

The plurality of feelings in the act of caring for hospitalized elderly family members

RESUMO | Objetivo: Descrever os sentimentos dos familiares cuidadores frente a hospitalização do idoso. Método: Pesquisa de abordagem qualitativa exploratória com entrevista semiestruturada e observação participante registrada em diário de campo submetidos a análise temática. Local da pesquisa, uma instituição hospitalar da região do Vale do Itajaí/SC no ano de 2017 após aprovação pelo Comitê de Ética em Pesquisa CAAE: 71416217.1.0000.0120. Resultados: Entre os familiares cuidadores durante a hospitalização encontrou-se sentimentos positivos como satisfação pelo dever cumprido, sentir prazer em cuidar e sensação de que vale a pena cuidar, assim como cansaço no ato de cuidar, sofrimento pela situação de fragilidade, impotência e sobrecarga, contudo manifestaram o desejo de ajudar o familiar hospitalizado. Conclusão: O estudo permitiu observar a pluralidade de sentimentos positivos e negativos apontados pelos familiares durante o cuidado dos seus entes idosos na hospitalização, mas consideram que este ato traz um sentimento de dever cumprido embora, nem sempre prazeroso.

Descritores: Cuidado; Família; Hospitalização; Idoso; Emoções.

ABSTRACT | Objective: To describe the feelings of family caregivers regarding the hospitalization of the elderly. Method: Exploratory qualitative approach research with semi-structured interview and participant observation recorded in a field diary submitted to thematic analysis. Research location, a hospital institution in the region of Vale do Itajaí/SC in 2017 after approval by the Research Ethics Committee CAAE: 71416217.1.0000.0120. Results: Among family caregivers during hospitalization, positive feelings were found, such as satisfaction with a duty fulfilled, feeling pleasure in caring and feeling that it is worth taking care of, as well as tiredness in the act of caring, suffering due to the situation of fragility, impotence and overload, however, expressed the desire to help the hospitalized family member. Conclusion: The study allowed us to observe the plurality of positive and negative feelings pointed out by family members during the care of their elderly ones during hospitalization, but they consider that this act brings a feeling of accomplishment, although not always pleasant.

Keywords: Caution; Family; Hospitalization; Old man; Emotions.

RESUMEN | Objetivo: Describir los sentimientos de los cuidadores familiares frente a la hospitalización del anciano. Método: Investigación exploratoria de enfoque cualitativo con entrevista semiestruturada y observación participante registrada en un diario de campo sometido a análisis temático. Sitio de investigación, una institución hospitalaria en la región de Vale do Itajaí / SC en 2017 después de la aprobación del Comité de Ética en Investigación CAAE: 71416217.1.0000.0120. Resultados: Entre los cuidadores familiares durante la hospitalización se encontraron sentimientos positivos, como satisfacción con un deber cumplido, sentir placer en cuidar y sentir que vale la pena cuidar, así como cansancio en el acto de cuidar, sufrimiento por la situación de fragilidad, impotencia y sobrecarga, sin embargo, expresó el deseo de ayudar al familiar hospitalizado. Conclusión: El estudio permitió observar la pluralidad de sentimientos positivos y negativos señalados por los familiares durante el cuidado de sus ancianos durante la hospitalización, pero consideran que este acto les trae una sensación de realización, aunque no siempre placentera.

Palabras claves: Precaución; Família; Hospitalización; Anciano; Emociones

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INTRODUCTION

The increased demand for hospital beds for elderly patients is due to the aging of the Brazilian population and the consequent increase in the number of chronic-degenerative diseases, so common among the elderly. ¹

In the hospital environment, the situation of vulnerability of the elderly and their ability to maintain the physical and mental skills necessary for an independent life can worsen, requiring direct assistance and care by the health team and their caregivers. ²

The family is the main informal support for the elderly person (caregiver),

and this support also contributes to the care activities of the health team for the recovery and discharge of the elderly person. ³

