance of relatives exercising the role of caregivers, especially elderly women. Considering the need for technical know-how to guarantee the well-being of the dependent person, and the caregivers, it becomes essential to understand how they have been learning to carry out home care.

Regarding the care of relatives, it is known that these depend on the assistance of third parties to carry out their activities of daily living. This assignment usually falls to a relative (Castro & Abramovay, 2017). Although essential, family caregivers, for the most part, are informal, considered as any caregiver without any guidance or preparation, without remuneration, and may or may not have an affective relationship with the other (Brasil, 2012). In this regard, a survey conducted with 20 caregivers of elderly patients, the majority being older than 50 years, shows that even though they were not family members, they had not undertaken any course to exercise care activities (Gutierrez, Fernandes, & Mascarenhas, 2017).

It is important to note that the non-preparation of informal caregivers compromises both the quality of life of the dependent person and the health of the caregiver. A study carried out in Minas Gerais with 26 institutionalized elderly caregivers concluded that 53.8% negatively define the elderly and that the lack of qualification, as well as emotional and social support, contributes to a poor quality service for the elderly, which may compromise the care offered (Sampaio, Rodrigues, Pereira, Rodrigues, & Dias, 2011). Research carried out with ten family caregivers of bedridden patients also alerted to the unpreparedness, evidencing, not only, the commitment on the assistance to the entity, but also the possible harm to the health of the caregiver (Yavo & Campos, 2016), which was also confirmed in a cross-sectional study with 99 caregivers who developed pain, spine and vision problems, hypertension, anxiety, and insomnia (Brigola et al., 2017).

Specifically, on the risks to the health of the caregiver, it is worth noting that these are intensified when dealing with elderly people, especially women, occupying this role. An

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investigation carried out in Spain with 85 caregivers reaffirms this issue when it is evident that all were familiar with a mean age of 60.46 years, thus signaling to the hegemony of elderly caregivers (Soto-Rubio, Pérez-Marín, & Barreto, 2017). Consequently, the physiological changes characteristic of aging, which favors the progressive loss of bone and muscle mass, slow gait, impaired motor coordination, and balance, as well as decreased flexibility and mobility (Martoreli-Poveda, Prats, & Silva, 2016), should be considered. In the female gender, this situation is even more serious in view of the menopause, which reduces the production of calcium, making them more vulnerable to musculoskeletal problems; therefore, the elderly women have become an expressive group of family care (Daiene de Moraes, Terassi, Inouye, Luchesi, & Pavarini, 2016; Soto-Rubio et al., 2017; Souza, Silva, Quirino, Neves, & Moreira, 2014).

Thus, given the implications of caring for family members at home, whether for the caregiver or the caregivers themselves, it is essential that they be prepared to perform the tasks correctly and safely. In this sense, this study questioned how elderly caregivers learn to care for family members at home? The objective was to know how elderly caregivers learn to care for family members at home.

### METHOD

It is a study with a qualitative approach. We adopted this approach because it allows us to understand, to interpret the phenomena, and to study the meaning of people's lives in daily conditions. It covers the employees in the performance of their daily roles under their real conditions, taking into account subjective traits and particularities of individuals (Marconi & Lakatos, 2010; Yin, 2016). This approach allowed a better appropriation of the experience of elderly caregivers of people with dependency at home.

### Sample

The setting was the homes of elderly caregivers of people registered in one of the bases of the Brazilian public home care program "Better at home", located in a large public hospital in

Salvador, Bahia, Brazil. Each base has a multi-professional team composed of two physicians, one nurse, four nursing technicians, and one physiotherapist, in addition to a support team composed of a social worker, a nutritionist, and a speech pathologist (Ministério da Saúde, 2016). For each registered patient, a responsible caregiver is considered, and may or may not be a member of the family, through a form already established in the program called Social Assessment of Eligibility, which presented all who lived in the same household, their ages and identified the primary caregiver.

The participants were elderly caregivers of family members enrolled in said home care program. Adoption criteria were: to be at least 60 years of age and to be a caregiver dependent on care. The exclusion criteria were: elderly caregivers residing in a place of risk to the physical integrity of the researcher, according to the orientation and evaluation of the home health care team.

