Needs of the Relatives of Patients Hospitalized in an Intensive Therapy Unit

Necessidades de Familiares de Pacientes Internados em Unidade de Terapia Intensiva

Necesidades de Familiares de Pacientes Internados en Unidad de Terapia Intensiva

Vanessa Carla Batista¹; Lorenna Viccentine Coutinho Monteschio ²; Fernando José de Godoy³; Herbert Leopoldo de Freitas Góes⁴; Laura Misue Matsuda⁵; Sonia Silva Marcon⁶

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ABSTRACT

Objective: The study’s goal has been to identify the needs of the relatives of people hospitalized in an Intensive Care Unit from the interior of the Paraná State. Methods: Data were collected from May to September 2017, through the application of the Critical Care Family Needs Inventory (CCFNI) to 55 patients’ family members. It was performed a descriptive and inferential analysis. Results: The most valued needs were those related to information, safety in knowing that the family member is receiving the best treatment and having access/possibility of being able to talk with the physician at the visit time. Conclusion: Knowing the needs of family members is an important tool to assess the aspects related to the delivered care, and also provides subsidies for implementing actions that guarantee better quality of care for the patients and their families.


¹ Nursing Graduate, MSc student enrolled in the Nursing Postgraduate Program at UEM. Universidade Estadual de Maringá (UEM), Brazil.
² Nursing Graduate, PhD student enrolled in the Nursing Postgraduate Program at UEM. Universidade Estadual de Maringá (UEM), Brazil.
³ Registered Nurse of the Intensive Care Unit at Hospital Santa Casa de Maringá. Hospital Santa Casa de Maringá, Brazil.
⁴ Nursing Graduate, PhD in Nursing, Professor of the Nursing Department at UEM. Universidade Estadual de Maringá (UEM), Brazil
⁵ Nursing Graduate, PhD in Nursing, Professor of the Nursing Department at UEM. Universidade Estadual de Maringá (UEM), Brazil.
⁶ Nursing Graduate, PhD in Philosophy of Nursing, Professor of both the Nursing Graduation Course and the Nursing Postgraduate Program at UEM. Universidade Estadual de Maringá (UEM), Brazil

INTRODUCTION

A hospitalization is an event that causes instability within the family cycle. Such a change is of a sudden character and causes inconvenience not only to the patient, but to all family members, as it represents a threatening experience and the suffering is intensified by feelings of anxiety, conflicts, and compromising the balance of family dynamics.¹

During hospitalization at the Intensive Care Unit (ICU), both the patient and the family can face crises due to discomforts caused by the deprivation of living with the family member, the possibility of losing it, the change in the routine of family life, the lack of information about the state of health or the need to adapt to the routines imposed by the institution where the care is performed.²

The ICU is considered an environment that enhances emotions, feelings, and frustrations. Therefore, the family experiences a crisis situation, since in general, the admission of the patient occurs as a result of an illness or trauma, causing an emotional instability, which will mobilize coping strategies to deal with the stressor event.³

Due to the constant expectation of emergency situations, high technological complexity and the concentration of severe patients subject to sudden changes in the general state, the ICU environment is characterized as stressful and generates an emotionally compromised atmosphere, both for professionals and for patients and their families.⁴

Relatives of ICU patients may experience important needs during the period of hospitalization of their relative. Needs are defined as essential, determined by people and, when they are provided, ease distress and anxiety and improve the perception of well-being.⁵

It is observed that the focus of nursing care is the attendance of the patient’s needs. Nevertheless, the patient is not the only one suffering from the illness and hospitalization, the family shares the anguish, fear, insecurity, and suffering of the moment.⁶

Hence, the nurse and his team must be able to recognize the relationship with the family member, establishing attitudes of sensitivity and empathy. The family has the right to be included in health care since for the patient’s well-being, the presence of the family is significant.⁷ Identifying the needs of relatives of ICU patients can make the environment more welcoming and less impersonal, especially with regard to the reception given to family members.⁸

This research targets to contribute to the nursing and other health professionals to reflect on and understand the situations experienced by their families. Furthermore, it provides subsidies for the strengthening of the humanization policies of the Ministry of Health that have indicated the reception as a tool that should be used due to the possibilities of expanding and carrying out the humanized care, since it advocates listening, bonding and respect between professionals and service users.⁹

Because it is essential to welcome the family in this scenario to promote their comfort, the following question emerged: does the specialized intensive care sector manage to overcome the technological barrier by meeting the families’ wishes for care as part of the humanization process? Intending to answer this question, the present study aimed to identify the needs of the relatives of patients hospitalized in an ICU.