The moral role assigned to the family and the importance given to affective bonds naturalize care as a family responsibility. The disease transforms the family into caregivers. And this caregiver is exposed to a series of stressful situations, such as the burden of tasks and diseases arising from the demands of work and the characteristics of the elderly. ⁴⁻⁵

The tasks/skills that must be developed in the family care process are numerous, some of them are identified as:

observing the person being cared for to ensure that changes are identified; stimulate activities and new achievements; listen, be attentive and show solidarity with the person being cared for; help with hygiene care, mobility and other needs that the person may have; access resources, which may be information or equipment/supplies for the full assistance of the person being cared for, among others. 4;6

It is with great vigor and determination that these people choose to be caregivers, giving up some dreams and personal commitments. They face changes in their experience and activities together with family members, imposing an adaptation to a new life full of tensions and concerns. 7

In the situation of hospitalization, the presence of caregivers/relatives is recognized as a factor that enhances the user's improvement and helps to reduce feelings related to the break with activities that are part of the person's daily life. 8 Therefore, it is known that the family caregiver is extremely important in caring because it brings security to the patient, helping in the daily life of the institution.

As a care partner, the needs of the family caregiver and their perception/feelings about the care of the elderly are relevant to the implementation of care practices and strategies by the multidisciplinary team throughout the elderly person's entire journey during hospitalization, including preparation for discharge. 8

The hospitalization process of elderly people who need family monitoring needs to be described and understood so that we, as health professionals, can reflect on the triple relationship: elderly – family – health professional/institution.

Therefore, it is presented as a guiding question, to understand what the feelings of family caregivers are regarding the hospitalization of the elderly.

METHOD

This is an exploratory descriptive research with a qualitative approach through thematic analysis of thematic-category content carried out in



É com muita garra e determinação que essas pessoas optam por serem cuidadoras, renunciando alguns sonhos e compromissos pessoais. Enfrentam mudanças na vivência e atividades juntamente com os familiares, impondo uma adaptação a nova vida repleta de tensões e preocupações



the medical clinic of a medium-sized hospital in the Health Region of Foz do Rio Itajaí Açu, in the state of Santa Catarina. In the period of data collection (September to December 2017) we had one of the researchers working as a clinical nurse, and in this way access

and knowledge about health and disease conditions, as well as the treatment of elderly patients was facilitated since they were attended by her daily.

Therefore, the choice of the elderly and their families was intentional because they already had prior knowledge of the length of stay, the constant presence of the family caregiver and the availability of acceptance to participate in the research. After the family member's understanding and confirmation, the Informed Consent Form was delivered, confirming the acceptance of participation.

The number of the initial sample was constructed by evaluating the average number of hospitalization days, which are on average 7 days or more, and the number of beds occupied. The approximate calculation per month of hospitalized patients would be the sum of beds multiplied by four weeks to have a total number of visits per month (interpreting 7 days as a hospital stay). As it is a medical clinic consisting of 27 hospital beds, receiving patients over 14 years of age (additional hospitalization is not exclusive), this total is 108 inpatients per month. The average hospitalization of elderly people in this clinic is approximately 30% of the beds, with a total of 32.4 elderly patients per month.

The total number of caregivers selected for the study would depend on factors such as the flow of admissions and demand from elderly patients, in addition to meeting the inclusion criteria, being over 18 years old, of both sexes, having a family relationship and, preferably, that they were the main caregiver.

As they are family caregivers of a specific group of patients - elderly - in the same place of hospitalization, for a time considered relevant, many of them sharing the same hospital room and similar experiences, it was observed as the interviews were carried out, the narratives were transcribed and the re-

searchers assessed the need to carry out a number of interviews until reaching data saturation. Fact achieved with the quantity of 10 family caregivers of hospitalized elderly.

It corresponds to the suspension of inclusion of new participants when the data obtained start to present, in the researcher's assessment, a certain redundancy or repetition, and it is not considered relevant to persist in data collection. 9

Data collection was carried out from September to December 2017, but its results were presented in the master's thesis defended at the end of 2018 and corresponds to the second article in this study. The first article, although submitted in 2018, was only published in 2020, which corresponded to part of the results related to the relationship between the health team and family caregivers during hospitalization. The time between submission and publication discourages the researcher from submitting new articles, however we understand the specificity of each journal and decided to continue publishing the other results. Even after three years have passed, we believe that the results indicated are still relevant and current.

