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Internação em Unidade de Terapia Intensiva: percepções de familiares de pessoas gravemente enfermas.

Hospital in intensive care unit: perceptions of family members of people seriously ill.

Hospital en la unidad de cuidados intensivos: percepciones de la familia personas gravemente enfermas.

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RESUMO: O estudo tem como objetivo descrever a percepção dos familiares sobre a situação de ter um familiar hospitalizado em uma Unidade de Terapia Intensiva. Trata-se de um estudo exploratório-descritivo de abordagem qualitativa, desenvolvido na Unidade de Terapia Intensiva (UTI) de um hospital referência da zona norte do Ceará. Os sujeitos do estudo foram quatorze familiares de pacientes internados na UTI. Os dados foram coletados durante os meses de novembro e dezembro de 2015. A análise das informações permitiu traçar o perfil dos pacientes internados e seus familiares e revelar os efeitos da internação em UTI no cotidiano das famílias. Os familiares expressaram diversos sentimentos, como, tristeza, angústia, desespero, medo e dor, e os relacionavamàs incertezas do processode hospitalização e a possibilidade de perda do seu ente

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querido, além de considerarem a situação de ter um membro em desvio de saúde emuma UTI como uma experiência dolorosa e de grande sofrimento. Assim, conhecer a percepção dos familiares que enfrentam situação de hospitalização de um dos seus membros em UTI permitiu a identificação dos efeitos da internação sobre a família, constituindo um importante passo para a reflexão da necessidade de uma elaboração de um plano de assistência à família, considerando as necessidades e expectativas do binômio paciente-família.
Descritores: Unidades de Terapia Intensiva; Enfermagem; Família.

ABSTRACT: The study aims todescribethe perception of familyabout the situation of havinga family memberhospitalizedin an IntensiveCare Unit. This is an exploratory-descriptive study of a qualitative approach, developed in the Intensive Care Unit (ICU) of a reference hospital in the northern area of Ceará. The study subjects were fourteen family members of ICU patients. Data were collected during the months of November and December 2015. The analysis of the information allows us to trace the profile of hospitalized patients and their families and reveal the effects of ICU stay in the family's daily lives. The family members expressed various feelings as sadness, anxiety, despair, fear, pain, and the related uncertainties of the hospitalization process and the possible loss of their loved one. In addition to consideringthe situation of havinga memberinhealth deviationinICUas a painfulexperience and greatsuffering.So, know the perception offamiliesfacing hospitalization ofone of its membersinICUsituationallowed the identificationof the effects ofhospitalizationon the familyas an importantstepto reflectthe need foran elaborationof afamily careplanconsideringthe needs and expectationsof the patient-family binomial.
Descriptors: Intensive care unit; Nursing; Family.

RESUMEN: El estudio tiene como objetivo describir la percepción de las familias acerca de la situación de tener un miembro de la familia hospitalizado en una Unidad de Cuidados Intensivos. Se trata de un estudio exploratorio-descriptivo de abordaje cualitativo, desarrollado en la Unidad de Cuidados Intensivos (UCI) de un hospital referencia de la zona Norte de Ceará. Los sujetos del estudio fueron catorce miembros de la familia de los pacientes de la UCI. Los datos fueron recolectados durante los meses de noviembre y diciembre de 2015. El análisis de la información permite trazar el perfil de los pacientes hospitalizados y sus familias y revelar los efectos de la estancia en la UCI en la vida cotidiana de la familia. Miembros de la familia expresan diversos sentimientos como la tristeza, la ansiedad, la desesperación, el miedo y el dolor, y las incertidumbres relacionadas con el proceso de hospitalización y la posibilidad de la pérdida de su ser querido. Además de considerar que la situación de tener un miembro en la desviación de la salud en la UCI como una experiencia dolorosa y gran sufrimiento. Por lo tanto, conocer la percepción de las familias que enfrentan la hospitalización de uno de sus miembros en situación UCI permitieron la identificación de los efectos de la hospitalización en la familia como un paso importante para reflejar la necesidad de una elaboración de un plan de cuidado de la familia teniendo en cuenta las necesidades y expectativas del binomio paciente-familia.
Descriptores: Unidad de terapia intensiva; Enfermería; Familia.

INTRODUCTION

The Intensive Care Unit (ICU) is a closed unit composed by numerous equipments and by trained professionals to assist the needs of patients considered critically ill, being considered a place for the promotion of a high complexity assistance[1]. Thus, its physical structure and intense activity of its health personnel make people think this unit as a hostile environment, generating negative feelings, as fear, insecurity, anxiety and depression in patients and relatives[2].