METHODS

It is a cross-sectional and descriptive study that was performed in a medium-sized philanthropic hospital in Guarapuava city, located in the central-western region of Paraná State, and which predominantly assists patients linked to the Sistema Único de Saúde (SUS) [Brazilian Unified Health System]. The ICU of the institution has ten beds, provides clinical and surgical care and is a reference in the specialties of neurology, cardiology, and nephrology. In the aforesaid unit, the presence of a companion is not allowed. Visits are released daily in the evening period.

RESUMO

Objetivo: Identificar as necessidades dos familiares de pessoas internadas em uma Unidade de Terapia Intensiva (UTI) no interior do Estado do Paraná.

Método: Os dados foram coletados no período de maio a setembro de 2017, por meio da aplicação do Inventário de Necessidades e Estresse de Familiares em Terapia Intensiva (INEFTI) a 55 familiares. Realizado análise descritiva e inferencial.

Resultados: As necessidades mais valorizadas foram as relacionadas com informação, segurança em saber que o familiar está recebendo o melhor tratamento e de ter acesso/possibilidade de poder conversar com o médico no momento da visita.

Conclusão: Conhecer as necessidades dos familiares se faz como uma importante ferramenta de avaliação dos aspectos relacionados ao cuidado prestado e fornece subsídios para implementação de ações que garantam melhor qualidade da assistência ao paciente e a família.

Descritores: Unidades de Terapia Intensiva, Enfermagem Familiar, Determinação de Necessidades de Cuidados de Saúde, Cuidados Intensivos.
for 30 minutes, allowing the concomitant entry of two people. Family members who arrive at the hospital are referred to a waiting room, where a psychologist approaches them and explains how the dynamics of family visits work.

The data were collected from April to August 2017, when attending the institution to visit the family member. The subjects were approached and invited to participate in the study while awaiting the release of the visits. At this time, they were clarified about the objectives of the study and the form of participation desired. Those who agreed to participate were invited to move away from the other people present in the waiting room, to then answer questions related to identification (kinship, number of days of hospitalization, and patient age) and the Critical Care Family Needs Inventory (CCFNI) questionnaire. Sometimes, the person himself would signal the answers and in others, one of the researchers would read the questions and indicate the response indicated by the participant.

The inclusion criteria adopted were, as follows: age equal or superior to 18 years old and to have some bond of proximity (kinship or friendship) with the hospitalized patient. People with emotional lability were excluded from the study.

The instrument used in the data collection was the CCFNI, adapted and validated for the Brazilian culture by Castro (1999). This instrument assesses the needs of family members of ICU patients and, consequently, their satisfaction.9

The CCFNI consists of 43 items, organized into four areas of need, namely: 1) need for knowledge/information; 2) comfort; 3) emotional security; and 4) need for access to the patient and the unit’s professionals.10

The answers are presented on a Likert scale of four points: (1) not important, (2) less important, (3) very important and (4) extremely important. The higher the value assigned to the item, the greater the degree of importance to the need in question.

The data were typed and organized into a spreadsheet in the Excel 2013® program and submitted to descriptive and inferential statistics in SPSS 20®. The averages, medians and respective Standard Deviations (SD) of the scores obtained in each of the items were calculated. Due to the values of the means and the medians being approximated, it was chosen to present the averages.

The development of the study was carried out in accordance with the Resolution No. 466/2012 from the National Health Council and the project was approved by the Research Ethics Committee involving Human Beings from the Universidade Estadual de Maringá (UEM) under the Legal Opinion No. 2.071.635 and Certificado de Apresentação para Apreciação Ética (CAAE) [Certificate of Presentation for Ethical Appraisal] No. 66253517.7.0000.0104. All participants signed the Informed Consent Form (ICF).

