



RESEARCH

PERCEPTIONS AND NEEDS OF RELATIVES OF PATIENTS HOSPITALIZED IN AN INTENSIVE CARE UNIT

PERCEPÇÕES E NECESSIDADES DE FAMILIARES DE PACIENTES INTERNADOS EM UNIDADE DE TERAPIA INTENSIVA

PERCEPCIONES Y NECESIDADES DE FAMILIARES DE PACIENTES INTERNADOS EN UNA UNIDAD DE CUIDADOS INTENSIVOS

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ABSTRACT

Objective: Know the perceptions and needs of the relatives of patients hospitalized in an intensive care unit. **Method:** This is a descriptive study with a qualitative approach. Data were collected from relatives of patients hospitalized in an intensive care unit of a university hospital, through a semi-structured interview. The findings were analyzed according to the Content Analysis theoretical framework. **Results:** Data show that the relatives experience contradictory feelings with regard to the intensive care unit. Although the relatives perceive it as a sector where fear of death prevails, they also see it as the sector where one finds the best quality of care. The relatives show, particularly, a need for interaction with the multiprofessional team, through an effective communication with the professionals. **Conclusion:** One concludes that there's a need for establishing an effective dialogic process along with the relatives of patients hospitalized in an intensive care unit, in order to enable them to experience this period in a smoother manner. **Descriptors:** Nursing care, Family nursing, Humanization of care.

RESUMO

Objetivo: Conhecer as percepções e necessidades dos familiares de pacientes internados em unidade de terapia intensiva. **Método:** Trata-se de estudo descritivo com abordagem qualitativa. Os dados foram coletados com familiares de pacientes internados em uma unidade de terapia intensiva de um hospital universitário, por meio de entrevista semiestruturada. Os achados foram analisados de acordo com o referencial teórico da Análise de Conteúdo. **Resultados:** Os dados evidenciam que os familiares vivenciam sentimentos contraditórios em relação à unidade de terapia intensiva. Embora os familiares a percebam como um setor onde prevalece o medo da morte, eles também a veem como o setor onde se encontra a melhor qualidade de cuidados. Os familiares demonstram, principalmente, uma necessidade de interação com a equipe multiprofissional, por meio de uma comunicação efetiva com os profissionais. **Conclusão:** Conclui-se ser necessário estabelecer um processo dialógico efetivo junto aos familiares dos pacientes internados em uma unidade de terapia intensiva, com vistas a possibilitar que vivenciem de forma mais tranquila esse período. **Descritores:** Cuidados de enfermagem, Enfermagem familiar, Humanização da assistência.

RESUMEN

Objetivo: Conocer las percepciones y necesidades de los familiares de pacientes internados en una unidad de cuidados intensivos. **Método:** Esto es un estudio descriptivo con abordaje cualitativo. Los datos fueron recogidos con familiares de pacientes internados en una unidad de cuidados intensivos de un hospital universitario, por medio de entrevista semi-estructurada. Los hallazgos fueron analizados según el referencial teórico del Análisis de Contenido. **Resultados:** Los datos evidencian que los familiares vivencian sentimientos contradictorios con relación a la unidad de cuidados intensivos. Aunque los familiares la perciban como un sector donde prevalece el miedo de la muerte, ellos también la ven como el sector donde se encuentra la mejor calidad de cuidados. Los familiares demuestran, principalmente, una necesidad de interacción con el equipo multiprofesional, por medio de una comunicación efectiva con los profesionales. **Conclusión:** Se concluye que es necesario establecer un proceso dialógico efectivo junto a los familiares de los pacientes internados en una unidad de cuidados intensivos, con el fin de posibilitar que vivencien de forma más tranquila ese periodo. **Descritores:** Atención de enfermería, Enfermería familiar, Humanización de la atención.

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INTRODUCTION

In recent years, one has observed growth and improvement of policies and actions which promote the humanization of care in the health care context as a whole, including the intensive care units (ICUs). Among these actions, one may mention the National Program of Hospital Care Humanization (PNHAH), established by the Ministry of Health in 2001. Humanization should be part of the nursing philosophy and practice in various scenarios, especially in the ICUs, where material resources and technology are very important, however, they aren't more significant than human nature.^{1,2}

The ICU is a hospital environment aimed at severe patients, but those presenting a clinical status with possibility of recovery, constituting a sector of qualified professionals, with high technology and continued assistance. As a result, the ICU environment translates itself into the complexity of care provided to very severe patients, the invasiveness, and the risk of death, and it seems to be hostile, negative, and distant from health production.^{3,4}

