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Meanings of care for the hospitalized elderly from the perspective of caregivers

Sentidos do cuidado com o idoso hospitalizado na perspectiva dos acompanhantes

Sentidos del cuidado con los ancianos hospitalizados desde la perspectiva de los cuidadores

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Abstract

Objective: This study aimed to identify and analyze the meaning of care for the hospitalized elderly from the perspective of caregivers. **Methods:** Qualitative, exploratory and descriptive research. The study included 30 caregivers of hospitalized elderly. Individual interviews and systematic observation were adopted. For the data analysis, the software Alceste was used. **Results:** Results show the prevalence of female family caregivers. The meanings the caregivers attribute to elderly care rest on the care activities, relationship between caregiver-user and caregiver-nurse, institutional support and care guidelines. **Conclusion:** The meanings of care are based on the needs and demands of caregivers to take better care of the elderly in need of their care and, therefore, health education by nurses is an important strategy to be implemented with elderly patients in hospital.

Keywords: Aged; Hospitalization; Caregivers; Nursing.

Resumo

Objetivo: Objetivou-se identificar e analisar os sentidos do cuidado ao idoso hospitalizado na perspectiva dos acompanhantes. **Métodos:** Pesquisa qualitativa, exploratória e descritiva. Participaram 30 acompanhantes de idosos hospitalizados. Realizou-se entrevista individual e observação sistemática. Os dados foram analisados pelo *software* Alceste 2010. **Resultados:** Os resultados mostram a prevalência do acompanhante familiar, do sexo feminino. Os sentidos atribuídos pelos acompanhantes ao cuidado do idoso se amparam nas atividades de auxílio, relacionamento entre o acompanhante e o usuário e o enfermeiro, apoio institucional e orientações de cuidado. **Conclusão:** Conclui-se que os sentidos do cuidado se assentam nas necessidades e demandas do acompanhante, para melhor cuidar do idoso que necessita de seu auxílio e, para tanto, a educação em saúde por parte do enfermeiro emerge como importante estratégia a ser implantada junto a eles no hospital.

Palavras-chave: Idoso; Hospitalização; Cuidadores; Enfermagem.

Resumen

Objetivo: Identificar y analizar los sentidos de la atención al anciano hospitalizado desde la perspectiva de los acompañantes. **Métodos:** Investigación cualitativa, exploratoria y descriptiva. Participaron 30 acompañantes de ancianos hospitalizados. Se realizó entrevista individual y observación sistemática. Los datos fueron analizados por el *software* Alceste 2010. **Resultados:** Los resultados muestran la prevalencia del acompañante familiar de género femenino. Los sentidos atribuidos por los acompañantes a la atención del anciano se amparan en las actividades de auxilio, relacionamiento entre el acompañante y el usuario y el enfermero, apoyo institucional y orientaciones de atención. **Conclusión:** Se concluye que los sentidos de la atención se asientan en las necesidades y demandas del acompañante para mejor cuidar del anciano que necesita de su auxilio y, para tanto, la educación en salud por parte del enfermero emerge como importante estrategia a ser implantada junto a ellos en el hospital.

Palabras-clave: Anciano; Hospitalización; Cuidadores; Enfermería.

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INITIAL CONSIDERATIONS

There are different forms of characterizing the term aging. These include successful aging and unsuccessful aging, including fragile or dependent elderly.

Successful aging has turned into a conglomerate of characteristics, such as: longevity, independence, low risk of diseases and disabilities, good physical and mental functioning, active involvement with life, social participation, subjective wellbeing, satisfaction with life, autonomy, psychological wellbeing, coping strategies, prevention of morbidities, ability to accept the physiological changes deriving from age and positive adaptation[1,2].

Unsuccessful aging, on the other hand, occurs in case of losses of life projects; lack of acknowledgement; difficulty to satisfy one's own needs; feelings of weakness, inability, low self-esteem, dependence, helplessness, solitude and despair; besides anxiety, depression, hypochondria and phobias. The diseases that put life at risk, the death of people nearby, children leaving home, changes of residence, loss of autonomy and material losses are important risks to establish an unsuccessful aging process[3].

Frailty and dependence are other important concepts with regard to aging. Frailty is defined as an individual vulnerability to the challenges of the environment, which arise due to a combination of diseases or functional limitations that reduce the individual's capacity to adapt to the stress caused by acute diseases, hospitalizations or other risk situations[4]. Frailty presents signs and symptoms that characterize it as a syndrome: weakness, fatigue, weight loss, loss of equilibrium, low levels of physical exercise, slow performance of the motor process, social isolation, mild cognitive changes and increasing vulnerability to stressors. These manifestations are mutually associated and not isolated[5].