RESULTS AND DISCUSSION

Considering the 55 family members interviewed, the majority were female (67.3%), more than half were children of the patient (58.2%). The patients’ age ranged from 18 to 84 years old, average of 58.2 (±15.3) years old and were hospitalized in the ICU between one and thirty days. The mean length of hospital stay at the time of the interview was 6.9 days. It is noteworthy that 21.8% of the patients were hospitalized only one day and 49.1% had a maximum of three days.

The most frequent cause of ICU admission was the immediate postoperative period of cardiac surgery (23.6%), followed by clinical disorders of the circulatory system (21.8%), respiratory diseases (16.4%), neurological diseases (14.5%) and external (9.1%).

A general analysis of the data shows that the domain that reached the highest average and, therefore, represents the needs most valued by the participants was knowledge/information (average of 3.2) and the least valued was the need for comfort (2.8). Although the differences between the four domains are minimal, they indicate, to a certain extent, a hierarchy in the needs perceived by the family members.

Table 1 shows that there are no significant differences between the sexes in relation to knowledge/information needs. Among these needs, the most outstanding ones were knowing the reason for which procedure was carried out and receiving guidelines such as what to do next to the bed of my sick relative, while the less valued ones were to be warned about the religious services existing in the institution and to be informed about other people who could help with the issues.

Table 1 – Need of knowledge/information of relatives of patients hospitalized in an ICU from a hospital. Guarapuava city, Paraná State, April/August 2017.
Concerning the second area of CCFNI, which investigates aspects related to comfort, it can be seen in Table 2 that men assign greater value to all the questions, however, there was a significant difference in the question of having comfortable furniture in the waiting room, punctuated by men as an important necessity. It is noteworthy that having a toilet near the waiting room was the most valued item in this field, and having comfortable furniture in the waiting room was the least scored.

Table 2 — Comfort needs of relatives of patients hospitalized in an ICU from a hospital. Guarapuava city, Paraná State, April/August 2017.

<table>
<thead>
<tr>
<th>Comfort needs</th>
<th>Average (SD)</th>
<th>Fem. (SD)</th>
<th>Male (SD)</th>
<th>Gender</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Having a toilet near the waiting room</td>
<td>3.0 (1.0)</td>
<td>3.0 (1.0)</td>
<td>3.1 (0.9)</td>
<td>0.335</td>
<td></td>
</tr>
<tr>
<td>Having a place in the hospital where you can be alone</td>
<td>3.0 (0.9)</td>
<td>2.5 (0.0)</td>
<td>3.2 (0.9)</td>
<td>0.940</td>
<td></td>
</tr>
<tr>
<td>Having good food available at the hospital</td>
<td>3.0 (0.9)</td>
<td>2.9 (1.0)</td>
<td>3.2 (0.8)</td>
<td>0.38</td>
<td></td>
</tr>
<tr>
<td>Having a telephone near the waiting room</td>
<td>2.7 (1.0)</td>
<td>2.7 (1.0)</td>
<td>2.7 (1.1)</td>
<td>0.751</td>
<td></td>
</tr>
<tr>
<td>Having the waiting room next to my relative</td>
<td>2.6 (1.1)</td>
<td>2.5 (1.1)</td>
<td>2.8 (0.9)</td>
<td>0.077</td>
<td></td>
</tr>
<tr>
<td>Having comfortable furniture in the waiting room</td>
<td>2.5 (1.1)</td>
<td>2.3 (1.2)</td>
<td>3.0 (0.8)</td>
<td>0.024</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>1.8</td>
<td>2.7</td>
<td>3.0</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Made by the authors.

The third domain of CCFNI assesses the need for emotional security, and the results presented in Table 3, show that there was no significant difference in the perception of this need between the sexes. Nonetheless, it is noted that men feel more need for a practical order such as talking about the possibility of death, while women more often need to make sure that the family member is receiving the best treatment and need to feel hope.

Table 3 — Emotional security needs of relatives of patients hospitalized in an ICU from a hospital. Guarapuava city, Paraná State, April/August 2017.