The hospitalization of a family member in ICU occurs, generally, unexpectedly, being possible to represent a threat to the family, a family networking rupture even though, many times, it is temporary, furthermore the adversities which will affect emotional, affective, social and financial aspects[2].

Nowadays, public politics have been reinforcing the focus on the family, and not only on the individual, being healthy or ill, in the health and nursing care, yet there is a predominance of an assistance focused on the biomedical model with its acting centered in the individuality and directed to the body and the illness. In this perspective and aiming this reality's changing, the nursing has a fundamental role in providing care to the families.

The family plays an important role in its own health promotion, through the first care in family environment, also plays essential functions to life maintenance in all its phases, developing each member's potentialities for self care. Therefore, considering the family as a unit and an important support to the sick individual.

Family is thought as a dynamic system in which, each component is responsible for exerting a function, however, when one of those who compose this system is affected and is away, as it occurs when hospitalized, causes an outbalance[2].

Thereby, believing in the necessity to see the family also as a caring object of the health and nursing team, specifically in the health context of an ICU, it is necessary to comprehend the meanings of this situation lived by each family member. Therefore, knowing the family members' perception about the hospitalization situation of one of their own in ICU may reveal peculiarities capable of impelling reflection on the care humanization in this context, as well as the need to intervene to provide a integral and holistic response to the patient-family binomial in order to avoid a compromise in family dynamics.

Thus, this study aims to describe the perception of family members about having a relative hospitalized in ICU, also aiming to contribute to care humanization in this context.

METHODS

This is an exploratory descriptive study with qualitative approach, carried out in a adult Intensive Care Unit at a reference hospital of the north zone of Ceará state. This type of study aims to provide more familiarity with the situation, in order to make it more explicit, and to describe characteristics of a particular population or phenomenon[3].

The ICU is located in an area close to Surgical Center, has nine individual beds divided by boxes and consists in a multiprofessional team composed of doctors, nurses, physiotherapist, nutritionists, social worker, nursing technicians, among others. Patient visits can be done daily.

The participants of this study were fourteen relatives of eleven patients hospitalized in an Adult ICU at a reference hospital of the north zone of Ceará state. The data collection was performed during the months of November and December of 2015, by signing the Informed Consent Form (ICF).

The inclusion criteria were: to accept to voluntarily participate of the research; to have a relative hospitalized in the unit for at least 48 hours; to have age equal or superior to 18; to have and maintain a close relationship with the patient; to have visited the patient at least one time during the hospitalization; to present conditions to comprehend and answer the questions in the instruments used.

The technique used for data collection was a semi-structured interview. The first part of the instrument consisted of a form which contained open questions about sociodemographic data of the relative and the patient, as also questions pertinent to the hospitalization. The second part was composed of topics that helped to achieve the desired goals and the guiding question: How is it for you and your family to have a loved one hospitalized in the ICU?

The interviews were recorded and transcribed in their whole so that it allows more reliability on the collected information. In order to guarantee the anonymity of the study's participants, it was adopted codes for their identification using the initials according to the degree of relatedness of the participants involved, M, W, C, S, referring to mother (M), wife (W), children (C) and siblings (S), respectively, followed by the interview numerical order (E.g.: M1, M2, M3... W1, W2, W3...).

For the data analysis and elaboration of analytical categories, it was used the theoretical reference Symbolic Interactionism. The Symbolic Interactionism consists of an approach which allows understanding the experiences and actions of the subjects as something subjective and product of the subjects' interactions with other people, with themselves and with the situations of the present moment, mediated by beliefs, social values and social motivations and determined by the environment[4].

This study was guided by Resolution 466/12, which ensures respect for human dignity

through special protection due to participants in research involving human beings[5]. The project was evaluated and approved by the Research Ethics Committee of Vale do Acaraú State University, with favorable opinion No. 1,323,469.

RESULTS

The meticulous information's analysis allowed a profile drawing of the hospitalized patients and their relatives and a revealing of the effects of an ICU hospitalization in the families' daily lives. In this sense, from the family testimonials, four categories emerged: Understanding the lived experience; Biopsychosocial Impacts/Alterations in personal, social and professional life; Faith and spirituality as a support in facing the situation; Family relationship with the patient and the health team.