In this context, hospitalization, due to major and unexpected illness, can lead to imbalance in the family structure. The family may be understood as a close and interdependent system of relations. This way, depriving one of its members of participation may result in loss of one of its reference points. Thus, the participation of family members in the care process is essential, and the nursing professional must be sensitive to their needs. Several aspects should be clarified for the family members, because, since the onset of disease until the diagnosis and prognosis, there're crises and disagreements within the family, which needs to feel supported and safe and have their doubts clarified.^{5,6}

In the intensive care context, this process
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becomes even more delicate. Having a family member hospitalized in the ICU is usually a cause for more stress and anxiety, since, typically, the presence of family members is allowed for short periods and patients are, on an integral basis, receiving care from the health team. In face of this, it's indispensable that the nursing professional embraces the family of the patient hospitalized in these sectors, paying attention to its fears and anxieties, in order to minimize them through a humanized care.

The humanization of nursing care in the ICUs goes beyond allowing or not the family member's visit, it also includes the establishment of a trust and help relationship, in which the nursing team has the function of identifying the actual needs of family members. The earlier the interaction between nurse and family takes place, the better it'll be for the family and, consequently, for the patient.⁷

This way, it becomes indispensable to know which feelings and needs permeate the experience of family members of patients hospitalized in ICUs, in order to foster discussions providing means for a more effective nursing professional action along with these family members. One starts from the assumption that the humanization of care implies knowing the other, her/his experiences, expectations, fears, in an attempt to share knowledge and experience.

Given the above, this study has the following research question: "What are the perceptions and needs of relatives of patients hospitalized in an intensive care unit?". For this, one aims to know the perceptions and needs of relatives of patients hospitalized in an ICU. The expectation, besides increasing knowledge on the theme, is providing reflections on the establishment of strategies to embrace the relatives, taking into account that their participation is essential to optimize the recovery

process of patients hospitalized in the ICU.

METHODOLOGY

This is a descriptive and exploratory research with a qualitative approach carried out with 9 relatives of patients hospitalized in an adult ICU of a university hospital in the countryside of the state of Rio Grande do Sul. This university hospital, since its founding, in 1970, constitutes a health care reference center to 34 towns in the central region of Rio Grande do Sul. The adult ICU is located at the 5th floor of this hospital, and it has an infrastructure with 9 beds and, out of these, 1 is for isolation.

Data collection took place between November 2011 and April 2012, through a recorded semi-structured interview, after approval by the Research Ethics Committee of the institution, under the Opinion 23081.013113/2011-89. At first, three test interviews were conducted, in order to test the data collection instrument and the interviewer. The interviews were conducted soon after the relatives' visit time in the ICU, and they took place at a private room, prioritizing the relative's well-being, who spontaneously accepted to participate in the study, by signing the free and informed consent form, in accordance with the Resolution 196/96, from the National Health Council. The invitation was made individually to each relative who waited for the visit at the ICU'S waiting room. The inclusion criteria were: relatives older than or aged 18 years, who visited the patients within the period when the interviews were conducted and spontaneously agreed to participate in the research.⁸

In order to preserve the anonymity of subjects, the testimonies were identified by the letter I, standing for interview, as well as Arabic numerals, which didn't follow the sequence in which the interviews were conducted. Data were collected until the time of its saturation.

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After the conduction of interviews, data were transcribed and analyzed according to Bardin's Content Analysis, which consists of 4 steps: gathering of the analysis corpus; pre-analysis: initial reading of collected data; data categorization; and, finally, interpretative analysis. The content analysis led to the definition of 3 categories, which will be presented below.⁹

RESULTS AND DISCUSSION

The participation of subjects consisted of 9 relatives, out of these, 6 were women and 3 were men. The subjects' age ranged from 30 to 61 years, they were relatives who, generally, had a first or second degree kinship to the hospitalized patient and dedicated themselves to various professional occupations.

Some respondents had no consanguinity degree, they were friends who regarded themselves as being part of the family, due to their strong friendship with the sick person. Only 4 people had already had a previous experience with hospitalization of relatives and/or friends in the ICU. The educational level of subjects ranged between incomplete Primary School and complete Higher Education.

Regarding the subject's birthplace, one observed that a large part of them was from the same town that the institution under investigation. The vast majority (80%) stated having a good relationship with the hospitalized relative and living together with her/him almost on a daily basis.

