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The experience of the informal caregiver in the light of the General Theory of Nursing

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ABSTRACT

Aim: To understand the experience of informal caregivers in the care of the elderly victims of fall and proximal fracture of the femur and surgery. **Method:** This is a qualitative study carried out in a teaching hospital, using Bardin's content analysis as a methodological reference, and Orem's General Theory of Nursing as a theoretical reference. **Results:** Of the 14 informal caregivers, the majority were female and daughters of the patients. From the speeches of the participants, the thematic categories emerged: The day of the fall, a traumatic event; agony and tension by waiting for the bed and surgery; fear, frustration, and lack of preparedness of the informal caregiver; changes in the life, deprivation and overload of the caregiver; resilient care. **Conclusion:** Informal caregivers should be trained from the prevention of the event to the transition from hospital care to home rehabilitation, rescuing the role of the nurse within the multidisciplinary team, and with the support by the General Theory of Nursing.

Descriptors: Caregivers; Aged; Accidental Falls; Femural Fractures; Perioperative Nursing.

INTRODUCTION

The progressive increase in the elderly population in the world has been one of the greatest challenges in public health. An important problem faced is the high incidence of falls, which should be considered an important event in the life of an elderly individual[1-3]. The fall causes a decrease in the capacity of the elderly, both for functional independence and for the instrumental activities of daily life, making them more dependent for their performance[1-2]. The consequences of falls in the elderly range from simple excoriations and fear of a new fall, to severe injuries, such as Proximal femoral fractures (PFF) in need of a surgical treatment[3-5].

A meta-analysis including studies by 2012 indicates that approximately 25% (4) of the elderly will die within a year after a fall followed by PFF and surgery. A study conducted in Germany, including 391 elderly aged 60 years or over, found that the predictors of mortality are: cognitive status, health conditions, pre-fracture quality of life, and being male[3]. In Brazil, an analysis of 2,126 deaths from falls in the elderly showed that the probability of death is significantly higher for the female sex, for the age group above 69 years for white-skinned elderly people, for widows or unmarried[6].

Considering the intense population aging, the high incidence of falls in the elderly is a promising context for PFFs, with consequent impairment of functional independence. Most of the time, rehabilitation demands a new family arrangement to meet the needs of the elderly[7-8]. The great challenge for health professionals is to make the elderly return to pre-surgery conditions, and the recovery of their functional independence and quality of life is also a challenge for their relatives.

When considering the role of the caregiver of the elderly, the investigations highlight the negative effects of this function, with emphasis on physical and psychosomatic diseases, anxiety, depression, and stress[8-10]. There is an intense approximation of the nursing scientific community[8], which has deepened the studies with the elderly and caregivers, with a focus on the strategies and experiences that demonstrate the importance of the qualification of the families to carry out the care[10-12]. However, difficulties in terms of care, financial tension, conflicts with the elderly and social support perceived as insufficient are the main causes of caregiver overload and distress[8].

It is known that families present several concerns, many of them linked to the stage of recovery through which the elderly pass[8], and that caregivers are inserted in all stages, being or not prepared to perform or face them. Knowing the experience of the informal caregivers, as well as knowing the needs of this population also vulnerable to the consequences of falls in the elderly, allows inserting them as important agents in the prevention of falls, in the care and rehabilitation of the surgical elderly.

The study becomes relevant considering the aging of the population, the high incidence of falls followed by PFF in the elderly, and the need to prepare families from prevention to rehabilitation at home. It is justified to carry out this research, since knowing the experience of informal caregivers will allow professional and social investments, in the sense of guaranteeing the quality of life of caregivers and consequently of the care given to the elderly.

In view of the above, we ask: What experience has the informal caregiver experienced since the fall event and PFF until the postoperative care at home? In order to respond to this concern, this study aims to understand the experience of informal caregivers in the care of the elderly victims of fall of their own height followed by PFF and surgery.

METHOD

This is an exploratory study that uses a qualitative approach, recommended when the research question demands the understanding of the experience of the other to elucidate different facets of the phenomenon. The research was conducted at the orthopedic outpatient clinic of a teaching hospital in the countryside of São Paulo, belonging to DRS VI, with a coverage area of 68 municipalities.

Included in the study are the informal, unpaid caregivers responsible for the care of the elderly (60 years or older) who fell from their own height followed by PFF and surgery in the last 12 months. It is excluded from the study the caregivers of the elderly who did not attend the outpatient return.