The elderly's dependence involves economic issues, family care, lack of formal support networks for the elderly and the relatives, social security and issues that also involve the dependence of the family members and elderly without relatives. In addition, to be able to advance in these issues, aging with dependence needs to be acknowledged as an important public health issue, including health promotion strategies until the establishment of support networks for long-term community-based care, backing the dependent elderly, with or without family support[6].

Hence, the frail elderly are at greater risk of dependence, institutionalization, falls, acute illnesses, hospitalization, slow recovery and mortality. Frailty represents a risk for dependence, which takes the form of fundamental help to accomplish the elementary acts of life.

According to data from the Informatics Department of the National Health System/SUS (DATASUS)[7], the dependence rate of the elderly in Brazil increased from 13.8 in 2000 to 16.6 in 2010, indicating the need for specialized care to cope with the social, economic and health consequences of the aging process, including comorbidities, which can lead to hospitalization and can directly influence the quality of life of the elderly and their relatives.

The SUS Hospital Information System of the Ministry of Health (SIH/SUS)[8] shows that, in one year (from January 2011 till January 2012), the hospitalization rate of elderly people in Rio de Janeiro ranged between 12,000 and almost 14,000 hospitalizations per month. Hospitalization in general causes great suffering for the users as well as their relatives. When drawn from their social context, the users lose part of their autonomy, mainly with regard to their habits, conducts and routines, which are altered and incompatible with the hospital routine. The relatives suffer because they want to stay with the users at the hospital, or out of insecurity, interest in the user, feeling of co-accountability for the user's recovery, learning opportunity, obligation, respect and/or simply to be together[9].

In chapter IV, article 16, the Statute of the elderly says that: "The elderly who are hospitalized or under observation are guaranteed the right to a companion, and the health institution should offer appropriate conditions for his/her full-time stay, at the physician's discretion"[10:20]. In this case, the caregiver can be a relative or a community member (informal caregiver) or a formal caregiver. The informal caregiver emerges from the interpersonal relationships and is constructed in family and social life. The family selects this individual, who normally has little or no experience in taking care of ill people, but with some decision power. The formal caregiver delivers care to users, receive a salary and have reduced decision power, as they perform tasks delegated by the family.

Independently of this caregiver's bond with the user (relative, formal or informal caregiver), it is important to identify how these subjects understand care for the elderly, as well as their participation in this care, as that permits discussing and elaborating strategies to construct a care practice that is in line with the needs and desires of the users and caregivers, in which the professional can accommodate or negotiate on the care actions, turning care for the elderly safer and more effective. Therefore, the objectives in this research are: to identify and analyze the meanings of care for hospitalized elderly from the caregivers' perspective.

METHOD

Qualitative research with an exploratory and descriptive approach, which explored the meanings the caregivers of elderly people attributed to the care they need.

The subjects were 30 caregivers of elderly people (subjects aged 60 years or older), hospitalized in the medical and surgical clinics of a public federal University Hospital in the city of Rio de Janeiro - RJ. The age range (60 years or older) refers to the classification by the World Health Organization (WHO), which chronologically characterizes people aged 60 years or older as elderly in developing countries. A convenience sample was constructed, upon the researcher's invitation to all caregivers who complied with the inclusion criteria. The closure was determined by the empirical research design.

The inclusion criteria were: caregivers (family members or not), full or part-time, male and female, and which participate

passive or actively in care for the elderly, in any shift (morning, afternoon or night).

Two data production techniques were applied: systematic observation and in-depth interview. The data were produced between October 2012 and February 2013, with the application of the interview technique, held individually by means of a semi-structured instrument. This instrument consists of closed questions and is aimed at capturing the research subjects' sociodemographic profile, a task needed to understand the conditions for the production of the meanings the subjects attribute to the objects they find relevant; and open questions to explore the research object. Electronic equipment was used for registers, which were reliably transcribed at the end of each interview.

Simple statistics and percentages were applied to the psycho-sociodemographic data, in order to be able to better explore the meanings of the care in the light of the identity of the groups the subjects who produced them belong to.