The patients who were hospitalized within the data collection period had various diagnoses, and the average ICU stay was 20 days. Through data analysis, three categories emerged, namely: Relatives' perceptions on the ICU: mixed feelings; Family's needs: health care demands; Communication between relatives and health care team.

Relatives' perceptions on the ICU: mixed feelings

Many of the relatives perceived the ICU as a unit where a greater amount of means predominates, where machinery and equipment are crucial for the patient's survival, since ICU patients undergo a severe condition and they're at risk of imminent death. Respondents also mention that they believe to be, the ICU, the place where their relative receives the best care, as there's greater surveillance, the professionals are closer and on constant alert, a fact which provides the relatives with confidence.

They manifest that being in the ICU represents being very sick, but that, in face of the care provided, by the professionals, within the unit, their relatives have the opportunity to recover and go home better than when they were admitted. These facts are exposed in the following testimonies:

I think he's being better cared for here, because in the ICU we know that surveillance is greater and there're more professionals to assist him. He receives a better care. (E1)

I know that it's the Intensive Care Unit, where critical patients who need a more specific treatment and those who are able to recover come! Here, we have the confidence that she has closer professionals and, then, there's always a professional with her. (E4)

In addition to this time of knowledge and adaptation to the ICU, the hospitalization of a family member in this unit generates many negative feelings, such as fear, sadness, yearning, and even some uncertainties with regard to care, and they were also reported. However, at the same time, this situation also causes positive feelings, such as hope of an improved hospitalized person's health status and confidence that "in the end, everything will work out".

The main feeling is confidence, thinking that he's being well assisted here! (E1)

They also mention the fact that patients being always clean, dressed up, bathed, with
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clean linen, as well as the organized unity make them confident, because it shows their relative is receiving the appropriate care.

But the service is good, the care for my grandfather is good! When we get there to visit him, he's always bathed, the linen is clean, he's dressed up! (E1)

She's always very clean, they're always organizing everything, because they know that the family is there, everything is nicely, as we can see there. (E3)

It's worth highlighting that a large part of the relatives of study subjects, hospitalized in the ICU, went through a moment of hospital stay in other units of the institution, especially in the emergency care sector. Thus, many subjects expressed a certain "relief" by seeing their relative at the ICU, where there's, according to their view, higher quality of care than in other sectors. At many times, situations which currently characterize the difficulties faced by emergency care sectors were reported, especially the public ones, related to lack of personnel and infrastructure to meet a growing demand of patients.

Furthermore, they characterize the hospitalization in an ICU as a situation which they never expected to happen and, also, as a difficult time to accept, and it's at this time that the family seeks to unite to promote the patient's well-being, something which is revealed through the interlocutors' statements:

Hospitalization here brings a bad feeling, it's difficult, because we're leaving a relative to be assisted by people who we really don't know nor the way how they care for, the particular way how they'll care for, whether they'll provide due attention or not. (E2)

The family was very disoriented! For the family, it's a pretty difficult time. (E4)

Through the reports, it becomes clear that the family recognizes the hospitalization of a family member as a difficult time, stating that, often, it feels helpless, with little information on

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the patient's health status, as well as frightened by the situation, when fear and anguish are combined to the unknown. However, they rely on the belief in the excellence of care provided in ICUs to better withstand the period away from the hospitalized relative, as well as to nourish hope in the recovery.¹⁰

The family members state that the admission time of one of its members is a period when the family seeks to be more united, in order to join forces to promote the health and well-being of the patient hospitalized in the ICU, and this becomes the most accessible way to face such a situation. The admission of a family member leads the relatives to go through adaptation phases. At first, there's a fluctuation period, when one observes confusion, uncertainty, stress, and the relatives can't notice their needs. Afterwards, there's the period of searching for information, when family members try to understand the events. At this moment, when they receive information about the hospitalized relative, they're able to better adapt themselves.¹¹

Then, there's the follow-up and evolution period, when family members observe and analyze the care and respect in the assistance provided for the family member. Finally, there's the period of seeking means, when the family tries to meet the needs of the hospitalized relative and those of its own. However, the phases may not occur in the sequence presented and the family system may regress during the process of hospitalization of the sick relative.¹¹

One infers that, due to the relative's length of hospital stay and after better experiencing and understanding the ICU, the family members start recognizing and identifying the importance of this environment for full recovery. With this, they start seeing the ICU as the sector which is most prepared to receive J. res.: fundam. care. online 2013. jul./set. 5(4):622-34

patients and care for them, thus ensuring the survival of patients undergoing a severe health condition. The ICU environment may pose a threat to the family, since it's faced with a totally strange and unknown place, providing them with an image of disruption of affective and emotional interdependence among its members, as already noticed.¹²