The study was conducted in the second half of 2014 and in the year 2015. Data collection was performed through a semi-structured interview prepared for this study, using a form composed by the characterization of the caregiver and the following guiding question: What are your experiences, feelings, and difficulties encountered in caring for the elderly after falling, surgery and home care?

The interviews with the caregivers were carried out in a single moment, in a reserved space in the orthopedic clinic, which guaranteed the privacy of the researcher and interviewed throughout the period. There was no interruption at the time of the interview. The audio was recorded in its entirety on a voice recorder. The caregivers, for the purposes of this study, were identified with the numbering attributed to them at the time of the interviews (C01, C02, etc.), to maintain their anonymity. The sample closure occurred due to theoretical saturation, i.e. the inclusion of new participants was suspended when the data obtained began to present repetition and redundancy, failing to contribute significantly to the study [13].

This is a subproject approved by the Research Ethics Committee (CEP) - Letter 16-2014, linked to the research project "Functional Autonomy and risk of falls in the elderly in the postoperative period of hip fracture: from estimation to prevention at home ", Approved by the CEP - Protocol 3967 - 2011. Participants signed the Term of Free and Informed Consent after being informed about the objectives and methods of the research with the guarantee of secrecy and anonymity.

For data organization and analysis, the Content Analysis according to Bardin[14] was adopted as a methodological reference. The content analysis is a set of communication techniques that aims to obtain systematic and objective procedures for describing the content of the messages, allowing the knowledge of the conditions of production/reception of the messages, which define it as a research technique for objective description of the manifest content of the communication. The content analysis method consists of three phases: pre-analysis (data organization, initial reading of the entire content, choice of documents or records, and criteria determination); exploration of the material (codification in themes, which allows achieving thematic representation of the content, composing the categories); and interpretation (data are treated in a way that it is meaningful and valid)[14].

The findings were discussed in the light of the General Theory of Nursing proposed by Orem[15], based on the premise that everyone has the potential, to varying degrees, to take care of himself and those under his responsibility. This theory is constituted by three theoretical constructs - self-care, self-care deficit and nursing system. Self-care describes and explains the practice of care performed by the person

with a need to maintain health and well-being. The self-care deficit is the essence of the Theory, for outlining the need for nursing care, and is justified when the individual is incapacitated or limited to provide continuous and effective care. And finally, the nursing system describes and explains how people are helped through nursing and the fully compensatory system when the individual is incapacitated or limited; partially compensatory, when the nurse and patients participate in the actions; and system of support and education, when the individual needs guidance and teaching[15].

RESULTS AND DISCUSSION

The sample consisted of 14 informal caregivers of elderly individuals who suffered falls following PFF and surgery. Of the caregivers, eleven were female and three were male, between the ages of 35 and 68 years. Of the participants in the study, six had high school education, five attended elementary school, two had higher education and one was illiterate. The monthly income of the interviewees ranged from two to seven minimum wages. The care was performed predominantly by son or daughter (9), followed by husband or wife (2), friend (2) and daughter-in-law (1).

From the subjects' speeches, five thematic categories emerged: The day of the fall, a traumatic event; Agony and tension by waiting for the bed and surgery; Fear, frustration, and lack of preparedness of the informal caregiver; Life Modifications, Deprivations and Caregiver Overload and Resilient Care.

Category 1 - The day of the fall, a traumatic event

From informal caregivers' speeches, we realize that the first challenge becomes the unexpected event of the fall, since often the elderly person was independent, and the caregiver still did not play this role. The study participants seem unprepared to take care of the elderly, and the fall becomes a traumatic event, according to testimonials:

- C5 - The one who helped her was the neighbor, then my sister arrived from work, called the ambulance that brought her. The next day, I left work and came here.
- C6 - It was difficult. We think of everything; that she could not walk anymore. At that moment we feel fear, anguish. The hardest time was when I saw her lying on the ground because we never think the person will fall and get hurt again.
- C7 - I think the hardest part was seeing the rescue team arrive, immobilize him and take him to the hospital.
- C12 - The only thing we felt was scare, because the rest we let go; we have to get through. The problems that we think; what happened; Will it improve? we don't know what it will be like. It's difficult.
- C13 - When she fell we couldn't get her off the ground, so we called the ambulance. There were no orthopedists there. It was a psychological ordeal; we were shaken, scared and we didn't know what to do... everyone was nervous.

