

Facing the hospitalization of the adult patient by the caregiver family member

Enfrentamento da internação hospitalar do paciente adulto pelo familiar cuidador

Frente a la hospitalización del paciente adulto por el cuidador familiar

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Abstract: Objective: to know how the caregiver family member faces the hospitalization of the adult patient. **Method:** descriptive and exploratory qualitative research conducted in April 2018 at a University Hospital in southern Brazil. A total of 20 caregiver family members participated in the study. Data were collected through interviews and subjected to Thematic Analysis. **Results:** The feelings presented regarding hospitalization were worry, anxiety, fear of death and tranquility. The family elected one of the family members to be the primary caregiver or took turns. Sometimes the caregiver needed to take time off to care of the patient, other family members dedicated themselves to aspects of living outside the hospital, and the family expanded. **Final Considerations:** It is important to direct care to the caregiver family member, contemplating humanization, bonding and communication, as he/she is the greatest ally of the health team members in the hospital. **Descriptors:** Caregivers; Family; Hospital; Patients; Nursing

Resumo: Objetivo: conhecer como o familiar cuidador enfrenta a internação hospitalar do paciente adulto. **Método:** pesquisa descritiva e exploratória de cunho qualitativo realizada em abril de 2018 em um Hospital Universitário no sul do Brasil. Participaram 20 familiares acompanhantes. Os dados foram coletados por meio de entrevistas e submetidos à Análise Temática. **Resultados:** os sentimentos apresentados em relação à internação foram de preocupação, ansiedade, medo da morte e tranquilidade. A família elegeu um dos familiares para ser o principal cuidador ou realizou revezamento. Às vezes o cuidador necessitou pedir dispensa do trabalho para cuidar, outros familiares se dedicaram aos aspectos do viver fora do hospital e a família expandiu-se. **Considerações Finais:** é importante direcionar a assistência ao familiar cuidador, contemplando a humanização, a criação de vínculo e a comunicação, pois ele é o maior aliado dos membros da equipe de saúde no hospital. **Descritores:** Cuidadores; Família; Hospitais; Pacientes; Enfermagem

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Resumen: **Objetivo:** saber cómo el cuidador familiar enfrenta la hospitalización del paciente adulto. **Método:** investigación cualitativa descriptiva y exploratoria realizada en abril de 2018 en un Hospital Universitario en el sur de Brasil. Participaron veinte familiares acompañantes. Los datos fueron recolectados a través de entrevistas y sometidos a análisis temático. **Resultados:** Los sentimientos presentados con respecto a la hospitalización fueron preocupación, ansiedad, miedo a la muerte y tranquilidad. La familia eligió a uno de los miembros de la familia para ser el cuidador principal o se turnó. A veces, el cuidador necesitaba tomarse un tiempo libre para cuidar, otros miembros de la familia se dedicaron a aspectos de la vida fuera del hospital y la familia se expandió. **Consideraciones finales:** es importante dirigir la atención al cuidador familiar, contemplando la humanización, el vínculo y la comunicación, porque él es el mejor aliado de los miembros del equipo de salud en el hospital. **Descriptor:** Cuidadores; Familia; Hospitales; Pacientes; Enfermería

Introduction

Hospitals have become spaces for examining, investigating and treating the health conditions of the population, occupying an essential place in the health system. During the work of the nursing staff at the hospital, daily coexistence occurs, especially with caregiver family members, who usually accompany patients throughout the hospitalization. Hospitalization can be a source of stress for the family, and there is a need for an adaptation period in which the nurse and the nursing team must provide care, assistance and safety to the patient and his/her family.¹

In the hospital environment, the disruption of the routine of the caregiver family members is noticed, as their attention is focused on the possibility of recovery or life risk of their hospitalized family member. In this sense, this change in their routine requires the caregiver to adapt their social and professional life to be close to their relative, allowing them to follow their clinical condition closely.²

In order to assist the family member in experiencing this moment, in a less traumatic way, communication and bonding can be important tools between health professionals and caregiver family members. Communication makes it possible to understand the characteristics, needs and expectations of the family to direct care, so that the actions taken match to the reality

of each family. A study that aimed to identify and describe family members' perceptions about hospitalized patient care suggested that professionals, especially those working in the inpatient scenario, should perform interventions aimed at minimizing the impacts of the care task and, consequently, improving quality of caregiver family members in the hospital environment.³⁻⁴

Hospitalization can be configured as a disruptive and traumatic event for the family capable of generating feelings such as fear and insecurity. For this reason, it is understood that nurses and their staff should offer support and safety to patients and their families, guiding them how to share daily care for patients.⁵

During the hospitalization period, caregiver family members may feel physically and emotionally exhausted. The routine of the inpatient unit, with invasive procedures and full of unknown technologies can result in conflicting feelings for the family. A study that investigated the perceptions and feelings expressed by family caregivers in the hospital pointed that they reported insecurity, fear, anxiety, worry, feelings of deprivation of liberty and at the same time, gratitude for care, comfort, safety and proximity when watching the care provided.⁶ In this sense, it is necessary the affective support and appropriate interventions of the nursing staff to make this moment less frightening.