As a data collection technique, semi-structured interviews were used, followed by participant observation, recorded in a field diary. And, it took place in two stages, as described below.

In the first stage, the semi-structured interview was conducted within the institution in a room used in the inpatient unit so that the interviewees did not need to be away for a long time, thus causing greater comfort and safety for the family and patient. The duration of the interviews was approximately 45 minutes. The interviews were recorded and transcribed, and the data obtained were analyzed using the thematic-categorical content analysis technique.

Thematic categorical analysis consisted of three stages: 1) pre-analysis, exploration of the material, and treat-

TABLE 01: Characterization of family caregivers and reason for hospitalization of the elderly, Itajaí (SC), 2017.

Family	Gender	Age	Kinship	Occupation	Reason	Abbreviation
Family 1	M	56	Son	Acupuncturist	Ischemic Stroke	Fa1F1
Family 2	F	23	Wife	Housewife	Severe TBI	Fa2 E2
Family 3	F	59	Wife	Attendant	CKF/ Urinary sepsis	Fa3E3
Family 4	F	49	Daughter	General Services	Severe COPD	Fa4F4
Family 5	F	48	Daughter	Cleaner	Diabetic coma	Fa5F5
Family 6	F	41	Daughter	Cosmetics company	DVT in the LLL	Fa6F6
Family 7	F	55	Wife	Housewife	Bladder Cancer Pneumonia	Fa7E7
Family 8	F	43	Wife	Housewife	Suspected tetanus/ Stroke I and SAH	Fa8E8
Family 9	F	54	Daughter	Housewife	Diarrhea 1 month ago/ weight loss (15kg)/ Suspected bowel cancer	Fa9F9
Family 10	F	63	Daughter	Businesswoman	Bronchopneumonia	Fa10F10

Source: SANTOS; SANDRI, 2017.

Table 01: Presentation of the thematic category

Thematic category: Feelings of family caregivers		
Subcategories		
1. Satisfaction for the completed duty	2. Suffering from the situation	3. Tiredness combined with frustration and impotence

Source: SANTOS; SANDRI, 2017.

ment of the obtained results and interpretation. The pre-analysis is done by selecting the documents to be analyzed and retaking the initial research hypotheses and objectives. 2) exploration of material, seeks to achieve comprehension of the text, looking for meaningful categories or words in a speech so that

its content is organized. 3) treatment of the results obtained and interpretation, when it is possible to highlight the information obtained. From there, the interpretation of the results is carried out, which is to identify data that stand out relating to the theoretical foundation initially constructed or opening new

interpretations. 10

For the second stage, information was recorded by the researchers through participant observation, where they reported their impressions in a Field Diary right after the observations, in order to minimize the loss of relevant information. Participant observation was carried out during nursing care for the elderly with the participation of family members. In general, the field diary aims to record the rite and interferences of the interview, as well as the interviewer's perception of the care actions performed by family members during hospitalization.

The techniques used to carry out this research were relevant for understanding the data collected and identifying them, thus leading to a classification and categorization of the study. Participant observation, together with the completion of the field diary, fostered the understanding of the research and interpretation of the lines cited in the interview due to the opportunity of comparison in everyday life with the reality experienced by family caregivers.

The study met the norms of the Resolution of the National Health Council nº 466/12, being approved by the Research Ethics Committee (CEP), according to CAAE: 71416217.1.0000.0120, with the Embodied Opinion nº. 2,212,063. Only after this approval did the data collection begin. All participants received code names through the symbolism of Fa (family), numeral (1 to 10), corresponding to the temporality of the interviews and the initial letter of F (son or daughter), E (Wife), followed by the same family number (1 to 10).