From the words of the caregivers, it is inferred that the fall brings fear, especially since it means the incapacity of the elderly person to take care of himself. According to Orem, the requirements of self-care are: maintenance and sufficient intake of air, water and food; provision of care with elimination; balance between activity and rest and between solitude and social interaction; prevention of risks to life, functioning and human development and in social groups. Orem considers that adults are able to take care

of themselves; however, due to old age and illnesses, the elderly may require the presence of a caregiver[15], including for the prevention of falls.

Literature review concludes that among the prevention measures for falls, multifactorial intervention is described by academic studies as the most effective, using adaptation of the environment, incorporation of physical exercises, vitamin D supplementation, withdrawal or reduction of medication dosage, especially the psychoactive ones, and evaluation of postural hypotension[2] .

The elderly's perception of risk factors for falls does exist, but often they are not avoided, since the individual considers "taking care" as an infallible weapon in terms of prevention, which brings to the fore the phenomenon of invisibility of some health risks[5]. Regarding the family members, a cross-sectional study including 89 informal caregivers of elderly people who suffered PFF points out that 57.3% of informal caregivers considered they had no knowledge about falls prevention in the elderly, and 85.4% reported not receiving guidance from the health professionals on the prevention of falls. In this sense, the prevention of falls is an essential aspect in the health care of the elderly and a challenge to health professionals and families[16].

It should be emphasized that nurses and those who coordinate emergency and intra-hospital emergency services should be prepared and trained to work in situations of fall, through adequate physical and human resources[17].

Category 2 - Agony and tension by bed waiting and surgery

The tension of the acute fall event followed by PFF also influences the hospitalization and scheduling of the surgery, causing the elderly to wait for the bed and to for the performance of the surgical treatment, increasing the stress of the relatives, as reported by study participants.

- C2 - Waiting all this time, so long; it is an agony to have to wait for so long. We arrived there, and spent 12 hours waiting for a bed, away from home. She had to wait to be transferred because there was no vacancy, so it took her a week. Everything was bruised, swollen, getting black.
- C4 - He was hospitalized for 10 days; he had pneumonia and stayed there for more than 12 days, so it took him quite some time. While he had a fever, he could not undergo operation, and my blood pressure was high.
- C8 - Waiting to get a bed was very difficult. [...]
- C10 I had to wait for a vacancy; this wait was bad, I think it was the hardest. [...] it freaks me out [...]
- C11 Waiting for surgery is exhausting [...]
- C14 It took long for her to be operated, so it was difficult this time [...]

Orem's theory is interrelated with the Systematization of Nursing Assistance, enabling the nurse to assist the elderly and their families throughout this process, involving the individuals in the care process, aiming at the quality of care performed and minimizing the complications arising from hospitalization[15].

This waiting time referred by the informal caregivers may be related to the increase in the incidence of falls among the elderly, because of the increase in the life expectancy of the population. The delay in performing the surgery is due to the fact that the elderly present comorbidities and need a clinical stabilization before the procedure. Studies show that age, comorbidities, cognitive status, and waiting time for surgery are the main predictors for mortality after fracture[3,6].

A study that estimated the risks of death and readmission of elderly people with PFF discharge in hospitals of the public health system

of Rio de Janeiro, Brazil, including 2,612 elderly people with non-elective hospitalization for PFF, showed that the readmission rate in one year, with the exclusion of deaths during this period, was 17.8% and the mortality rate independent of readmission was 18.6%. The most frequent causes of death were diseases of the circulatory system (29.5%) and almost 15% of the causes of readmission were surgical complications. Age greater than or equal to 80 years presented a higher risk of readmission and death[1].

Category 3 - Fear, frustration and lack of preparation of the informal caregiver

After the stress experienced by the fall and after the surgery is carried out, the caregivers experience a new stage in caring for the elderly at home. Often this situation can be difficult for the caregiver, mainly because of the lack of preparation when facing this new function, as stated by the caregivers.

- C1 - It was difficult at first because we were not prepared. It was a radical change, a means of urgency and I had nothing prepared to receive him at home and I had to arrange everything at a moment's notice.
- C2 - Now she is like this: the physiotherapist says she has the strength and everything, but she can't walk anymore.
- C3 - When she walked, she would go to the bathroom; she did everything herself. Now, it's not like this. She wears diapers, she has to be fed; we do everything. She doesn't walk anymore; she's in a chair or in bed.
- C7 - It seems that he is a child again, psychologically, mentally and in the motor part, because he became totally dependent.
- C8 - The only hard time was willing her to walk, but she is not being able to do that so fast.
- C13 - In the early days, she was bedridden. We had difficulty and we were afraid she would have bedsores, because she only stayed in bed. So, it was difficult for us. We would change her clothes on the bed, then she started to sit down, she got better, but the beginning was difficult, very difficult.
- C14 When she was in bed, we had to feed her in the mouth, we had to help in everything, had to put her in the chair, everything, and so that was the worst. When she was in bed, she was very dependent. At first, we were afraid, she didn't want to walk anymore, she was afraid to fall, to hurt again.