As a result, the ICU is, perhaps, the most uncomfortable and stressful sector for the family, although it can also be an environment which promotes the recovery and rehabilitation of critically ill patients. Family members have mixed feelings with regard to the ICU, perceiving it as a place which generates fear, but, at the same time, it provides confidence and hope in the relative's recovery.^{13,14}

It's worth highlighting that, in face of the hospitalization of a relative in the ICU, it's inevitable to make contact with family members, since these facilities refer to the idea of finitude, given the severity of the patients' health status. Family members directly relate the ICUs to the death issue, being under the responsibility of the nurse and/or the nursing team the holistic and personalized care for the patient and, also, for the other individuals concerned.¹⁵

Given the above, one may say that the situation experienced and reported by the family members about a hospitalization in the ICU allows stating that hospital stay affects the family's organization and daily life to a greater or lesser degree, requiring, from nursing, sensitivity to identify when its members require care. There're families which manage to overcome the difficulties of hospitalization and organize a structure to follow-up the hospitalized relative. This organization becomes important for such families, since life outside the hospital institution continues. This way, nursing must be sensitive to recognize the moments of greatest distress and

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anguish of the family, so that one can offer a humanized care also for the hospitalized patient's relatives. Within this period, the family must reorganize itself in order to overcome the difficulties which will arise, both in the affective, social, and economic aspects.^{5,12}

The nursing team plays a key role in this process, through the demonstration of receptivity and embracement to these families. For this, besides the technical and scientific knowledge required to work in an ICU, one highlights the importance of sensitivity, sensitive listening, the ability to communicate with these relatives, in order to make available the opening needed for the expression of doubts and fears, allowing the construction of an effective dialogue.

In fact, the family/professional interaction which can be obtained through this dialogue offers the prospect of establishing a relationship of trust and sharing of experienced situations, minimizing the anxiety caused by the hospitalization of a relative in the ICU. Besides, it opens pathways to meet the numerous needs of the family, promoting comfort and the opportunity to conduct education activities. To do so, it's essential to meet the needs of these relatives.

Family needs: care demands

The greatest needs expressed by the study subjects were those related to failures in the communication process with the team, the lack of guidance, and the short visit time.

Regarding communication, family members report that there's a lack of clarity in the information passed on by health professionals. A negative factor, pointed out by the relatives, was the use of highly technical language, which made it difficult to understand what was being said to them. The following testimony clarifies this situation:

Talking more at the patient's level, the relatives', so that we understand, and explaining the procedures. (E2)

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For the subjects, there's a great need for having more knowledge on what is happening with their relatives within the unit, besides being sure to receive the adequate assistance, from qualified professionals. Another factor which contributed so that the relatives manifest difficulties with regard to the communication process, concerns the contradictory information provided by various professionals, as exposed below:

We never know if it's right, because they never speak the same language, a person says one thing, explains the situation this way, says that the patient has this or that. Then, another person comes and tells that no, the patient don't have this or that, it's another thing. So what? What about our mind? Who should we believe in? (E3)

The fact that there's a need to receive guidance before the visit was recurrent in the respondents' testimonies, since they feel almost completely disoriented when they're with the patient, because they don't know how to proceed at this moment, whether they may or may not touch her/him, for example. It'd be ideal and comfortable for these visitors if there was a reference professional, in order to facilitate the communication process, as well as to make relatives feel embraced at this moment, as one can observe below:

There could be, you know, someone always there to provide information at the visit time, to avoid this kind of situation, the presence of people who don't know how to inform anything to the family, because there're people who aren't used to that and may be shocked, as they don't know how they'll find your relative. We arrive here and he has a lot of pipes, tubes, this and that ... you don't know what that is, you don't want to touch him, you don't know if you may speak, I think there could be someone to guide before going in to visit, only some 15 minutes before going in, explain what you can do or not. (E4)

The team often doesn't mind explaining this new environment to the relative, who hostilely experiences it in face of the advanced and frightening technologies. The team dedicates

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itself to patients in a limited way, being absent at these moments of family visitation because, according to the professionals, the family needs this time or because there's lack of time for an integral dedication; such aspects reveal the professional's escape from the context experienced.⁴

Regarding the visit length, during each shift, i.e. thirty minutes, it was regarded as insufficient by respondents, who claim they'd like to visit the relative for a longer period, or even at periods additional to the predetermined visiting hours. The testimonies below demonstrate these needs:

