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EXPERIENCE OF FAMILY CAREGIVERS OF ELDERLY PEOPLE WITH FALL ANTECEDENT

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ABSTRACT

Elderly people with fall antecedent demand intense care during and after rehabilitation, which can lead to physical and psychological caregiver burden, with impact on quality of life. This study aimed to know the experience of family caregivers of elderly people with fall antecedent. This qualitative research used semi-structured interviews with 19 caregivers, and content analysis according to Bardin to analyze data. Family caregivers were predominantly female, unmarried, aged between 47 and 57 years. Three analytical categories were identified: "Fall context": it was common to be alone at the moment of fall, antecedent pathology favored its occurrence, as well advanced age; and presence of sequelae as a result. "Support network": there was not expectations of help from other family members, there was satisfaction in relation to Health Center support, especially due health agents visits, since they had age or sequelae limitations. "Satisfactory caregiver experience": feelings pointed to the gratification and satisfaction of bea caregiver, through what they felt fulfilling a social role of retribution, particularly in cases between parents and children. Its concluded that the experience of the elderly family caregiver involves feelings of usefulness and satisfaction, despite burden and lack of support network.

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INTRODUCTION

According to the demographic census of the Brazilian Institute of Geography and Statistics (IBGE; 2017), the population of São Paulo city is about 45.094.866 people, and 9.46% of them is elderly, what corresponds to 4.264.243 people in this age group. The trend towards population aging has been growing all over the world, so being a caregiver is also an activity that is increasing in Brazil, especially the number of family caregivers. When an elderly person gets sick, either due to clinical conditions or to falls, approximately 90% of them remain in their home being cared by their relatives, so that the state is responsible for less than 10% of the care given to this public (PAHO, 2003, Parreira, 2013, Ramos, 2002). Studies carried out with elderly caregivers point to the occurrence of several types of psychological suffering such as anxiety, depression, stress and insomnia, as well as physical problems, being the most common: hypertension, digestive disorders, respiratory diseases and propensity to infections. Thus, there is a worse health-related quality of life in this population when compared to non-caregivers (Oliveira, D'elboux, 2012; Ramos, 2002; Rezende, 2010). It is known that support to family caregivers of elderly people consists of a new challenge for the Brazilian health system, in view of the rise in the number of this population. Assessing and monitoring caregiver burden contribute to planning actions, adapting health services, and preparing professionals to support families in their specific needs, benefiting both the caregiver and the elderly population. Care for the elderly implies a series of tasks that can lead to the exhaustion of the caregiver and emotional burden experienced by the caregiver, which may interfere with the care given to the elderly, as well as the quality of life of the caregiver. Moreover, burden appears as a predictor of hospitalization among caregivers (Oliveira, D'elboux, 2012; Ramos, 2002; Rezende, 2010). Considered as a public health problem, the fall is a fairly common and devastating event in the elderly. Although it is an avoidable consequence of aging, it may signal the onset of fragility or indicate an acute illness.

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The fall has a multifactorial etiology occurring mostly by the combination of intrinsic factors (age, cognitive deficit, muscular weakness, postural hypotension, visual deficiency, vestibular system deficits, walking and balance abnormalities, foot problems and medications) and extrinsic factors (behaviors, activities of the individual and their environment) (Fabre, Ellis, Kosma, Wood, 2010). In general, fall tends to significantly impair the quality of life, especially the loss of independence, leading to withdrawal from social life and fear of fall again (Ramos, 2002). The literature is abundant in presenting several studies that show the experience of caregivers of elderly with Parkinson's (Stella, 2009), Alzheimer's (Novelli, 2006), neurological sequels (Gomes, 2009). However in the state of the art it is not possible to identify publications about elderly caregivers of post-fall elderly, what motivated the presentstudy.