When interacting with the nursing team, the family seeks to share feelings and perceptions regarding the life and fragility of their hospitalized family member. The presence of a professional who clarifies their doubts and is available becomes important, strengthening the family structure, creating an affective and respectful bond, contributing to a well-being relationship in the hospital environment.⁷

The nurse's role in relation to the family caregiver consists in proposing strategies aimed at solving their difficulties, facilitating their care process in the hospital, but for this it is necessary to know their experiences in the hospital environment. In this sense, the study question was: How does the caregiver family member face the hospitalization of the adult patient? From this, the

objective was to know how the family caregiver faces the hospitalization of the adult patient. It is believed that this knowledge may support the nursing work with the adult patient's family, helping them to transition their role of caregiver in the hospital.

Method

A descriptive and exploratory research of qualitative nature was performed. Qualitative research deals with the universe of meanings, beliefs, aspirations, reasons, values and attitudes.⁸ It allows the author to be directly involved in the situation and allows observing the agents in their daily lives, socially living and interacting with them. Descriptive research aims to describe the characteristics of a given population or phenomenon.⁹

The study was conducted at the Medical Clinic (UCM) and Surgical Clinic (UCC) Units of a University Hospital in southern Brazil (HU). In addition to health care, HU develops teaching, research and extension actions. It is a hospital that serves the Unified Health System (SUS) patients and it is a field of practical activities for students of nursing, medical, psychology and physical education including the Multiprofessional Integrated Hospital Residency with emphasis on adult cardiometabolic health care. (RIMHAS).

The UCM has 50 inpatient beds with clinical complications, distributed in 12 wards, seven isolation beds. The UCC has 29 inpatient beds with surgical complications, distributed in eight wards, two isolations.

The study included 20 caregiver family members of patients admitted to the units in April 2018. The inclusion criteria were: to accompany the patient during hospitalization, provide continuous care in the Unit and be eighteen or older. Family members who only visited patients in the sectors were excluded. After being informed about the objectives and methodology of the study, family members who agreed to participate signed the two-way Informed Consent Form.

The number of participants was delimited by data saturation, that is, the number of people who participated in the study was determined when no new information came up, and the answers began to be repeated. An ideal qualitative sample is that which reflects, in quantity and intensity, the multiple dimensions of a given phenomenon and seeks the quality of actions and interactions throughout the process.¹⁰ After invitation there were no refusals to participate in the study.

Data were collected by the researchers through semi-structured interviews recorded in MP3 and transcribed for analysis. The interviews had an average timeframe of 45 minutes. They were held in the Units procedure room to guarantee privacy to the participants. They were asked how they faced the hospitalization of their family member.

The Thematic Analysis of the data was operationalized from the Pre-analysis, in which the float reading of the data, the grouping of the speeches and the elaboration of the registration units were performed. The material was also explored, in which data were coded and assigned to the meaning nuclei that represented the content expressed in the speeches. These were gathered into units, coded and organized into categories. Finally, the treatment of the results obtained, and interpretation were performed, in which the most significant statements were discussed from the authors to support the analysis.⁸

Ethical aspects were followed in accordance with resolution 466/2012 in human research. The project received approval from the Health Research Ethics Committee (CEPAS/FURG) number 30/2018. The participants' speeches were identified by the letter F followed by the interview number, in order to guarantee their anonymity.

Results

The characterization of the study participants and the themes generated from the data analysis are presented below. The study included 20 family members accompanying patients admitted to the UCM and UCC of the HU, eight from UCC and 12 from UCM. Their ages ranged from 28 to 72 years with an average of 49.25 years.

As for the relationship with the patient seven were daughters, three were sisters, three were husbands, three were wives, two were friends, one aunt and one son. Regarding schooling, seven had incomplete elementary school, six had completed high school, four were illiterate, two had completed higher education and one had incomplete higher education. Regarding the number of children, two family members had no children, however the others had between one and six children with an average of 2.33 children. Regarding the age of the hospitalized patient, this ranged from 17 to 92 years, with a mean of 62.7 years. The length of stay ranged from one day to three months.