Then, there's a lack of some things, the visits are very short, they don't have time enough to take a look at him [...] the team could tell us more about his case and say what we can do when we are there. (E7)

The ideal would be going in when we wanted to see him. (E8)

The length of stay of relatives in the ICU, usually regarded as very small, is directly related to the patients' high complexity, with the risk of organic instabilities in a continued way and with the fact the team has many activities, which require full attention. Another fact, which may be pointed out as limiting the length of visits, is related to the numerous technical procedures, many of them invasive, to which the patient is exposed, besides the strict regulation to prevent and control cross infections, which, usually, limits the flow of visitors in ICUs. This way, access of other people to the ICU, such as relatives and friends, is restricted and, when it occurs, it's for short periods predetermined according to the hospital routines, to avoid the risks of infection or in order to prevent compromising the care for patients.^{15,16}

The visit and the companions are perceived, often, as elements obstructing work at the hospital, constituting a demand which needs

to be limited. The justification for the lack of access of family members to the ICUs also involves the lack of physical structure and human elements aimed at embracing visitors and companions, difficulty for understanding the visitor and companion's function on the patient's rehabilitation process, and lack of possibilities for keeping companions there, full time, within the hospital environment.¹⁷

However, one of the devices to be adopted in the humanization of health care services in Brazil is the open visit, since it increases the visitors' access possibilities, in order to ensure the link between the patient, his social network and the other services within the health care network, keeping latent the patient's life project. Nevertheless, this process needs to be gradual and planned, without compromising the quality of services provided to the patient in ICUs and cross infection control.¹⁸

Nursing, as a profession committed to processes and policies for humanization of care, needs to seek a practice which fosters the participation of patients and their relatives in decisions and care, promoting the individuals' autonomy. In this sense, the approach between the critically ill patient's family and the nurse can also enable a rapprochement with the lived world of those in your community. Thus, the nurse in ICUs, by turning to human care, in order to achieve integrality, will be hand in hand with education and the sharing of experiences.¹⁹

In this sense, one observed that family members who participated in the study share the idea that visiting hours, in the ICU, constitute an important moment for enabling communication between the health care team and relatives. With this, understanding the need to adapt the visit time, for example, is an effective measure to control the family's stress caused by

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hospitalization, besides strengthening its bond to the team.^{5,20}

This way, one infers that family members of ICU patients require further attention, because they're facing an unknown situation, where there's a sudden family breakdown, in a unit where the visit time is referred to as insufficient and whose patients, often, don't communicate verbally to the relative. The visitor, in face of this, feels totally unprepared to face such a situation, especially when he doesn't receive any guidance with regard to the visit time. Family members suffer from the patient's disease severity, as they don't know how to tackle this problem and they find, in the ICU, an unknown and frightening world, thus seeking support from the team to resume the connection to the relative.²⁰

On the other hand, when relatives receive, in an adequate way, information about the patient's health status, they show to feel relieved and confident with regard to the care received and, thus, the family, when feeling embraced, exposes its doubts and concerns, creating a bond of trust between the team and family. However, such attitudes weren't observed in this study, something which led the subjects to manifest, as their major needs an effective communication to the team and embracement for the visit moment.²¹

Taking into account the relatives' anxieties, feelings, doubts, and expectations is indispensable to provide a humanized care. Caring for the human being isn't only treating her/his body, but her/his universe, including the family and social context where she/he is included. Care consists in making decisions and developing activities along with the family, during hospitalization, when nursing and family, in an interaction process, seek to know each other, sharing and exchanging knowledge, beliefs, and

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values, in a situation of health and illness. For this, the professionals who assist families need to offer clear information, which address the actual needs of each family. Communication should be effective and appropriate to the understanding of each family.²²

Given the above, one should emphasize that it's always appropriate to explain to the family what it'll find on the other side of the door in the ICU, prepare it to see and be with the ill relative, contributing so that it feels safe and understands that appropriate assistance is being provided to her/him. The family member seeks, in her/his relationship with health professionals, support and confidence, both through technical procedures and a special attention provided by the team. The clearer the information to the responsible relatives, the easier the family will adhere to treatment.²³⁻²⁵

It's also important to take into account that family members are affected by the patient's illness in many ways: social role changes, uncertainty of the patient and family's future condition, loss of emotional control, permanence in an unknown environment (ICU), financial constraints, and fear of loss. So, the clearer the information about the illness process, the more supported and confident the family will feel.⁵

Another strategy of attention to the family members corresponds to the clarification, on the part of various professionals working at the sector, about its role along with the patient, which makes the family confident. This opportunity also leads to clarification of doubts, establishing a bond with the team and the family. Thus, the health team and, especially, nursing, would act jointly, making information more consistent, avoiding incomplete conversations and doubts. In these situations, notions of feeding, diet, hygiene, prognosis, and interventions could be presented, making family

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closer to the care context, hitherto distant and frightening.