Table 1 - Characterization of patients admitted to an adult ICU in the city of Sobral, state of Ceará, 2015 (N: 11)

VARIÁBLES	N	%
AGE		
20–29	2	18,1%
30–39	0	0%
40-49	4	36,4%
50-59	1	9,1%
OVER 60	4	36,4%
GENDER		
MASCULINE	6	54,5%
FEMININE	5	45,5%
RESIDENCE		
SOBRAL	3	27,3%
OTHER LOCATIONS	8	72,7%
SCHOOLING		
INCOMPLETE ELEMENTARY SCHOOL	5	45,4%
HIGH SCHOOL	2	18,2%
ILLITERATE	4	36,4%
OCCUPATION		
PAID ACTIVITY	7	63,6%
HOUSEHOLD	3	27,3%
RETIRED	1	9,1%
HOSPITALIZATION CAUSE	9	81,8%
NEUROLOGICAL	2	45,4%
CLINICAL		

Source: by the authors

The majority of the interviewed patients' relatives, 7 (63,6%), was between 20 and 59 years

old and only 4 (36,4%) were over 60 years old. Related to gender, 6 (54,5%) were of masculine sex and 5 (45,5%) of feminine sex. The majority resided in other locations, 8 (72,7%), and only 3 (27,3%) lived in the city where the hospital is located.

Out of these, 7 (63,6%) had paid activities, 3 (27,3%) worked caring for their houses and 1 (9,1%) was retired. Regarding the schooling level, 7 (63,6%) had some school degree and 4 (36,4%) were illiterate, according to their relatives. The main reasons for hospitalization were for neurological causes, 9 (81,8%, being 5 (45,4%) for Traumatic Brain Injury and 4 (36,4%) for Stroke and for clinical causes only 2 (18,2%). The average length of stay in ICU was 23 days.

Table 2 - Characterization of the relatives of patients hospitalized in an adult ICU in the city of Sobral, state of Ceará, 2015 (N: 14)

VARIÁBLES	N	%
AGE		
18-19	1	7,2 %
20–29	3	21,4%
30–39	3	21,4%
40-49	4	28,6%
50-59	3	21,4%
GENDER		
MASCULINE	4	28,6%
FEMININE	10	71,4%
MARITAL STATUS		
MARRIED/STABLE UNION	7	50%
SINGLE	7	50%
SCHOOLING		
INCOMPLETE ELEMENTARY SCHOOL	8	57,1%
HIGH SCHOOL	4	28,6%
COLLEGE DEGREE/ UNFINISHED COLLEGE DEGREE	2	14,3%
KINSHIP		
MOTHER	2	14,3%
CHILD	9	64,3%
WIFE	1	9,1%
SIBLING	2	14,3%
RELIGION		
CATHOLIC	11	78,6%
EVANGELICAL	2	14,3%
NO RELIGION	1	7,1%

Source: by the authors

Out of the 14 interviewed relatives, 10 (71,4%) were female and 4 (28,6%) were masculine. Regarding the age group, they had variable ages between 18 and 59 years.

The majority, 8 (57,1%), had not concluded middle school, 2 (14,3%) had concluded a college degree or it was still ongoing, only 4 (28,6%) had concluded high school. Concerning the marital status, half (50%) reported to be married or keep a stable union, the other half reported to be single. All the relatives had consanguinity ties, of which 9 (64%, 3%) were children, 1 (7.1%) was a wife, 2 (14.3%) were mothers and 2 (14.3%) were siblings. All believed in God, most were Catholic 11 (78.6%), 2 (14.3%) were evangelicals and 1 (7.1%) mentioned not having religion, but believes in God. Only 5 (35.7%) of the relatives had experience with other hospitalizations in ICU.

DISCUSSION

Understanding the lived experience

This category expresses what the hospitalization represents to the relative and to the family making explicit their perceptions and their main feelings related to the lived experience by some family members.

The first moment when the relatives receive the news about the necessity of a hospitalization in ICU is followed by feelings many times originated from doubts about the hospitalizations, from the possibility of losing their loved one and from the needed physical separation, since in ICU the relatives cannot be constantly in their loved one's company.

> *For me, I thought I would never go through this, as for my family, to tell you the truth I am being the strong column, I talk to one, to another, I give strength, only God himself. All of them cry, fall into despair… When she got in, I was accompanying her, when I told the news that she was going to do a surgery and go to ICU nobody believed it, they all feel into despair. (C4)*

The majority of the relatives used the word "difficult" to describe the experience of having a loved one in an ICU and in many moments they exposed verbally or not, to experience sadness, pain, anguish, fear, among other negative feelings, caused by the abrupt separation of their loved one from the family life, as stated in the following speech:

> *It is hard, we lose ground…[…] just today, what the doctor was talking about and what I saw didn't make me happy, didn't make me, (CRY), but it's like this, I know we go through this, that this happens to anyone, but we never expect it and we're never ready. It is a suffering, and anguish, we always think and hope that tomorrow we have a better news, that she will be okay, but it's not like we expect.(F7)*

Hospitalization alone triggers several of these negative feelings in the family and when in an Intensive Care Unit, such feelings are intensified for it is an unknown situation, also causing separation, uncertainties and fears due to the likelihood of death of the loved one[6].