It should be noted that the research was linked to the matrix project entitled "Elderly caregivers in the care of the other at home: intervening in the overload of care", approved by the Research Ethics Committee of the Nursing School of the Federal University of Bahia, under opinion number 1,762,501 as at 10/05/2016. In order to guarantee anonymity, it was used fictitious names of flowers.

### Instruments

The data collection took place in the period from March to June 2017 through a semi-structured interview. The interview consisted of two parts: the first stage contained sociodemographic data of the participants and the second with the following guiding questions: "Who directed you to provide the necessary care to the family member?" and "How did you learn the care you take with your family member?" The interviews were performed at the residence where dependent relatives lived. They were recorded and transcribed in full. In order to guarantee anonymity, we identify each participant as a different kind of flower. We choose to use flowers as a pseudonym considering that the elderly people are delicate and they transmit vitality as

well as the flowers. It worth noting that in order to test and validate the instrument, four pilot interviews were conducted with volunteer caregivers who were not part of the program.

### Procedures

For the selection of the caregivers of elderly patients, a total of 53 patients' records were consulted, which were linked to the chosen base, during the collection period, with a reading of the medical record, mainly the Social Assessment of Eligibility instrument. In this first search, we found only the record of an elderly woman as a caregiver. In an attempt to find older caregivers, a new consultation was carried out on the medical records with a focus on the identification of patients whose family structure presented the elderly, which totaled ten situations. After telephone contact with these families, it was discovered that in seven of them, the elderly took care of their relatives, being all women. Of the total of eight caregivers of elderly patients, two did not agree to participate in the study, and six signed the informed consent form.

### Analysis

To organize and systematize the data, we used the Content Analysis proposed by Bardin, which consists of three stages: pre-analysis, material exploration, and treatment of results. The pre-analysis consisted of the first moment of the material organization. At this point, we selected the documents to analyze. This is also when we formulated our hypotheses and guiding questions to support the interpretation and final preparation. In the exploration phase of the material, longer and more exhaustive, we carried out a detailed analysis of the data and identification of those that shared the same core meaning. Hereupon, we started the process of categorization based on the similarity of the thematic categories. In the third phase, result processing, we inferred and interpreted the findings from the scientific categories, by constructing the statements according to the central ideas of each category (Bardin, 2016). Once we organized the results, we presented them through thematic categories, which were

discussed and corroborated with the current national and international literature.

### RESULTS

The six collaborators were between 60 and 79 years of age. Some looked after their mothers (n = 3), others of their children (n = 2), and the other of their grandson (n = 1). All experienced a situation in which their bodies received professional assistance, an event that provided an opportunity for learning. The three representative categories of how the elderly caregivers learned to take care of the family were: By observation of the professional doing; for professional guidance; and experience in care.

#### *By observation of professional doing*

The study revealed that, when attending the care provided to the family member by the health team, the caregivers observe carefully to learn such care, including procedures such as dressings, polls, change of position, among others.

I learned how to dress by observing the professionals. (Orchid, 63 years old, caretaker mother of 91 years)

During the months of hospital stay, I learned a lot, including aspiring by watching physical therapists on a day-to-day basis. (Rose, age 63, caretaker of 31-year-old son)

In the hospital, I learned a lot by watching the nurses who took care of her. [...] I learned the best way to turn my mother into bed and to shower in bed. (Jasmine, 72 years old, caretaker mother of 98 years)

#### *For professional guidance*

The testimonies showed that the caregivers learn to care for their dependent entity through the guidance of the health team, either in the hospital, especially at the time of discharge, or at home, with professionals integratinfg home care.