MATERIALS AND METHODS

This is an exploratory and descriptive research that used the interview technique, with a qualitative methodological approach. It was developed with attendees of two Health Center of the District of Capão Redondo, Municipality of São Paulo/Brazil. The study was approved by the Research Ethics Committee of the Municipality of São Paulo. Participated in the study 19 family caregivers of elderly people with fall antecedent. In the text production, the caregivers were identified as C1 to C19, to guarantee the anonymity of them. The interviews were carried out based on a semi-structured instrument with 8 questions addressed to know the experience of family caregivers of post-fall elderly people, type of support they expected from family, friends and professionals from Health Center; adjustments made at home, feelings about the experience of caring for a family member who has fallen, and how being a caregiver affected their private lives. Caregivers were personally contacted by the researchers, who explained in detail the objectives of the study and the operationalization of data collection. They clarified the guarantee of anonymity, the willingness to participate, the signing of the Informed Consent Form, the interview response, which would be recorded, and other questions about the research. The interviews were conducted at home, at a time established by the participant. After the interviews were held, the speeches were transcribed and the data was evaluated. The technique used was the content analysis of Bardin (1977), who sought to understand the experience of family caregivers of the elderly with a history of falling in their home.

RESULTS AND DISCUSSION

Among the 19 participants, 15 were female, 4 were male, aged between 47 to 57 years, 13 declared themselves white and 6 declared themselves brown; 12 were single, 2 were divorced, 4 were married and 1 was a widow. Analyzing the content of the interviews, the following categories were identified: context of fall, support network and satisfactory experience as a caregiver, as presented below.

Context of fall

The falls episodes, in general, had similarities, such as the absence of an accompanying person in the moment of fall, presence of antecedent pathology that favored the occurrence, as well advanced age and the sequelae as a result, that lasted for months in some cases.

"In fact, one of the worst falls she has had was in 2005; it was the first and I was not with her. She was in a farm; she slipped and fractured her ankle. "C8.
"I was traveling in 2014 and he was fine, then he crashed. Time passed and he crawled across the floor with his broken femur. The neighbors called me. When I arrived, he was in bed all broken. "C9.

According to Mazza and Lefréve (2004), the Brazilian economic situation forces daughters and wives, who should be the first option when choosing an informal caregiver, to make a double journey, working out during the day and taking care of housework at night. Thus, they get unable to meet the most basic needs of the elderly, who spend most of the day home alone. Some caregivers, when faced with the fall of the elderly, reported have felt fear, fright, despair and sadness. Even apprehensive, they sought immediate help often hoping for the worst. All of them provided immediate care, but not all were referred to the health service immediately. There was often an expression of despair in the moment of fall. Even though the first fall would lead to greater despair, the feeling would recur every episode. Moreover, the caregivers reported a great fear that due the constant falls the elderly people would be bedridden, aware of how negative this situation would be for them, associated to the sum of tasks in this circumstance. The feeling of fear that the fall would happen again was not reported only by the caregiver, but many said that the elderly also feared a new fall.

"God, it's a shock we take, I'm scared" C6.
"We were scared" C20.
"It makes you nervous; I was scared" C3.
"It was bad because she left there practically dead, it was a thud" C14.
"It was very difficult to maintain the routine, because it disrupted the development of jobs and it took a lot of money, it was also difficult to maintain her spirit, because the elderly feel self-esteem decrease after a fall." C15.

Both the falls and the fear of falling are common syndromes with potentially serious outcomes in the elderly. Fear of falling is characterized by anxiety when walking or excessive worry about falling. This can lead to less confidence in the ability to walk. Fear of falling is associated with worse health conditions, such as old age, depression, difficulties in daily living activities, decreased social interaction, sedentary lifestyle and even injuries caused by the fall itself (Before, Schneider, Benedetti, D'orsi, 2013). The posture of many caregivers after the fall showed caution, mainly due sequelae, that ranged from mild fractures as isolated limbs to more serious lesions such as the femur, clavicle and skull.

The severity of the lesion was related to antecedent pathology, which led to an evolution in dependence as a result of the sum of the sequelae of the fall with the antecedent pathology. Among the late sequels, there was a reduction in mobility, depression and constant pain that occurred in almost all cases. The routine after the fall has changed; the caregivers reported a great difficulty in dealing with elderly care because they were very afraid of causing more pain when mobilizing him according to his needs. There was also a lack of information regarding the specific care to be provided to the family member in this post-traumatic situation. Caregivers reported learning to cope with the new situation as needed, day by day. Few were sure about their knowledge, the term "well" was

little used after being asked how they were going through this stage.