The difficulties pointed out by the interviewees are as expected, considering the care provided to the elderly by lay caregivers. These difficulties can be minimized with greater support to the informal caregiver in the transition from hospital care to home care. Orem's theory provides insight into the phenomenon of nursing by allowing the nurse, along with the individual, to implement self-care actions tailored to their needs, so that the help relationship is expressed in open dialogue and promotes the exercise of self-care[15]. The theorist identifies five self-care deficit-relief methods for which families must be prepared: Acting or doing for another, guiding the other, supporting the other (physically or psychologically), providing an environment that promotes personal development, how to become capable of satisfying future or current demands for action and teaching the other[15].

The literature recommends the use of health education as a strategy to minimize overload, considering that caregivers who presented knowledge about falls prevention in the elderly, even if incomplete, used preventive measures for new events; however, these were not yet included in the process of caring for the elderly[16]. The failures in self-care are due to the lack of information at the hospital discharge, which is the responsibility of the nurse, especially

regarding the dressing, the correct cleaning and maintenance of the surgical wound. Such failures make continuous and satisfactory home care impossible[19].

Considering the educational support system proposed by Orem, which is indicated when the individual needs assistance in the form of support, guidance and teaching, it is necessary to train families systematically, considering their needs. This is an adequate measure to minimize the stress experienced by caregivers and also to increase their safety in home care[15].

Category 4 - Changes in life, deprivation and caregiver overload

The overload of informal caregivers is widely discussed by the scientific community[8]. Considering the different scenarios experienced by families, the overload in the life of the informal caregiver becomes a frequent situation, as we can identify in the speeches of the participants.

- C2 - It changed my life, because now, I'm living for her; it changes everything. I had to stop working and I had to stop studying what I was studying.
- C3 - Someone has to stay to take care of her all the time. We went to the doctor with her, went to the church; she has practically turned into a child; we must put diaper on her, bath her, feed her in the mouth, like a child.
- C5 - I worked at night and took care of her during the day.
- C6 Not that it disturbs me, but many things that I wanted to do, I can't, because I have to take care of her, but it doesn't disturb me.
- Caregivers report the difficulties faced in the process of caring for the elderly at home and the deprivation of other activities such as caring for their children, the home, and work, among others. An accumulation of these activities leaves the caretaker overwhelmed, which can even lead to some kind of illness.
- C10 - Everything changed. I had to stop working; I worked out and had to stop. The money has changed, now I don't earn that money any more.
- C11 - Everything has changed because everyone has to help a little. Everyone's routine had to change. Her granddaughter had to quit her job to help me take care of her; these things.
- C12 I got stuck inside the house. Before I used to go back and forth and now I have to depend on others, and I don't like asking others. We need to have more responsibility, to make appointments. This issue keeps us in indoors.

Difficulties in care, financial stress, conflicts with the elderly and social support perceived as insufficient are the main causes of informal caregiver overload and suffering. Participation in decision-making, improved access to legal and medical information, the possibility of sharing care experiences, the existence of a secondary caregiver, and increased social support promote mental health and boost self-efficacy of care; however, without significant reduction of overload of the caregiver[8]. The physical, emotional, and socioeconomic overload of care for a family member is immense, complex, and requires a lot of caregiving, and this overload can, in a way, contribute to the onset or worsening of illness. Thus, the overload generated by the care process, besides presenting a multidimensional concept, also suffers from the diversity of influences associated with the elderly and the caregiver himself[18].

A cross-sectional study including 178 elderlies and their caregivers identified that 102 (57.3%) caregivers presented moderate overload; 44 (24.7%), presented small overload; 28 (15.7%) had moderate to severe overload and only 4 (2.2%) had severe overload. Men

presented higher chances of lower overload than women and the more independent the elderly, the greater the chances of lower caregiver overload. The authors recommend the encouragement of actions aimed at the promotion of active and healthy aging, focused on the maintenance of the functional capacity and autonomy of the elderly, as well as the implantation of strategies of organization of the care in the home, that include the health of the caregivers, who can contribute to minimize the effects of overload on them and improve their quality of life[18].