<table>
<thead>
<tr>
<th>Emotional security needs</th>
<th>Average (SD)</th>
<th>Fem. (SD)</th>
<th>Male (SD)</th>
<th>Gender</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being informed about the religious services available in the institution</td>
<td>2.7 (1.1)</td>
<td>2.7 (1.1)</td>
<td>2.7 (1.0)</td>
<td>0.164</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>3.7</td>
<td>3.2</td>
<td>3.7</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Made by the authors.

Overall, the items with the highest scores were precisely the ones most valued by women, while the less frequent needs were to have someone in charge of my health and to be free to be alone at any time.

The fourth and final domain of CCFNI assesses the family members’ access to professionals, the institution, and the patient. The results presented in Table 4 show that there were no significant differences in the perceived needs of this domain between the sexes. The most frequently reported need for men and women was to talk to the doctor every day. Additionally, the men reported a need to know the care of the team in relation to the relative, while the women made reference to the need to have the time of the beginning of the visit respected.

It is noteworthy that in general, the less pointed need relates to having someone to help in financial problems.

Table 4 — Access needs of relatives of patients hospitalized in an ICU from a hospital. Guarapuava city, Paraná State, April/August 2017.

<table>
<thead>
<tr>
<th>Distribution of the access needs</th>
<th>Average (SD)</th>
<th>Fem. (SD)</th>
<th>Male (SD)</th>
<th>Gender</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Having a specific person in the hospital to contact and hear from my relative when he can not be present at the visit</td>
<td>3.4 (1.0)</td>
<td>3.4 (1.0)</td>
<td>3.2 (1.1)</td>
<td>0.357</td>
<td></td>
</tr>
<tr>
<td>Knowing how the team is taking care of my relative</td>
<td>3.4 (0.6)</td>
<td>3.3 (0.8)</td>
<td>3.4 (1.0)</td>
<td>0.37</td>
<td></td>
</tr>
<tr>
<td>Telling the start time of the visit respected, in other words, informs the visit on time</td>
<td>3.3 (1.0)</td>
<td>3.4 (1.0)</td>
<td>3.2 (1.1)</td>
<td>0.657</td>
<td></td>
</tr>
<tr>
<td>Feeling my relative frequently</td>
<td>3.3 (1.0)</td>
<td>3.3 (1.0)</td>
<td>3.2 (1.0)</td>
<td>0.774</td>
<td></td>
</tr>
<tr>
<td>Being able to modify it under special circumstances</td>
<td>3.0 (1.0)</td>
<td>2.9 (1.1)</td>
<td>3.2 (1.0)</td>
<td>0.502</td>
<td></td>
</tr>
<tr>
<td>Being able to visit anytime</td>
<td>2.7 (1.2)</td>
<td>2.7 (1.2)</td>
<td>2.9 (1.2)</td>
<td>0.926</td>
<td></td>
</tr>
<tr>
<td>Having someone to help with financial problems</td>
<td>2.0 (1.2)</td>
<td>2.0 (1.2)</td>
<td>2.4 (1.2)</td>
<td>0.891</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>3.1</td>
<td>3.1</td>
<td>3.1</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Made by the authors.

Table 5 shows that there was no difference in the needs assessment according to the age of the patient. For the two groups of relatives (of patients aged between 20 and 59 years old and above 60 years old), the domain most valued was the knowledge/information, while the least valued domain were those of the comfort domain.

When considering the number of days of hospitalization in the ICU, it is verified that the relatives of patients hospitalized more than 15 days ago, demonstrated that significantly (0.041) perceived the need related to the domain more than the relatives of patients with less than 15 days of hospitalization.

Table 5 — Difference of the domains’ score means of CCFNI according to both age and days of hospitalization. Guarapuava city, Paraná State, April/August 2017.