Quantitative and qualitative analysis techniques were applied to the data obtained through the open questions, through lexical analysis of the textual data, processing the material in the software Alceste 2010. This software analyzes lexemes that co-occur in a set of text segments. It permits the segmentation of the text, establishment of similarities between segments and ranking of word classes, leading to premises or trajectories of interpretations for the qualitative studies that use discursive materials.

In compliance with National Health Council Resolution 466/12, approval for the research project was obtained from the Research Ethics Committee at Anna Nery School of Nursing (EEAN)/Teaching Hospital São Francisco de Assis (HESFA), under opinion 84115. Institutional authorization was obtained for the execution of the study and all subjects signed the Informed Consent Term. Anonymity was guaranteed by the code associated with elements in the testimonies that were constituted in the common lines. The icu (initial context units), ecu (elementary context units) and chi-squared of each text segment were extracted from the lexical analysis.

RESULTS

About the Subjects' General Identification Characteristics

Among the 30 caregivers who participated in the research, 25 (83.3%) were female and five (16.7%) male. All of them were born in Brazil and 22 (73.3%) in Rio de Janeiro. Concerning the age, the subjects are distributed among the following age ranges: six between 25 and 35 years old; five between 36 and 46; 11 between 47 and 57; six between 58 and 68 and two between 69 and 79 years old. Thirteen (43.3%) caregivers are single, 12 (40%) live with their partner, two (6.7%) are married, 2 (6.7%) widowed and one (3.3%) divorced.

As regards religion, ten (33.3%) caregivers declared they were evangelical, nine (30%) Catholics, (16.7%) spiritists, 4 (13.4%) no religion, one (3.3%) Jehovah's Witness and one (3.3%) umbanda. The personal income ranged from one to five minimum wages and the family income from one to more than 11 minimum wages.

Among the participants, 26 (86.7%) had some kind of family bond with the user, three (10%) were informal caregivers and one (3.3%) was a formal caregiver. Concerning how long the caregiver stayed with the elderly at the hospital, half of the research subjects (50%) stayed full-time and the other half (50%) part-time, ranging between two and twelve hours.

About the lexical analysis using the software Alceste

The corpus consisted of 30 initial context units (icu). The software divided the corpus into 1,026 elementary context units (ecu), consisting of 3,735 words or distinct word forms. Then, the software reduced the words to their roots, producing 677 analyzable and 236 supplementary words.

Out of 1,026 ecu, the software selected 826, totaling 81% of the corpus. The lexical analysis of the 30 interviews distributed the contents in three classes, whose classes one and three centered on care for the hospitalized elderly (meanings and practices of care, respectively), and class two refers to the trajectory of accompaniment at the hospital.

This article explores the contents present in class one, as that class concentrates the words that explore the meanings of the care, which this discussion is focused on. These data represent 39% of the analysis corpus.

The results of the software inform the words with the greatest statistical association with the class, that is, the highest chi-squared (chi2), as well as the ecu with the strongest impact on their constitution.

The words with the strongest statistical association with the class, that is, with the highest chi-squared coefficients, were: person (chi2 = 73), elderly (chi2 = 41), patient (chi2 = 40), I think (chi2 = 38), patience (chi2 = 38), attention (chi2 = 32), caregiver (chi2 = 30), thing (chi2 = 28), taking care (chi2 = 25), family (chi2 = 24), lack (chi2 = 18), times (chi2 = 16), I know (chi2 = 14), demands (chi2 = 14), important (chi2 = 14), same (chi2 = 13), people (chi2 = 12), change (chi2 = 11), be (chi2 = 11), like (chi2 = 11), form (chi2 = 11), relative (chi2 = 11), cries (chi2 = 10). The words nearby (chi2 = 9), contributes (chi2 = 9), listen (chi2 = 8), bond (chi2 = 8), tranquility (chi2 = 8) and relationship (chi2 = 8) scored a lower chi-squared coefficient, but show 100% of presence in the ecu in class one, which is why it is important to highlight them in this study.

DISCUSSION

The results indicate that the caregivers are predominantly female and family members, in line with studies in this area[11-14]. It should be highlighted that the caregivers' determination is not biologically related to the female gender, although the psychosocial influence of care on the female gender is still present in daily life. The caregivers' choice is based on the family's preference or need, instead of personal skills or earlier experiences:

We decided who was going to stay here. We are in three children, so we take turns. (ecu Nº. 290, icu Nº. 8).

I am her daughter-in-law. She has three other daughters and him. I was the most available person to be here. The other one lives very far and the other works. So I made a deal. I proposed to take turns with her. (ecu Nº. 367, icu Nº. 12).