Besides the overload, there is still a discussion in terms of the vulnerability of the elderly. A Brazilian study aimed at uncovering the vulnerability situations, reported by elderly people who suffered falls and by their caregivers in a public hospital, shows that individual vulnerability is related to the comorbidities of the elderly. Social vulnerability was observed through environmental risks and by the absence of a family nucleus prepared for the process of caring for and rehabilitating the elderly. Institutional vulnerability revealed itself in hospitalization and the meanings of the fall, alerting to the fear of falling, guilt, disability, loss of autonomy, pain and discomfort of the elderly. The authors emphasize that health professionals should be able to care for the elderly from the identification of situations of vulnerability to fall and, with this, to act in a preventive way[17].

Category 5 - Performing Resilient Care

The speeches of the caregivers demonstrated an affective feeling increased by the elderly after experiencing the event of fall, fracture and surgery. Despite the difficulties reported by relatives, the closest interaction also brought positive aspects that were experienced during the care, especially by the restructuring of the bond.

- C1 - Today he has his little room, because he lives with me, in the same house. We had affection for him, but after we took care of him, that son and father thing increased, so it was bad for him to have broken his hip, to have fallen and broken it, but it was good for me, to be able to see my father better, to like my father.
- C5 - I would take care of her and make her look cute. It was easy, and I didn't have to change anything. Everything worked just fine, the schedules; everything fell into place.
- C6 - It doesn't bother me. She's my mother, so it's okay, I try to put her up and I try to do my best.
- C8 - I want the health she has. She makes my life easy; she does everything we ask. Do I have affection for her... wow!! This week, when she took a step towards me I was moved, I cried. The difficult thing is to have to leave her later when she starts walking better.
- C12 I like her a lot, I like her to stay home; she's good company. So, we learn; we go through things. I'll miss it when she leaves the house, because we get used to it. If I'm alone the time does not pass, I want her to go because that's what she wants, but then there's no problem; then I go for a walk and spend the day with her.

Resilience refers to a tendency, even under stress, to respond flexibly rather than rigidly. The resilience of family caregivers of the sick and dependent elderly is a subject that appears as a new research strand, possibly because of the visibility that the phenomenon has been gaining in recent years, where increasing longevity and the need for care have become more palpable facts in clinics and families[20].

The present study corroborates with the literature, pointing out that not all caregivers develop diseases or become dissatisfied with the

task of caring. This can be explained by the use of different individual strategies to deal with the situations considered exhausting[20,21]. Literature review concludes that family closeness with the patient, black ethnicity, good quality of life, healthy living habits, optimism and satisfaction with life seem to influence the increase in the resilience of caregivers[21]. Resilience has also been shown to be promoted through adequate family, social, and financial support, by helping and dividing the care responsibilities, by the better physical and emotional state of the caregiver, and by the knowledge that the caregiver has about the illness[21], the role of nurses in health education. These factors corroborate to soften the physical and emotional overload; strengthen and enable the confrontation of adversities and challenges. This confrontation is consequently carried forward in quality in the care of the person cared for. The performance of a resilient care, reported by informal caregivers, is a subject little discussed in the literature, indicating the need for new studies.

Finally, the study makes an important contribution to nursing, reinforcing the importance of prevention planning for falls and health education as well as the importance of inserting the caregiver as a "partner" in the elderly's health care.

One of the limitations of this study is that it did not include a sample group of elderly caregivers who experienced a fracture of the femur followed by severe complications and death, situations that could bring new findings to the study. In addition, the results found here cannot be generalized, and studies on the subject must be carried out with other methodological designs.

CONCLUSION

The fall of an elderly person followed by PFF is also an acute and traumatic event for informal caregivers who are unprepared for this new stage. Difficulties happen from the day of the fall, to hospitalization, tension in waiting for hospitalization and surgery, and accentuated in home care, which often happens without adequate preparation.

Even with the commitment of families, the elderly often does not regain their functional independence and conditions for self-care, further frustrating the informal caregiver. This entire problem ends up generating an overload in the life of the informal caregiver, who often needs to deprive himself of his needs to meet the needs of the elderly. However, it should be noted that some caregivers perform a resilient care, and often the task of caring allows the reestablishment of the affective bond and the recovery of many positive feelings.

Finally, understanding the different phases and needs and making planned care for each family is still a great challenge to be addressed about the quality of life of the elderly and caregivers. The study indicates that informal caregivers should be trained from the prevention of the event to the transition from hospital care to home rehabilitation, rescuing the role of the nurse within the multidisciplinary team being supported by the General Theory of Nursing.

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