RESULTS

Among the ten family caregivers, only one is male; four consisted of wives, five daughters and one son; aged between 23 to 63 years; diversified profession, but most had an employment relationship and three identified them-

selves as home caregivers.

Category: Feelings of family caregivers

Through the analysis of the interviews, it was possible to list the following thematic category – Feelings of family caregivers, having as subcategories: 1. Satisfaction with the fulfilled duty; 2. Suffering from the situation and 3. Tiredness combined with frustration and impotence.

Subcategory 1: 1.Satisfaction for the completed duty

The family caregiver, who cares directly and who assumes all responsibility for the act of caring - sometimes for an entire family - is not always prepared for this task, however what motivates them to assume is the desire to repay the care that was received by them one day, thus providing a sense of accomplishment.

In the speech of Fa4F4, she states that she is doing for her mother what she did for her, she even relates the care she received with what she is doing, saying that it is not out of obligation that she takes care, but out of love. And Fa7F7 wants everything to go as smoothly as possible, even if her husband dies, she will have a clear conscience.

[...] I'm doing for my mother what she did for me many years ago, right, treating me, changing, staying there, losing nights and more nights of sleep. So, this part is very complicated for me. I said: I'm not here out of obligation, I'm not obligated to be here. I'm here because I love you, you're my mother. If I need to turn over the weeks, days and nights I do. (Fa4F4)

If he's gone, I have my clear conscience that I did what I could. (Fa7E7)

The feelings of enjoying the work

done and feeling pleasure in caring and the feeling that it is worth taking care of were mentioned by family caregivers.

Subcategory 2: Suffering from the situation

Other feelings such as sadness were present, but not because of the act of caring, but because of the elderly person's conditions, causing suffering due to the situation. However, Fa10F10 feels calm and secure because she understands that she could not provide care alone and considers that she is doing what is most appropriate for her family member.

I feel sad that she is here, but on the other side I know she is being taken care of. At home I couldn't be doing what you guys do here. So I feel calm, safe, at least she is being observed, monitored [...]. (Fa10F10)

Fa7E7 talks about her desire to keep her husband close to her, but without causing him more suffering and pain, as does Fa5F5 when talking about her mother and the care she needs.

It's not easy to take care of a person you saw who got up, showered, drank coffee, went to work, drove, independently and nowadays, he sees himself totally dependent. Just seeing him like that makes me think, 'my God!' But I'm selfish, asking God not to let you go [referring to the patient], but I have to ask for the best to happen, because I don't want him to suffer. Because every minute I suffer along with him. (Fa7E7)

[...] Here, it's very unfortunate to know that she depends on me to turn her over in bed, to wipe her ass, to eat the little things that are made! (Fa5F5)

The desire to be in a situation other than suffering leads to a reflection on life and its possibilities. The care provided to the patient, together with the imminent possibility of death, often leads the family caregiver to an overload of care that generates fatigue and, consequently, the feeling of impotence in the face of the disease.

Subcategory 3: Tiredness combined with frustration and impotence

The feeling of tiredness, together with the frustration and impotence of not knowing what the result of all the care provided to the patient will be, is mixed in the speech of two daughters. Fa4F4 says it is tiring and stressful, but she considers herself used to the routine, yet she shows uncertainties in the future, causing some frustration because she doesn't see improvement and doubts if in fact she will return. An expression that can be contained in the prospect of having the person back before the illness. Fa6F6, on the other hand, says she is renewed from her fatigue when she gets home, she takes a relaxing bath and is ready to exercise care again.

[...] it's quite tiring, it's stressful, but I'm tired, like, I don't care because I'm used to it, but that's just thinking, my God will all this, this dedication, will she ever come home? (Fa4F4)

While it is, as they say, (silence) that I'm helping him, it's tiring for me. But that doesn't even say the other, from the moment I get home and take a shower, I come here, leave my tiredness aside and come back. (Fa6F6)

It is seen that the care of the elderly is generally held responsible to one person, a main caregiver, further increasing this individual's burden and fatigue.