Thus, we are confronted with caregivers with different, but also similar characteristics, with varying attitudes, postures, behaviors, habits, beliefs and experiences, which are confronted with the hospital standards and routines. Little is known or discussed about the role of the elderly's caregiver in the hospital context, which often boils down to availability and solidarity with the user.

We stay here as a caregiver. It is definitely important to have a caregiver here with him, although he is being well attended to by the team, they cannot stay here directly at his side. (ecu Nº. 694/icu Nº. 23).

I observed that the caregivers demonstrate kindness to the user, helping him to walk, wash, groom, remove dental prostheses and accompany him to the surgery room. They first feed the elderly and then themselves. (Field diary, 10/15/12).

In the caregivers' conceptions of their activities in the hospital context, helping the dependent or physically impaired users is highlighted.

I help with bathing. I always try to help. I pull her towards me (ecu Nº. 48, icu Nº. 16).

I help to carry all that. Take something in the closet. I am always supporting him. (ecu Nº. 693, icu Nº. 23).

The caregiver's presence also includes the demonstration of love, gratitude, emotional support; transmitting strength, courage, optimism; identifying and attending to the elderly's needs; facilitating communication; guaranteeing and supervising team care and monitoring the clinical evolution. These more simple activities are practiced to help with care while in hospital. These situations appear in class one, associated with the words person, elderly, patience, attention, caregiver, give care, nearby, bond, listening, contributes, tranquility and help.

Care means being around, being thoughtful, giving attention, monitoring. The elderly, I think, demand more attention. (ecu Nº. 947, icu Nº. 29).

And we need to transmit tranquility to the patient (ecu Nº. 923, icu Nº. 28).

It's difficult because it demands patience, the ability to listen and put oneself in the other's place. (ecu Nº. 1015, icu Nº. 30).

In these ecu, it is identified that, to take care of an elderly person, the caregivers report that they need to be patient, thoughtful and empathetic to deal with the elderly. An interesting point is that the caregivers indicate that this alone is not enough, that it is important to have institutional support and basic care orientations, as well as specific orientations according to the particularities of each situation, as a facilitator in care for the elderly.

The only thing I miss here at the hospital is psychological or psychiatric support for her and for me. There are people who lose it in here. I have to work. I abandoned by work to stay here with her. I've got my boss's support, but one day he'll say it has become impossible. (ecu Nº. 805, icu Nº. 27).

They explain it to me. It's good for me to learn. [...] I hadn't seen how the dressing was, how the hole was. (ecu Nº. 77, icu Nº. 26).

The nurse needs to prepare the caregiver to perform integral and not fragmented care actions, which normally happens. This is a concerning situation, as the caregiver is not included in their action planning. Hence, the caregiver needs knowledge that is fundamental for care, so as not to cause problems for the patient[13].

When I was going to take care, I used to wear gloves. I used to do the dressing myself. A lady taught me what I had to do, how to do it and I used to do it the way she had said. (ecu Nº. 311, icu Nº. 9).

In this interval, the relation between professionals and caregivers emerges, as the latter's presence represents a link between the elderly and the health team. Therefore, the professionals need to see the caregivers as agents who participate in care for the elderly, permitting information sharing and care congruent with the elderly and the caregivers' needs[14].

It's good care, it's a good relationship with the doctors, nurses and with the patient himself. (ecu Nº. 707, icu Nº. 23).

And information to the family members. The family members suffer a lot. The patient suffer because of the pain, for the relatives it's the emotional, it's the feeling. And that's very important too because the person can get depressed. So giving the information, having a good relationship is very important. (ecu Nº. 708, icu Nº. 23).

No consolidated position exists yet about the health professionals, particularly the nursing professionals' perception of

the elderly caregivers' presence in the hospital context. A study points out that the family member's presence and participation in care, such as meals, locomotion and hygiene, is important for the nursing team[11]. Most of the publications are focused on child or woman's health though. In another paper, the presence of the caregiver is discussed, emerging as a disorder in the institutions' physical characteristics as well as in the health professionals' attitudes, in the creation of bonding, in care and the care quality itself, exactly because the hospital has not been properly planned, from the physical viewpoint, nor prepared with regard to the understanding of the dynamics of the social relationships that happen there[12].