Anyway, the relatives of patients hospitalized in the ICU mention having many care needs, demanding attention not only from nursing, but also from the multidisciplinary team. The quest for meeting these demands represents a challenge for intensive care sectors, particularly by requiring for a new attitude towards the health care process, not restricted to a technician care, but related to a human-driven work model and focused on the multiple dimensions which make up the health-illness process. In this case, it's noteworthy taking into account the family, on the part of professionals, as an essential component for the recovery process of critically ill patients.

Communication between relatives and health care team

The subjects point out that the health team in the ICU is proactive, but they don't have an open attitude in face of the family members, so that they can solve their doubts about the patient. The nurse has been characterized as an absent worker, although the commitment to be present at the visit time or at previous moments, with the mission to inform and answer questions from visitors, as one can observe in the following testimony:

If you don't ask, they don't say anything. The team seems pretty proactive, but I do not see a nurse very present. Perhaps, as I'm a nurse, I ask the nurse to become more present, providing guidance and clarification. I don't see a very open attitude. (E1)

The respondents were often able to inform who are some of the professionals working at intensive care, but they couldn't identify them during the visit or at later times.

I know that there're the physician and the nurses, but I can't tell who is who in there! (E2)

A factor mentioned as a barrier for the identification of each professional were the

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clothes worn by them, since nursing assistants and technicians and nurses wear the same clothes (smocks and pants standardized by the institution), which have the same color, and it's possible to identify them only through their name tag or when they identify themselves.

I know there's the physician, who speaks to us after the visit, and there's the nursing personnel, but in there they use the same clothes, it's difficult to know. (E7)

Only if you look at the name tag! (E3)

Family members also state that some members of the team are present during the visit time, but they clarify the doubts and questions only when asked for it, otherwise, these professionals don't manifest themselves with regard to the patient's health status or in order to provide other information, for example.

The following testimony elucidates what was mentioned before:

If you ask something they answer, but at the visit time we see that they're always there, there're a lot of people to assist, if it's needed, but if they'll assist or not, this I don't know, but there're always people there. (E3)

One observes, through the reports of family members who visit their relatives in the ICU under investigation, the need to receive care from the health team in this unit, as it's a time of difficult coping, both for the patient and the family. This way, for these subjects, knowing which professionals work at the sector is very important, taking into account that it facilitates access to information related to the unit and the patient. Furthermore, the identification of professionals associated to clarity on what are the duties of each offers the relatives the trust that their hospitalized family member has been adequately cared for.

The relatives miss the presence of a nurse during the visit time, so that they can solve doubts, know better the professionals working at

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the ICU. In a way, the nurse may act as a link between the family and the hospitalized patient, constituting a reference to that family, to that patient, that is, creating a bond to these people, in order to facilitate this care process, having the family as an important ally in the patient's treatment and recovery.

This way, by feeling embraced and cared for by the health care team at the ICU, the relatives may face more smoothly the distressing situation of having a family member hospitalized in the ICU. However, this requires a review of the professionals' attitude, in order to offer the opening needed to meet this demand. Furthermore, during the communication process, there's a need for reviewing the way how information is being transmitted and the way how they're being absorbed and understood by those who receive it, since, as mentioned, the use of a highly technical and overly refined language hinders the communication process.

The communication between the nurse and the relative is an important tool to keep the family informed about the patient's reality, to explain the procedures performed and their goals, the reasons for the existence of certain behavior rules and standards; it's an action which shows to be, therefore, crucial for involvement and participation of the family in care. In fact, the nurses are a link between the patient and the family, since they're the health professionals who stay longer with the patient and those who are in a better position to dialogue and inform the family about the ill patient's health state.^{26,27}

However, the study participants reported that there's a certain lack of initiative on the part of nursing professionals to seek the patient's family. In this sense, the authors warn that it's usual to observe, in the ICUs, that the nurse doesn't look for the ill patient's relative to provide her/him with information, becoming clear

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the difficulty that this professional have to interact with the family.²⁶