The testimonials show that a hospitalization in ICU is the cause of great emotional impact, it is believed so because such place still carries the stigma of being a place to die. In ICU, the separation of the family member generally happens all of a sudden and unexpectedly, transforming significantly the family's daily life, causing, therefore, many discomforts through the separation and consequently threat of affective and emotional rupture, even if it is temporary[7].

Diverse factors can contribute to the occurrence of such discomforts, as the sudden worsening of the health framework, the sudden need of hospitalization in an intensive care unit and the uncertainties and doubts about the possibility of recovery determined by the health condition and the disease severity.

I was also observed great suffering related to the fear of losing definitively the loved one and dread of the possibility of this person become incapable to accomplish his/her daily activities.

In the unit of the study, neurological diseases prevailed as the main cause of hospitalization, with which it was observed that most of the relatives had a knowledge, even empirical knowledge that the head controlled the whole body and the fact that there was some problem with it would compromise the whole operation and would reflect directly on their ability to perform their normal day to day activities.

The fact that most of the interviewees did not have neither high school education nor completed elementary education did not compromise their understanding about the risks of their relatives to exposure to an ICU admission and the possibility of acquiring complications from certain diseases.

The relatives were informed and, thus were aware of the possibility that the family member would leave the hospital with some degree of dependency to fulfill his/her basic human needs and they already recognize themselves as future caregivers, and even though this would lead to a radical change in their daily lives, they expressed they preferred to have to do this than to lose permanently their loved one. Studies indicate that the absence of the member in the family already symbolizes a loss and anticipates the possibility of a definitive separation.

Biopsychosocial Impacts/Alterations in personal, social and professional life

This category reveals the psychosocial implications that the sickening and the consequent hospitalization generate in the family dynamics and its interference in the ability of the relatives to accomplish professional, social and personal activities.

Linked to the hospitalization of one of family member comes the necessity of being close to him/her, so the relatives feel obligated to be present, even if this compromises their social, professional and personal activities and their comfort and wellbeing, generally being absent from their homes, leaving aside their daily activities so they can follow their family member's hospitalization demand, as stated:

> *I am an only child, and so it's complicated because I have to be with him every day visiting him, and my family is worried, they want information all the time. It worries me to know that he is here alone, you know*? *Besides, to me it's complicated, not only because of the worries of having someone with him, but also because I miss being home, and when I'm home I miss being here. (C2)*

The relatives, specifically those who live more distant and which for some daily transportation difficulties have to stay longer away from home, they experience missing home and family, by contrast, they also experience satisfaction of being close of their loved one even if it is for a few moments, however, with the hospitalization, the hospital routine becomes part of the family routine promoting a disarticulation of their daily activities[7].

Another identified fact was the presence of emotional tensions related to responsibilities overload previously assumed by the hospitalized relative, for in some cases he/she was the main financial and/or emotion support of all the family[2]. Some relatives, even having constituted new family relationships and acquired financial independency, experienced feeling of helplessness.

> *He is the father of thirteen children, and for all of their lives these thirteen children had him as an example of life, he is the family pillar. […] One moment you think he's gonna die, other moment you think he's gonna overcome this. We think of the best also of the worst, of course, and in how the family is going to be after even though everyone has their own families and financial independency, he was a father, that real father for every hour. (C6)*

Studies on the family life experience showed that the absence of a family member on a daily basis and the interruption of family activities caused by hospitalization generate discomfort in the face of the unknown and the possibility of permanent loss of the family member[2,7]. The nearness and close relationship of interdependence between the relatives enhances these discomforts and leaves them even more vulnerable to the difficulties and complexities that permeate the situation of having a seriously ill family member.

Therefore, recognizing the family as a focus of care and intervening with it in order to help overcome the difficulties that will arise is necessary and will contribute to ease the discomforts of hospitalization by promoting the reorganization of personal life and emotional and affective stabilization[2].

It is important to recognize factors such as the family life stage, the role played by the sick person in the home and the impacts that the illness and hospitalization cause on individuals, because the way the family sees the situation can be influenced by these factors[6].