> *While I talked to a caregiver, a nursing professional signaled to the caregiver that it was time for the medication and went away. What is this caregiver's responsibility in the medication administration? In a short time period, she comes back and asks the other caregiver to change the user's position. What is the caregiver's role? And the nursing professionals' competences - technicians, auxiliaries and nurses?*

This research is not focused on nursing competences, but the consolidation of nursing practice as science and art should be highlighted, which is still under construction and, therefore, the characteristic forms of knowing, producing and validating the knowledge in nursing should be defined. When the nurses know what they are and do, they are able to assume and manifest conducts compatible with their rights and with the users' rights and the values of nursing as a social practice. Knowing-how-to-be and know-how become essential to understand nursing as the professional practice of giving care, helping and assisting, with care as the essence of nursing.

Returning to the more macro-level of care, the caregivers signal that both the hospital's physical structure and the interpersonal relationship with the health team can make the caregiver's presence and, consequently, care for the elderly person, easier or more difficult, mainly when they spend long periods at the hospital. This discourse surrounds the words: I think, lack, times, I know, requires, important, relationship, change and form.

> *Knowing how to take care of ourselves too, things that do not exist here sometimes. The nurses are very rude here. There are very good nurses, but some are very impolite. (ecu Nº. 249, icu Nº. 7).*
>
> *There's no place for the caregiver to sleep there either, but they are more thoughtful. (ecu Nº. 275, icu Nº. 7).*
>
> *It's exhausting. Like that man there, he stays here 24 hours, I don't know how he can stand it. Poor man. Sometimes he sits there in that chair, all day, takes a nap like that, he must sleep really badly. (ecu Nº. 320, icu Nº. 10).*

These observations are also present in the field notes.

> *About the caregivers' accommodation, there is a quilted, semi-reclining chair. Some caregivers sit in the normal chair. Some put their head on a cupboard next to the user's bed, to try and take a nap. But they wake up at the slightest movement in the nursing ware. (Field notes, 02/19/2013).*

Finally, it should be highlighted that most these caregivers will be the caregivers at home, making health education fundamental for the sake of self-care and the maintenance of the elderly and caregiver's quality of life[13].

> *During care for the elderly, the caregivers are always alert, attentive to the procedures. When they are asked about their postures, they informed me that they observe how the team does it, if there's anything different between what is being done at that moment and how it was done the last time and they say that they are learning, in case they need to repeat it at home. (Field notes, 02/19/2013).*

Therefore, greater integrality is needed among the health professionals in order to detect the caregivers' main problems and difficulties to accomplish daily care, including the caregivers as true allies in care practice, enabling them to take care of the elderly at home.

> The partnerships and moments of dialogue are fundamental to permit the care relation as, by sharing the other's concern and suffering, these professionals can perceive the relative with other eyes, starting to consider their needs, wants, desires, anguish and questions as to what they can do or not in the hospital area, for the purpose of better comforting their sick relative[12:16].

The intertwining between the meanings, ideas, conceptions and values the caregivers attribute to the care and the knowledge and meanings attributed by the health professionals - particularly the nursing professionals, for whom care is the actual reason for being, knowing and doing - will permit the articulation of effective strategies to achieve the humanization in care[15], considered based on the subjects' concepts of integrality, transversality and autonomy.

FINAL CONSIDERATIONS

The meanings of care for the hospitalized elderly emerged from the identification of the caregivers' role in the hospital context, characterized by an affectionate relationship, by activities to help the elderly, including the search for institutional support and care orientations. The caregivers also signal the importance of the hospital structure, which does not attend to their needs yet. The interpersonal relationship caregiver-nurse was signified through the health education about the care that can be provided in the hospital context, as well as about the preparation for home care.

Therefore, health education should start when the elderly is still in hospital, precisely to allow the relatives or caregivers to practice home care in a safe and effective way, avoiding further dependence for the elderly and an overload for the caregiver.

One strategy that should be used to facilitate the maintenance of the caregivers' orientations and training is the elaboration of educative materials that include the daily care needs and doubts, as well as general and specific orientations for each need the user presents, guaranteeing the continuity of care based on safe procedures the caregivers can perform at home.

In conclusion, the knowledge about the meanings the caregivers attribute to care for the elderly permitted understanding the true needs and the demands of the people who will continue the care. Therefore, it is important for the professional team to include the caregiver in their care plans, training these subjects for care after hospital discharge. These aspects contribute to the fundamentals of nursing care, considered as the essence of nursing, which is consolidated in the nurse's meeting with those subjects involved in care, whether these are the users themselves or their caregivers.

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