In contrast, the need for an immediate care due to the risk of life and the requirement of constant observation may end up turning the family's look more distant. The admission of a patient to the ICU usually requires a rapid intervention, because the patient has a high risk of instability of one or more physiological systems, with possible health risks, whose life may be reaching the border of death. Due to the urgency of an immediate technological action, an initial contact with the family members often becomes difficult, something which contributes to the understanding of the ICU as a facility where predominates coldness and an inhuman and distant actions.¹⁷

It's also important to highlight that the professionals' behavior, in a way, is a reflection of the institutional policies. Thus, the maintenance of a continued education process, associated to the supply of professionals in sufficient numbers to ensure a qualified care for patients and family members, enables a different professional action. The humanization of care, therefore, must be an institutional goal, and not just a goal of the professionals who work alone.

CONCLUSION

Through the conduction of this study it was possible to realize that the hospitalization of a family member is a unique and difficult moment not only for the patient, but for your family. Some mixed feelings with regard to the ICU were mentioned, since, although noticing it as a sector where fear of death prevails, people also understand that it's the facility where there's the better quality of care. Thus, anxiety and fear are some of the feelings aroused, and they're

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aggravated when the information about the treatment and the recovery chances are rare and unclear, causing mistrust, on the part of relatives, about the quality of service and the behavior of health professionals.

In this sense, strategies can be outlined as the flexibility of visiting hours offered to family members, allowing that all people interested can have a period close to the beloved person, and that explanations are given by the team, especially nursing, about the care being provided and its reasons. However, it's understood that the nursing team is often overloaded and it can't, despite its will, establish ties with the relative.

Through the analysis of this study, it was possible to reaffirm the importance of identifying the feelings and needs experienced by relatives of patients hospitalized in an ICU, since, this way, it'll be possible to improve and individualize nursing care. One observed that the family needs attention, as well as the patients, because when facing hospitalization of a relative or friend in the ICU, the family feels fragile and helpless. It was noticed that when assisting the family with regard to its needs and establishing an effective communication, clearly and objectively, the nurse enables the relatives the recognition of the potential for recovery of their beloved one.

It's pertinent to assume an attentive and humanized look, on the part of the health care team working with intensive care, towards these relatives who are facing such a hard time. The ICU professionals must have the sensitivity to recognize the feelings experienced by the very family during this hospitalization period, because, this way, the family will feel to be important in this hospitalization process and more confident to collaborate to the recovery process of hospitalized patients.

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REFERENCES

1. Brasil. Programa Nacional de Humanização da Assistência Hospitalar (PNHAH). Brasília (DF): Ministério da Saúde; 2001.
2. Vila VSC, Rossi LA. O significado cultural do cuidado humanizado em unidade de terapia intensiva: "muito falado e pouco vivido". *Rev Latino-Am Enferm.* 2002;10(2):137-44.
3. Silva GF, Sanches PG, Carvalho MDB. Refletindo sobre o cuidado de enfermagem em unidade de terapia intensiva. *REME Rev Min Enferm.* 2007;11(1):94-8.
4. Pinho LB, Santos SMA. Dialética do cuidado humanizado na UTI: contradições entre o discurso e a prática profissional do enfermeiro. *Rev Esc Enferm USP.* 2008;42(1):66-72.
5. Elsen I, Marcon SS, Santos MR, organizers. *O viver em família e sua interface com a saúde e a doença.* Maringá (PR): Eduem; 2002.
6. Morgon FH. *Mensuração das necessidades de familiares em unidade de terapia intensiva [dissertation].* Campinas (SP): Universidade Estadual de Campinas; 2003.
7. Pauli MC, Bouso RS. Crenças que permeiam a humanização da assistência em unidade de terapia intensiva pediátrica. *Rev Latino-Am Enferm.* 2003;11(3):280-6.
8. Brasil. Resolução n. 196/96. Diretrizes e normas regulamentadoras de pesquisa envolvendo seres humanos. *Diário Oficial da União, Brasília* (1996 Oct 21); Sec.1.
9. Bardin L. *Análise de conteúdo.* Lisboa: Ed. 70; 1977.
10. Martins JT, Robazzi MLCC, Garanhani ML. Sentimentos de prazer entre enfermeiros de unidades de terapia intensiva. *Cienc Enferm [internet].* 2009 [accessed 2012 Aug 22];15(3):45-53. Available from: http://www.scielo.cl/pdf/cienf/v15n3/art_06.pdf

Camponogara S, Santos TM, Rodrigues IL *et al.*

Perceptions and needs of...