Before discharge, I received all home health care team guidance because they perceived my difficulty in doing some care. (Tulip, 60, mother caretaker, 86 years old)

At the hospital, the nurse taught me how to do the catheterization. I thought I would not learn, but

they taught me until I could. (Sunflower, 73, caretaker of a 49-year-old son)

I learned from the physiotherapist of the home hospitalization program the correct way to raise my mother. (Jasmine, 72 years old, caretaker mother of 98 years)

#### *By the experience lived in the care*

The study also reveals that caregivers learn from the experience of experiencing this situation. The experiential learning can be illustrated from the following lines:

Since I had no help, I did not adapt with the platter. But as I knew it made it easier to move it, I had sewing large sheets to make it easier. (Rose, age 63, caretaker of a 31-year-old son)

Since I could not open my legs for intimate and healing hygiene, we had the idea of attaching a rope with the padded strap on the wall to place one of the legs. So when pulling the hospital bed, the legs are open. It worked very well! (Sunflower, 73, caretaker of a 49-year-old son)

[...] we made a book to write down and check because you cannot rely on memory anymore. In it, we put the telephones in an emergency. [...] we made a chart for vital signs, medications and diet times. (Orchid, 63 years old, caretaker mother of 91 years)

### **DISCUSSION**

The study revealed the ways of learning of elderly caregivers with regard to the care provided at home to the dependent entity. Among these is the professional care observation provided to the family member, whether in the hospital setting or, later, at home. In this context, the relatives reported that during the care work in hospital admission, they observed the procedures developed by health professionals, paying attention to the techniques performed in order to learn and reproduce them at home, when they no longer have professional support. Confirming, a survey carried out in Colombia with informal home caregivers also revealed that they learned to assist the family member through observations of the activities that health professionals performed during hospital admission, such as how to give the bath (Botero, 2017). This study also indicates that routine and repetitive care tasks, without professional guidance, may have implications for the caregiver's physical health. Such situations

may trigger pain in the musculoskeletal system, due to the caregiving as well as the somatization of the feeling experienced (Gomes et al. al., 2019).

Given the above, it is important to emphasize the need for careful management of the quality of care provided by professionals, since their behavior is being observed by family members and perhaps by caregivers, in order to learn the care process. Hence the importance of a responsible and secure doing so that family members can not only be protected with that action, but also reproduce correct information. For this, the caregiver needs to be properly trained by the health team, aiming for a transition of safe care. On this, studies support that the teaching by the professionals who assist the bedridden person favors the familiar understanding about home care techniques, allowing greater confidence in what the caregiver is doing, which improves of the quality of care provided (Carvalho, Rodrigues, & Braz, 2014; Rangel Gomes & Cavalcante Apratto Junior, 2016).

Despite the relevance of teaching the family the necessary care for the dependent person, a Brazilian study carried out in Paraná with family caregivers showed that most of the interviewees did not receive the necessary guidance to provide care at home (De Cola et al., 2017), with repercussions on physical and emotional overload. Research developed in Italy confirms that guidance to family caregivers is not a practice of health professionals. A study carried out with 59 elderly caregivers of elderly people with dementia showed that they are not oriented, being important the use of assistive technology in order to prepare them to improve the quality of life of the entities, since they need information on how to deal with the disease and take care of the family member at home (Conti, Garrino, Montanari, & Dimonte, 2016). Another study, which revealed the inefficiency of caregivers to provide family care, attributed this deficiency to the lack of communication between caregivers and health professionals (De Oliveira, Boaretto, Vieira, & Tavares, 2015; Souza et al., 2014).

It should be noted that the guidelines provided by professionals are recognized as

relevant and important for caregivers, especially in the prevention of complications (De Oliveira, Boaretto, Vieira, & Tavares, 2015; Souza et al., 2014). A survey of 13 elderly family caregivers showed that most believe that professional explanations help to alleviate difficulties, prevent complications, and facilitate the delivery of care (De Oliveira et al., 2015). Another study involving 50 caregivers of patients with dependence also corroborates the importance of professional teachings to family members, adding as a benefit the possibility of diminishing evils caused by malice (Souza et al., 2014).

At the international level, studies also point out the salience of professional teaching to family members favoring the prevention of problems for the health of the cared person. In Dallas, one study underscored the satisfactory outcome that caregiver education has brought to the family entity as reducing the incidence of health problems for the dependent person. He thus revealed the importance of formal guidance to family members (Drews, Macaluso, Piper, & Channabasappa, 2017). On the other hand, the lack of guidance to family members can have serious consequences for the health of the family, increasing the chances of secondary complications (Camargo, André, & Lamari, 2016).