Feelings presented by family members regarding hospitalization

In the context of hospitalization of an adult patient, the caregiver family member presents emotional needs related to the transition to the role of caregiver. The need to take care in the hospital, a different environment from home, might generate several feelings. One of the feelings presented by the caregiver family member regarding hospitalization was concern about taking care of the family member properly. They reported feeling sad due to the suffering and pain presented by their family member and other hospitalized patients.

Mostly worry, we've been married for so long, it's always the two of us alone. I worry that if something happens, I don't even have strength or to carry him. (F16)

Feelings of sadness to see the suffering, not only his, but of all the patients we see around here. A suffering. (F15)

It gets hard, we get sad because he is suffering and in pain. (F2)

They were afraid of the death of their relative. Despite the hope of recovery, with each new hospitalization it seemed that the death was closer, due to the worsening of the clinical condition and weakness of their relative. Death is seen as a frightening event, causing a universal fear.

I was so afraid, nervous, in agony and so afraid. She's old, but no one wants her to go. (F9)

We were very afraid. So Much. She had lung cancer over two years ago and last year had that infection, she was almost gone. Now I feared that the worst would happen. (F3)

Hospitalization may subject the family member to despair and discomfort. One of the family members reported accompanying hospitalization for living far away, which causes family breakdown.

Desperation. Two months here is brutal. I live on the island, it's hard. (F19)

Discomfort because we are not from here, it is all difficult because we are not in our city, the family is away, I stopped working and to get a medical certificate is not easy either, because I have to get there with certificate in 48 hours, and I am here. (F10)

Pity comes from observing the fragility and limitations imposed by hospitalization. The hospitalized relative becomes dependent on their caregivers.

Oh, I feel sorry, because she was always very enthusiastic, doing things on her own. She lives in the back of my mother's house. She is not married, so she lives alone, alone. She always liked to do things, pay her bills and since she is here, she can't do anything else. She depends on us for everything. It ends up being complicated. I have nothing else to do, I do what I can. (F8)

The accompanying family members reported being strained about hospitalization. The caregiver of a patient hospitalized with pneumonia said that the strain is due to the lack of

knowledge about what will happen in the hospital. Another caregiver for a patient who was admitted for colectomy surgery said that strain is because every surgery has risks.

My daughter kind of cried. We get nervous about what will happen. I said don't cry [...] it will be all right. (F20)

Well, I got a little strained. Every surgery puts the patient at risk. (F13)

Anxiety was due to the lack of stabilization of the clinical condition of the hospitalized relative. The worsening clinical condition makes the patient vulnerable and unable to perform activities of daily living, becoming dependent on the caregiver.

[...] we are anxious, his blood pressure went up yesterday[...]. (F14)

[...] anxiety, anxiety because I want to leave here and he is getting worse every day [...] he can't talk, walk. Every day he is more dependent. (F5)

The acceptance of hospitalization was due to the perception of the need for their family member to receive treatment that is available at the hospital. They are relieved by the hospitalization, recognizing it as important for the health improvement of their family member.

[...] terrible, but I must accept it, can't do anything about it. (F12)

[...] you must deal with it. Unfortunately, I am an elderly caregiver. This, everyone will go through it. (F18)

Feelings such as love, affection and respect are reported due to the relationship between the caregiver and the hospitalized patient. The caregiver feels responsible for accompanying the patient in the hospital, promoting comfort and assistance.

She has no children, no close relatives, no husband. I've been her friend for years. We worked as caregivers together. We were five and she was the boss. Then she left and I was in charge. We get closer than we should. I

feel responsible and day-by-day we get closer. You must have a feeling to do that. I do it because I like it. Do it with love, care and respect. (F6)

Ways of family organization for hospital care

Faced with the need for hospitalization, the family elects one of the family members to be the main caregiver in the hospital. It is up to this person to accompany the family member almost all the time, becoming the source of information about hospitalization for other family members. This person puts on hold his/her routine outside the hospital, such as home, family and children to be fully dedicated to hospital care.

[...] I abandoned my life. For our mother we do that. (F18)

[...] I left my husband, I left my house, I left everything to be with him and I will continue with him until the end. (F15)

Another way of organization presented is the rotating among family members to do 24 hours care daily. This way of organization allows several family members to contribute to the care, not overloading only one person.