"Pain, only pain as sequel. Even this last time when she had a lot of pain, she did tests and did not break anything. We are giving medicine and, as a family, we became nervous to see her in pain. "C12. "Yes, this sequel was explained, it's natural because the type of fall... the doctor explained that it would lose some of the reach of the arm movement. So here we are prepared ... I help in what I can ... I open some pot, medicines. I try not to leave the bottle caps closed very hard, so it is being followed to the letter, there is no problem. "C15. "There was no sequel; she did physiotherapy then the sequel she had was pain because of osteoporosis. She already had some leg pains and with the occurrence of the fall it worsened. Then her walk is already very slow, well impaired.

In the study conducted by Fabrício, Rodrigues and Junior (2004), the elderly investigated presented the fracture as a major consequence. This result differs from this study, since most of the caregivers interviewed report having no sequelae. In the cited study, the authors stated that the behavior of the elderly people is linked to a decline in their level of independence, their daily activities, whether for fear of exposing themselves to falling risk or by protective attitudes of society and relatives/caregivers. This fact is already in similarity with the present study, since the caregivers interviewed presented a great protective attitude after the occurrence of the fall, restriction of certain activities or facilitating their access to them, but always delimiting their tasks. Most caregivers reported to have received simple though resolute instructions on home care to reduce the likelihood of further falls, such as locked doors, rugs, scattered toys, space between furniture, to avoid falls of one own height caused by imbalance during wlaking. Caregivers were fully aware of the changes that should be made in the home as a preventive measure, but not all of them could be effectively implemented due to low family income. Among the changes reported, the most significant were the placement of bars on stairs and bathrooms, as well as the change of place furniture and the location of the room from the elderly to the lower floors of the house. However, one party reported that they had not made any changes in their home after the fall.

"There was not much change in the house, it was more instructions: not lock the door, be careful with the furniture ... we put the furniture with more space, she takes a shower in the chair, things like that. "C2.

"He sleeps in the living room, in this bed. My mother sleeps beside him, not in her bed. These things were the adaptations we made and he bathes down here now. "C3.

"We put in another mattress, we changed the mattresses, and put cushions on her side so that when she turns around, she will know when the cushions fall." C12.

"Constant vigilance, we eliminated carpet and other things that can slip... we take care. And everything else that I even know if it is correct, as the constant warnings every 15 minutes: 'mother, be careful where you step'. "C15.

"I changed the armchair that could hurt her, put another one in upholstery." C12. "Constant vigilance, we eliminated carpet and other things that can slip... we take care. And everything else that I even know if it is correct, as the constant warnings every 15 minutes: 'mother, be careful where you step'. "C15."I changed the armchair that could hurt her, put another one in upholstery." C12.

According to Floriano et al. (2012), every change to be planned by Nursing together with the family should address the extra daily life activities performed by the elderly. They must arrive at a consensus of a light but active routine in a known and safe environment. And if it is possible, the caregiver should involve the elderly in some activities, such as shopping, going out to pay bills, going to parks, among others.

Support Network

When they were asked about the family's position in caring process and how much support they received, opinions differed widely. A large group has shown disappointment and without expectation of assistance from the family, because they would be the main or sole responsibility for the elderly, so they did not expect that their family would help them at some stage in the care process. By the other hand, some of them was satisfied with superficial support such as phone calls and financial support.

"Oh, I do not know... the family I think is more the presence of children, nephews, friends...because our ouse has always been very ful... it seems that when we get old we no longer serve for anything. In that sense, there are some faithful people who are friends, but I think this thing that we can not blame people who do not come here because we do not have this movement either, because we have this mobility problem."C10.

Another group made many complaints about family abandonment, clearly demonstrating the need for emotional and psychological support as soon as they felt alone because they are a support network for the elderly, but necessarily need help mainly in the emotional realm. They presented their personal activities limited by the routine of the elderly, and the constant absence of family makes them unprepared for care in a certain way.