Fa5F5 demonstrates his tiredness when he states the difficulty in taking turns taking care of the mother with the sisters, leaving little time to carry out their own activities:

Today I am grateful that sometimes my sister comes and takes turns with me to stay at the hospital, but if I say: - You could stay with my mother this weekend, I would like to take a weekend to travel or... NO! (Fa5F5)

Caring is challenging and sometimes the expected results are not achieved with the actions taken. It does not depend on the caregiver to achieve these expectations, knowing the diversity of factors that influence the patient's improvement, including their previous history. Even so, the frustration with a person who cannot recover is remarkable.

DISCUSSION

As a care partner, the needs of the family caregiver and their perception of care for the elderly are relevant to the implementation of care practices and strategies by the multidisciplinary team throughout the elderly person's entire journey through hospitalization, including in the preparation for discharge. 7

Due to family caregivers not having previous experience in most cases, they ended up suffering from their own mistakes, facing difficulties as they arise. They also demonstrate a lack of psychological preparation when faced with the suffering of a loved one. 2-11

These caregivers learn in daily practice to provide care based on their experiences with the dependent elderly person, the feelings presented by them and the tasks they perform become a mixture of emotions with daily conquests glimpsed in the patient day after day.

Caring is considered part of Brazi-

lian culture and most family caregivers see care as something natural in life, an obligation to be fulfilled and not a choice. As a result, the caregiver may find it difficult to talk about their feelings. 12

By bringing the speeches in the subcategories listed as Satisfaction for the accomplished duty; Suffering from the situation and tiredness combined with frustration and impotence, the mixture of emotions causing pleasant sensations and others not so much in the daily routine of care is remarkable. The sense of accomplishment is brought about in caregivers due to the awareness that they have done everything within their power. Caregivers are pleased to see the patient's joy and comfort achieved through the care provided. 13

This feeling does not persist when the desire to reduce/end with the suffering of the loved one is faced with the feeling of impotence that occurs in family caregivers, when they perceive the sick relative, in pain and depressed, and their inability to end the suffering of the other. 14

Signs of overload are fatigue and discouragement, especially for those caregivers who are also responsible for household chores. The sum of day-to-day activities, care for the home, work activities, with the caregiver attributions further increases the fatigue of these family members. 15

When witnessing family members in hospital in the exercise of being a companion, it was realized how much the assigned routine impacts their lives because they end up demanding almost all of their time in this activity, especially those who are alone, without having someone to take turns with the hospital monitoring, a fact that weakens him physically and emotionally, as shown in his narratives. Given this prerogative, it is clear that each of the family caregivers shows their emotions in a peculiar way, which may or may not interfere favorably with the de-

velopment of this task.

CONCLUSION

Feelings regarding the hospitalization period and the monitoring of the elderly family member were witnessed through the narratives of the family caregivers. These feelings, expressed with different characteristics, ranging from the satisfaction of the accomplished duty, to enjoy the work done, feeling pleasure in caring and feeling that it is worth taking care of, but there are those who have stated tiredness in the act of caring, suffering due to the fragile situation, sadness, impotence and overload with care, antagonize the first feelings, showing the diversity found.

It was possible to confirm this plurality of feelings at times together with the family member and the elderly during participant observation, and understand the feelings they incorporate during care.

The family caregiver plays a fundamental role in caring for the elderly. Strengthening these caregivers and facilitating their role of support and care brings countless benefits to the hospitalized elderly. Knowing about the existence of these feelings provides greater knowledge about the emotions of family caregivers, facilitates the empathy of professionals, greater support in routines and think of proposals that can support these people who help their elderly family members in their

daily lives.

The results found may support further studies to expand the discussion on this topic that is so important to human life, which is the act of caring for a family member. Nursing as a care profession should guide these family members so that the post-discharge from hospital occurs safely and with less risk of readmissions, since information, when provided in a clear way, provides greater knowledge and effectiveness in care. Therefore, a closer look by these professionals can make a difference in people's lives, generating more positive feelings in the care process, which is often continuous.

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