[...] I take turns with my sister, she comes at night and I come in the day. (F2)

Usually, I stay during the day and someone comes in at night, when there is nobody to come, I stay with her around the clock. (F4)

When hospitalization is elective, there is a period for the family to organize and provide care in the hospital. In that time, they were able to decide how to take care of their children and obtained leave from work.

It was all so fast, they called us on Sunday for her to be hospitalized, then she came, had the surgery, then we were going home. My mother stayed with our son so I could stay here with her. (F17)

We already knew he would have to stay here, so we got organized. Since it's just me and him, and I'm retired, I came here. He was hospitalized yesterday, so we're still getting organized, but I'm staying all day and the kids at night. (F16)

In some situations, the organization for care in the hospital is difficult, because the caregiver family member needs to ask for work leave or have health problems incompatible with hospital care for the family member.

It was difficult because I had to ask for a work leave. The house is all disorganized, it has been difficult. (F11)

I had to quit my job because I have a health problem and I'm retired. So it's hard being here at the hospital. (F15)

While the family member cares for the hospitalized patient, other family members are dedicated to taking care of other aspects of living, such as taking care of children who have stayed at home or other family members who also need to be cared for.

[...] One of the children picked her up, put her in the car and brought her. We organized things and came to the hospital. The kids help us a lot, help to take care of the boy who is handicapped, put him in the chair, bathe him, so we thought it would be better to bring her here. (F9)

Family social support network for hospital care

The main source of support for the caregiver is the nuclear family. From the study, it was found that siblings, children and partners are those who dedicate most of their time to the care of hospitalized patients.

Sometimes my sisters, when they can, help me. Sometimes I pay someone to help me. But for now, there `s only me. (F18)

Our children work, but they help. Me during the day and them at night.
(F16)

When there is no caregiver in the family nucleus available to care during hospitalization, this companion comes from the expanded family. Other family members organize themselves to meet this need while keeping family identity. It was found that nephews, grandchildren, brothers-in-law were the ones who provide the most care assistance.

My daughter said she didn't even want to say she was going to operate. [...] Then I came to help because it is my responsibility and my girl is only 20 years old. She is a child to be alone, that's why she decided to let us know. [...] because she thought she couldn't stand being alone with her aunt in the hospital. (F20)

Her granddaughter and I take care of her. (F3)

In some cases, there was the no support networks for the main caregiver, leading them to change the routine of their lives, remaining full time in the care of the hospitalized patient.

No. Just me. Just me and God. (F19)

No, I always stay. (F13)

When there is no family or extended family available for care, friends come to help with this task, setting up the non-related family. People who do not have blood ties approach in times of need due to lifelong built affinities. Support plays a decisive role in adapting and exercising the role of caregiver and relying on someone to unburden and to be recognized for caring efforts from friends is very important to the caregiver.

[...] I'm the only one who takes care of her. She refuses someone else taking care and since she can get up, do everything herself, it ends up not having to. A friend of mine helps me. It gets a little late for me to go home.
(F7)

Since she lived alone, we already knew that eventually she would need help. I tried to organize my appointments and spend time taking care of her. She's my godmother, like a mother. Overall it is fine. (F8)

Discussion

Hospitalization of a family member causes family breakdown, adversity interferes with family balance and dynamics, causing it to try to reorganize it to keep balance.¹¹ This reorganization is often followed by suffering and conflict, and abdication of self to care for others and some caregivers interrupt their daily lives to follow the hospitalization process.¹²

Regarding the feelings presented by family members about hospitalization, it can be observed: insecurity, fear, anxiety, worry, feelings of sadness, and at the same time, gratitude for the care provided and relief from hospitalization for recognizing it as important for relative's health improvement. Such feelings show the need for caregiver family members to get help with care in the hospital. There is a need to express their feelings, minimizing their doubts and fears about the future.¹³ In a study with family caregivers in the hospital, they stressed that the transition to the role of caregiver may present itself as an unexpected and unknown moment, generating intense feelings.¹⁴

Hospitalization is a stressful event and physically and emotionally destabilizes the whole family. Caregiver family members may worry if they are taking care of the family member properly. They may feel sad because of the patient's suffering and pain and fear of death.¹⁵

Another observed feeling is the pity. The pity comes from observing the fragility and limitations imposed by hospitalization. The hospitalized relative becomes dependent on their caregivers. They are anxious for the family member's unstable clinical condition. His/her vulnerability situation and their inability to maintain the physical and mental skills necessary for independent living can be aggravated, leading to anxiety.³

This experience brings positive and negative aspects in the hospital environment. Negatives are related to changes in their daily routine, physical and emotional tiredness and often financial problems.¹⁶ A study conducted in the United States with 488 families found that family involvement in the care process for relatives with dependency resulted in physical, emotional and psychological overload, indicating depressive symptoms.¹⁷

However, on the other hand, caregivers are pleased to be able to help their relatives.¹⁶ Accepting hospitalization can be due to the perception of the need for their relative to receive treatment that is available in the hospital and to find that he/she continues to receive love and affection and be treated with respect.