"I would like more family presence because I want to go out and need someone to take care of her. For example, today I wanted to go out and to cut my hair, my sister was with her and my brother appeared because if she falls I can not lift her alone and not even my sister, it is necessary two people to raise her, so it's difficult. "C12.

"It's more emotional support, not so much helping physically, but emotionally. Being with her, helping her. "C2.

One part of the group was satisfied with the support provided to them, since theyconsiderated t kept in touch to know about the recovery process of the elderly was a form of support. "Yeah, the support of the family already exists because they take my mother, take her out, get distracted." C15."The support has been good, I have nothing to complain about." C16. "

Keeping a subjective view on this theme, we have to agree that the support of the family is extremely relative, it is related to the form of love expressed by the group where the individual grew; some are satisfied with superficial contact, others complain of affective support in some cases that are

unattainable. It was possible to perceive among the interviewees an altruistic stance in relation to the subject, and even if they report the family abandonment in relation to the elderly, few indicated their needs as a priority. This behavior, however, over a long period of time, can lead to a drop in self-esteem. The reports provided go according to the literature in a more real and palpable way, since Floriano et. al. (2012) states that many national and international studies have shown how complex the care provided by the informal caregiver is, due to physical and psychological burden and social isolation, lack of institutional and family support, difficulty with the environment / infrastructure to perform care and difficulty to financial management.

To Floriano, Azevedo, Reiners & Sudré (2012), the family posture can be shaped by the health professionals who are in theire field of influence, and, to him, it is a state responsibility to involve the family in this process. Among the primary care professionals, nurses plays an important role is this sense, trough which must involve and enable all the family members available in care process. When asked about the external support of the Health Center (HC), they were satisfied with the support of the team in general, and with the accessibility by the Family Health Strategy, mainly through the visits of health agents, which facilitates several processes, since they may not always be in the basic unit due to age or care limitations.

"[...] HC should be as it is today, give support to people, guidance." C12.
"[...] HC sent here his physiotherapist who taught some exercises that helped a lot." C15.
"[...] we get a bit support from HC, drugs... they come here to check her blood pressure. "C11.
"[...] is has been good, HC is collaborating with the necessary referrals." C1.
"[...] HC is a bit slow, almost never has a doctor there." C6.

According to Costa, Castro (2014), nursing professionals need to recognize that it is not only the patient who needs care, but also their caregiver, and it is necessary to identify such needs, in a holistic way to take care of the caregivers, observing their physical, mental and spiritual dimensions, and developing interventions to improve the quality of life of family caregivers. Once the Self-Care Deficit Theory of Dorothea Orem (2003) states that nurses should not only perform self-care for the health care user who is classified as dependent on care, but include the family member who is responsible for care, who also need to teach, guide, guide, provide physical and psychological support and provide a suitable environment for the care.

Satisfactory caregiver experience

When asked about their personal feelings about falling, a shallow and general response has often been given: "I'm fine"; they simply say that they feel good, agreeing that their conduct at the time of the fall was the most appropriate, as well feeling confident in their skills as a caregiver. They also felt a preventive responsibility, even if it was the first fall they were aware of the importance of prevention. They considerated the fall as an apprenticeship, avoiding new falls with more specific methods based on what happened. A great majority dodged the answer while others carried a feeling of regret, rooted in their guilt over what had happened.

"It is a learning experience that we see as the cycle reverses, before she took care of me, nowadays I take care of her. I try to have a lot of attention with this falling thing, I tell her to take a shower with the opened door. Actually, it is like a inversion in life. "C2.

"I feel calm because it was an easy experience since we know about known friends that there are cases of other health problems, then the fall becomes irrelevant close to other problems that could have been affected, there are other serious dramas. So by the time I feel like benefited. "C15.

"I feel bad to see her suffer and not be able to solve "C6.
"It is difficult to overcome this trauma." C14.

"I feel that I have to be careful, you know. I feel responsible, do you understand? And I lack some guidelines because I have never looked after the elderly before, right?"C16.