Thus, it is important that professionals value teaching to caregivers throughout the process of follow-up to the entity, and not only at discharge. The transition care, defined by the American Geriatrics Society, is, therefore, advocated as actions aimed at coordinating health care at all levels of care (Coleman, & Boulton, 2003). It is observed, then, that the dynamics of professional care, whether in the hospital or home space, reveals itself as a learning space for family members that need to be valued.

In addition to the health professionals' careful observation, the family members also use the experience gained in their practice, to promote the care and necessary adaptations in the home routine. Consequently, caregivers adapt to reality and family needs, such as vital signs control instruments, medications, locomotion, and hygiene.

Faced with the need to perform the best care for the entity and also to facilitate their caring task, the elderly allowed themselves to be guided by their daily experiences, based on their mistakes experience and correctness. With this, they created their form of care at home care, appropriating it. These adaptations allow the self-management of care, offering a unique and individualized format, generated by the intimate relationship of the caregiver and the cared individual. According to a study carried out in New Zealand, after a time of training, family caregivers became specialists in care, and this expertise developed in their errors, experiences, deductions, and tests (McDonald, McKinlay, Keeling, & Levack, 2016). National research also argues that the learning of caregivers occurs through empirical and observational procedures (Gutierrez et al., 2017). In addition, many caregivers, because they are elderly, accumulate life experiences with the care of other members of their family, which contributes through skills, maturity, and motivation to perform these tasks, which aids in this expertise (Pedreira, Ferreira, Silva, & Freitas, 2015).

Therefore, health professionals must seek strategies that ensure the effective inclusion of the family in the sense that the family has the capacity to perform home care safely for the family and the cared person. Research advocates the need and relevance of nurses' actions in the process of preparing not only the dependent person to return to his or her home, but also the family caregiver, especially when it comes to helping to face the challenges inherent in the job to be performed (Landeiro, Martins, & Peres, 2016). To this end, professionals should be prepared to understand the real needs of the caregiver and the family and, in this way, facilitate adherence and adequate practice in care (Andrade, Silva, Galvão, & Pereira, 2015; Pavarini et al., 2017).

In this perspective, it should be remembered that caregivers are mostly elderly people and may, through senescence or senility, present changes over time that compromise their cognitive ability. Such situations demand greater attention from the professionals, with certification that the elderly relatives understood the way of carrying

out the care. In the care of dependent people, many tasks of home care are concomitant and require motor skills as well as memory. In a review of the literature on the state of consciousness in the elderly in 2013, they describe that they complain of memory problems, associated with stress and activity overload, and also highlights that advanced age also interferes with the performance of simultaneous tasks (José Mascarello, 2013). These situations are quite experienced during home care assistance.

Although the study is limited by not indicating the consequences of how this affects home care, and more precisely about the health of the dependent person or the caregiver, these findings are relevant in order to guide strategies that promote learning of knowledge and abilities on the part of family caregivers, especially considering the limitations of the elderly person.

A study carried out in Portugal that evaluated the effectiveness of the nursing intervention based on a psychoeducational program of stress management for the caregiver pointed out that after two months of intervention, the caregivers reported that they learned new coping strategies that improved well-being and especially, reduced the overhead. While, the nurses mentioned that the intervention favored the knowledge of the difficulties faced by the caregiver in the day to day (Vieigas, Fernades, & Veiga, 2018).

In this sense, careful management for the teaching of informal caregivers, with an emphasis on the specific characteristics of caregivers of elderly patients, requires health professionals who show concern about the care that the dependent person will receive in the domicile.

### CONCLUSION

Household care carried out by family members is anchored in the guidelines received by health professionals and in the observation of their doing, as well as the experience acquired in the act of experiencing the practices of caring need.

In view of the above, it is believed that the findings contribute to the management that focuses on the professional concern, not only for the proper exercise of its practice but also for guidelines for dependents and their families, for adequate home care, which favors the

minimization of errors, the promotion of health security and the quality of life of both.

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