Once the family finds out the need for hospitalization of their family member, it needs to be reorganized to be able to take care of him/her. And in this context, some relatives reported abandoning their social life to dedicate themselves fully to hospital care, they also do rotation, just so one caregiver is not burdened.

The patient usually needs be accompanied during hospitalization when the patient is suffering from an aggravation of the chronic disease, to perform elective surgery or due to an emergency. Acute periods are marked by frequent hospitalizations and consultations with specialist professionals. In such a way that when symptoms subside, it allows the family to feel stable. However, there are emergency situations in which the family routine changes abruptly and progressively, and the family member must organize to constantly provide care to the patient.¹⁸

The family choose one of the family members to be the primary caregiver in the hospital. This companion usually puts aside his or her life, home, family and children to dedicate themselves fully to hospital care. Historically, the family has always played a social protection role for its members, with women being the main agent in this process.¹⁹

Another way of organization presented is the rotation among family members to care 24 hours a day. While the family member cares for the hospitalized patient, other family members are dedicated to taking care of other aspects of living. A study that aimed to know and analyze caregivers' perceptions about the experience of caring for family members in the context of hospitalization showed emotional distress and physical burden of caregivers due to the caring of family members during hospitalization.²⁰

As for the family's social support network for hospital care, children, siblings and grandchildren were the main companions. The nuclear family presents itself as the main caregiver. Even in the face of societal transformations, the welfare model has the centralization and overvaluation of the nuclear family.²¹

However, it is noteworthy that at times these family members are unable to cope with the care and some more distant family members come together ensuring this assistance. The institutions encourage and promote the approach of the family during the patient's hospitalization and it can be said that this action is not a good action performed by hospitals, but rather a need to contribute to patient therapy, enhancing their improvement and offering comfort and emotional support at this critical time in his/her life.²¹⁻²²

The role of health professionals is crucial in helping family caregivers and patients to cope with this new reality. It is necessary to have a person who knows the situation and a professional to count on.²³ Knowing the preferences of family caregivers provides subsidies for nurses to plan educational interventions aimed at teaching realistically and in line with the preferences of this clientele.²² The guiding role of nursing professionals is evident, and dialogue is a source of reflection and knowledge acquisition.²⁴

Final considerations

The study allowed to know how the caregiver family member faces the hospitalization of the adult patient. In this sense, feelings of concern, anxiety about the lack of information about the possibility of discharge, fear of death and tranquility because of their family being under the care of the team were expressed. These feelings of caregiver family members regarding hospitalization certify the importance of their organization for the full care. In the organization of care, the division of tasks and the daily rotation is necessary, reducing the physical and emotional overload. The family's social support network is the nuclear family, and at a time when it is unable to manage care, friends and more distant family members also contribute, expanding its support network for hospital care.

This research had as limitation to portray a specific context of family care in UCM and UCC of an institution of the south of the country. However, it is believed that this work may contribute to the implementation of new research focusing on family care in the hospital, as this may encourage performing of expanded health care, focused not only on the patient, but also taking care of those who care for them.

The presence of the caregiver family member in the hospital favors the patient's improvement; however, it may also lead to the patient's exposure to complex situations of fragility. This family member needs greater visibility beyond the demands of care. It is necessary for the nursing staff to perceive him/her as someone also to be cared for and empowered to care, re-signifying his/her presence in the hospital context.

It was concluded as relevant to know the characteristics, needs and expectations of the family, to provide a more direct assistance, adapting to the reality actions of each family, in order to provide quality care, including humanization, bonding and communication, as he/she is the person who is in closest contact with the patient and should be the greatest ally of health team members.

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How to cite this article

Arruda CP, Gomes GC, Nicoletti MC, Tarouco VS, Souza CCS, Grehs AN. Facing the hospitalization of the adult patient by the caregiver family member. Rev. Enferm. UFSM. 2019 [Acesso em: Anos Mês Dia];vol9 e47: P1-P19. DOI:<https://doi.org/10.5902/2179769233506>