In general, the feelings caregivers presented in relation to the fall were based on fear of their lack of experience and preparation. According to Mazza and Lefreve (2004) the family caregiver is the most suitable for the elderly at this stage of life, as long as the lasting relationship with this relative avoids depressive feelings and isolation, because it is a known person, and the family closeness brings more comfort and safety to the elderly. Faced with this situation, health professionals involved with this public should focus on the appropriate training so these caregivers can feel safe. Besides, to provide psychological support so that they can meet their personal needs, and thus, provide security for the elderly. The experiences found as a family caregiver surrounded with gratification and satisfaction. They feel fulfilling a social role of retribution, especially in cases involving parents and children. They presented a dissatisfaction with the oscillation between improvement and worsening of clinical condition of the elderly, reported to be tiring. And some have reported happiness in the post-fall recovery period, when the elderly returns to do most of daily activities, what gives evidence of how laborious it is to deal with an elderly relative who has fallen, independently of the degree of the accident.

"My father ... is confusing things, he is not listening well, so I have to go after everything. There is a day he does not eat ... and it annoys me when he gets up and has a problem, we get upset. "C10.

"As a caregiver, I think I'm doing well, of course, because that's what I can do, not everything, but I do what I can." C11.
"Lately It has been calmer now because we already have pre-established activities and the general state of her health of lucidity, moving alone, not needing breathing apparatus, of nothing, it makes the experience easy. It only has the daily routine adjustment and a greater care in cases of colds. And constant attention that does not dispense more work. "C15.

When asked how being a caregiver affects their private life, they all felt affected, but in different ways. A considerable group saw work as leisure, and in this situation did not allowed them to perform employment activities. Some fit their activities into the routine of the elderly, others live completely the routine of others, as well reported the impossibility of leaving without having to ask a third party to accompany the elderly. Since the majority of participants in this study were over 50 years old, they felt overwhelmed with all the routine of

the elderly, which affected their ability to perform certain activities, as well as fatigue more easily. One group stood out because of the unusual ability to work at home and to be able to completely coincide with the elderly routine, and did not feel affected by the changes that occurred after fall.

"I can not say that it has not changed because I dedicate 24 hours every day, so of course I stopped going out by myself, I do not share many friends anymore, so I go out together. "C17.

"Affects, it does affect... because you... get nullified. You have to give your time to the person you are caring for and you yourself are left without your personal life. Your affective dimension is well compromised because most of the time the person who is with you, does not even understand what you are going through, you no longer devote yourself to that person so you are very flawed. "C8.

"More or less, it affects everything [...] he does not give me peace." C9.

The caregivers in this study presented a highly altruistic posture; they decided to give up their routine to live for their family member. The reasons that lead to this commitment according to Mazza and Lefreve (2004) were: concern for something wrong happening to the elderly; retribution to what he received as a child; have family ties with the elderly; wear and care burden; duty and obligation; reversal of roles in the mother-child relationship; ambivalence of feelings; care as devotion; among others. For Nelman and Dias (2013), many caregivers had no choice; the elderly was seen as a burden for family members considering some factors such as being woman, daughter, daughter-in-law, etc., so, the choice of the potential caregiver is surrounded by conflicts among family members. The caregiver's feeling about his activity toward his relative with weakness follows a linear path initiated by the sense of duty, followed by obligation, over time become love and satisfaction. "Taking care of someone who has always cared for me" was a feeling that have overflowed in the reports. Even with difficult, their work was satisfactory and generated in a sense of accomplishment the caregiver, a paid debt, a loving retribution.

Conclusion

It is concluded that the experience of the family caregiver envolves changes in daily life, burden of activities and fear of further falls. The burden of caring for an elderly person who suffered a fall seems to be greater because it adds distrust of the family with the him. The changes that occurred after the falls were more personal than physical, since many of the elderly do not have physical sequelae, but decreased capacity, such as a decrease in gait due to fear, what interferes in social life of the caregiver who cares many times in full time. Regarding external expectations, primary care is expected to provide guidance on adequate care for the elderly relative, in order to avoid further falls. The age group of the informal caregivers, also more advanced, interferes with the quality of care, since they have their own physical limitations. In this sense, nurses have an intrinsic role in supporting caregivers through orientations and providing social support.

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