11. Silva ALM, Andreoli PBA. O trabalho do psicólogo em UTI e UCO. In: Ismael SMC, organizador. A prática psicológica e sua interface com as doenças. São Paulo: Casa do Psicólogo; 2005; 37-51.
12. Bettinelli LA, Rosa J, Erdmann AL. Internação em unidade de terapia intensiva: experiência de familiares. Rev Gaúcha Enferm. 2007;28(3):377-84.
13. Puggina ACG, Silva MJP, Araújo MMT. Mensagens dos familiares de pacientes em estado de coma: a esperança como elemento comum. Acta Paul Enferm. 2008;1(2):249-55.
14. Ribeiro JA, Santos MSSS. Diagnóstico de necessidade da família de clientes adultos na unidade de terapia intensiva: revisão de literatura. Cogitare Enferm. 2008;13(3):437-42.
15. Camponogara S, Santos TMS, Seiffert MA, Alves CN. O cuidado humanizado em unidade de terapia intensiva: uma revisão bibliográfica. Rev Enferm UFSM. 2011;1(1):124-32.
16. Bettinelli LA, Erdmann AL. Internação em unidade de terapia intensiva e a família: perspectivas de cuidado. Av Enferm [internet]. 2009 [accessed 2012 Aug 22];27(1):15-21. Available from: http://www.enfermeria.unal.edu.co/revista/articulos/xxvii1_2.pdf.
17. Silveira RS, Lunardi VL, Lunardi Filho WD, Oliveira AMN. Uma tentativa de humanizar a relação da equipe de enfermagem com a família de pacientes internados na UTI. Texto & Contexto Enferm [internet]. 2005 [accessed 2012 Aug 22];14(Spec):125-30. Available from: http://www.scielo.br/scielo.php?pid=S0104-07072005000500016&script=sci_art.text.
18. Brasil. Cartilha da Política Nacional de Humanização [internet]. Brasília (DF): Ministério da Saúde; 2006 [accessed 2012 Aug 22]. Available from: <http://www.saude.sc.gov.br/hijg/gth/Cartilha%20da%20PNH.pdf>.
19. Dezorzi LW, Camponogara S, Vieira DFVB. O enfermeiro de terapia intensiva e o cuidado centrado na família: uma proposta de sensibilização. Rev Gaúcha Enferm. 2002;23(1):84-102.
20. Blanchard D, Alavi C. Asymmetry in the intensive care unit: redressing imbalance and meeting the needs of family. Crit Care Nurs. 2008;13(5):225-31.
21. Barbosa EMA, Brasil VV. Boletim informativo em UTI: percepção de familiares e profissionais de saúde. Rev Eletrônica Enferm [internet]. 2008 [accessed 2012 Ago 22];9(2):315-28. Available from: <http://www.fen.ufg.br/revista/v9/n2/v9n2a03.htm>.
22. Almeida FP, Veloso JWN, Blaya RP. Humanização em UTI. In: Knobel E, Laselva CR, Junior DFM. Terapia intensiva: enfermagem. São Paulo: Atheneu; 2009. p. 39-48.
23. Millani HFB, Valente MLLC. A família e a internação em UTI: a doença e a morte no Hospital Regional de Assis - SP. Nursing (São Paulo). 2008;11(20):235-42.
24. Maciel MR, Souza MF. Acompanhante de adulto na unidade de terapia intensiva: uma visão do paciente. Acta Paul Enferm [internet]. 2006;19(2):138-43. [accessed 2012 Aug 22]. Available from: <http://www.scielo.br/pdf/ape/v19n2/a03v19n2.pdf>.
25. Pereira LL, Dias ACG. O familiar cuidador do paciente terminal: o processo de despedida no contexto hospitalar. Psico (Porto Alegre) [internet]. 2007 [accessed 2012 Aug 22];38(1):55-65. Available from: <http://revistaseletronicas.pucrs.br/ojs/index.php/revistapsico/article/viewFile/1924/1430>.
26. Saiote E, Mendes F. A partilha de informação com familiares em unidade de

J. res.: fundam. care. online 2013. jul./set. 5(4):622-34

Camponogara S, Santos TM, Rodrigues IL *et al.*

Perceptions and needs of...

tratamento intensivo: importância atribuída por enfermeiros. *Cogitare Enferm.* 2011;16(2):219-25.

27. Mitchell ML, Courtney M, Coyer F. Understanding uncertainty and minimizing families' anxiety at the time of transfer from intensive care. *Nurse Health Sci.* 2003;(5):207-17.

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