In the face of hospitalization and the severity of the illness of the family member, the family begins to consider and prioritize their proximity to the hospitalized relative, thus showing no disposition to work and neither to other habitual activities of daily life, such as study and recreation. They also manifested difficulties in feeding themselves and in carrying out routine self-care activities. Thus,

it is necessary that health professionals focus on the assistance and to the care of the relatives, and also be able to recognize the changes and disorders the relatives face in order to help them find better ways to organize their personal, professional and family lives and self care[7].

Faith and spirituality as a support in facing the situation

When asked about which religion they followed and how their faith was in that moment they were experiencing the hospitalization process of a loved one in ICU, the majority of the relatives affirmed to follow a certain religion, while only one person stated to not follow no religious doctrine, but believed in God, confirming that all sees in faith and spirituality a support to face and accept the pain and suffering independently of religion or belief.

> *[...] The people are praying the rosary, masses, have many people calling from outside to say they are praying for her, even being from other religion. [...] the family is more united, we are praying more together, communicating more, everybody is giving strength to each other. (C7)*

Faith and spirituality have been the main source of support to those who experience a situation of a serious illness in a ICU, since the belief in a higher power and a proximity with God allows the ill person and his/her family to understand and face the adverse circumstances originated from the hospitalization[8].

This testimonial draws attention to the understanding that religion and spirituality are intensely lived by the relatives when those encounter some problem, stress or something that threats the life of one of their family members. Thus, spirituality is a relevant part of life an cannot be neglected in the therapeutic context, and must be considered inherent part to the care[8,9].

In contrast, it was observed that even expecting that He performs a great miracle and gives back their loved one, sound and free of possible complications to the family, some relatives worked to accept the possible outcomes of hospitalization. For many times, the relatives expressed that their faith in some moments was diminished, fact which is attributed to the severity of the disease and consequent slowness of recovery of their loved one[8,9].

Family relationship with the patient and the health team

Relatives exposed their perception on how the relationship with their hospitalized family member in ICU and with the health team is processed, bringing to a reflection the importance of establishing a bond between all involved in this process as a way to reduce fears, uncertainties and yearnings that permeate the hospitalization process.

When questioned about their relationship with the health team, the majority of the relatives reported being satisfied, attributing their satisfaction to obtaining clear and concise information about the state of health, the care and treatment adopted, as well as the diagnosis and prognosis of

the sick family member, as we see in the following speech:

> *The professionals are also being very good, related to the questions we ask they always answer with greater affection, nobody was arrogant, I don't know if it is because they know the severity and want to help. (F7)*

The manifestation of family suffering can also be identified through the manifestations of curiosity and the need to know about issues that permeate the hospitalization, so it is evident that the orientations and information provided through effective communication will enable a better quality of life for all those involved[10].

According to the relatives, the few moments with the patient represented a great suffering due to the impossibility of interaction by the sick family member, due to the illness itself, or by inherent barriers to treatment, for example, the use of sedation and other depressant drugs of the central nervous system.

It was found that the relatives usually experience great fear due to some reactions caused by psychomotor disorders, and it is up to the nursing professional to be attentive to this possible situation and intervene early to maintain an emotional balance and favor a better interaction between them.

The multiprofessional team must be able to guide and answer questions related to the hospitalization, and each element should be aware of the development of its role when orienting[10,11]. In this context, it is considered important that the nursing team, for they are closer to the patient and relatives, should approach the relatives at the first moment of contact with the patient, orient them to behave before them, and explain the possible motive of certain procedures, technologies used and possible reactions expressed by the patient. Maintaining attitudes like this will not only reduce levels of anxiety and stress, but will provide great help to better adapt to the situation[10].

The way of communication can have positive or negative implications, the more accessible and clear the communication with the family, the better the bond with the professionals will be and the greater will be their satisfaction and safety with the situation lived.

CONCLUSION

Thereby**, k**now the perception of the relatives that face a situation of hospitalization of one of their family member in an ICU allowed the identification of the effects of the hospitalization over the family, from feelings, sensations and meanings expressed, constituting, therefore, a important step towards the refection of the necessity to include the relatives as a part in the health and nursing care specifically, since an expanded look at the holistic and integral care of the family unit will alleviate the impacts caused by the great emotional overload and avoid compromising the family dynamics.

Thus, perceiving that the study unit in question does not dispose of a nursing assistance plan to the family, it is emphasized the need to create a nursing assistance plan that aims to soften the stressing agents originated from the hospitalization of a family member in an Intensive Care Unit and it is expected that this plan meets the needs and expectations of patients and relatives.

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