<table>
<thead>
<tr>
<th>Age</th>
<th>20 to 59 y.o.</th>
<th>More than 60 y.o.</th>
</tr>
</thead>
<tbody>
<tr>
<td>CCFNI Domain</td>
<td>Average</td>
<td>SD</td>
</tr>
<tr>
<td>Domain 1</td>
<td>2.6</td>
<td>2.1</td>
</tr>
<tr>
<td>Domain 2</td>
<td>2.7</td>
<td>2.7</td>
</tr>
</tbody>
</table>
The participation of female relatives was predominant (67.3%), in line with the results of a study carried out with relatives of patients admitted to the ICU in Spain. This fact may be related to the attribution of this social role to the woman, because it is culturally assigned the task of providing care for the home, culminating in a lower insertion of women into the labor market and, consequently, greater availability for activities related to family care, which includes visits to sick relatives. The fact of the majority of the participants being children of the patients is coherent, since it is an ICU that is a reference for care in the clinical and post-surgical areas of neurology and cardiology, problems that mainly affect the elderly.

The data presented in Table 1 show that the lack of information is a source of concern and discomfort for families. This is because they need explanations that clarify their doubts, fears, and anguish. Thus, clarifications regarding the diagnosis, prognosis, and treatment of the patient, which includes procedures performed or to be performed, as well as the equipment connected to the patient are essential for the relatives.

It is important to highlight that the hospitalization of a family member in the ICU is usually an unexpected event, marked by the imminent possibility of loss, which ultimately disrupts the family group. Under these conditions, the association of these factors increases the need for information in the family and of a good welcome on the part of the professionals who work there.

The reason for the greater need for information to be identified by relatives of patients hospitalized more than 15 days ago is due to the fact that a large part of the patients was hospitalized at the unit one day and during this period the professionals are more willing to provide information. As time goes by and the patient maintains clinical stability, practitioners feel that it is no longer relevant to provide further clarification.

The data presented in Table 2, show that for family members of patients hospitalized in ICU, their needs have little relation with physical aspects of the environment. This finding corroborates the results of a study on the experience of relatives of patients admitted to the ICU performed in two hospitals, one public and another private, which revealed that there was no significant difference between the two, demonstrating that the perceived needs are not associated with social or resources.

According to the data in Table 3, the family feels worried and insecure about the quality of treatment that their loved one is undergoing. These feelings show that, however much that is possible, if the family does not feel welcomed, they will be insecure about the care provided.

A study carried out in a private hospital found that to be sure that the patient is receiving the best treatment was the need for emotional security indicated by the greater number of relatives, a fact corroborated by this study. This result reflects the need for the human being to feel safe and to be sure that everything will go well, given the delicate moment that is experiencing.

It is important to note that only in domain 3, which deals with the need for emotional security, female relatives obtained, although with no statistical difference, a predominant mean (3.2) over males (3.1). This finding corroborates study information that revealed the needs felt by women related to information and/or support for the subjective aspects of care as a relevant factor that deserves more attention.

The restrictions on visits generate stress and suffering, triggering the emergence of needs that are valued by family members, a fact evidenced by the score attributed to some items in Table 4, such as: Talking with the doctor every day, knowing about the care given to the family member and have access to family news routinely, even when you can not be present at the visit.

The need to obtain information and access is due to some characteristics of the unit, such as the fact that it is a referral place for several specialties, among them post-operative in cardiology and neurology, which usually involves serious cases and still the limited access to the patient, since it is only allowed to visit once a day and it is limited to two people and for a short period of time. Consequently, the contact with the professionals of the team is restricted; furthermore, the doctor is the only professional responsible/authorized for providing information about the patient’s health status.

Service standards and visit-related restrictions hamper the nursing/family/patient relationship, and were also identified in a study that compared the needs of family members of patients hospitalized in a public and private hospital ICU, and found that contacts with professionals were much more frequent in the private institution. Therefore, family members of patients in this institution also had more access to information about their state of health.

A study carried out in São Paulo city, Brazil, with 39 relatives of patients showed that having the patient’s information, waiting for news related to an improvement in the clinical state, an increase in the probability of cure or a reduction in the risk of death, are generally the “good news” by family members. Thus, the moment of the visit is the most awaited moment for them, who long to withdraw their doubts, minimize their uncertainties and, above all, receive positive news regarding the patient.

In this framework, being present is a strategy of caring for your relative, albeit in a non-physical way. It is also the time when the family can become aware of the state of health of their loved one. Moreover, the visit should also promote...
the establishment of exchanges with the staff, a fact that is only possible through the building of a bond and willingness on the part of the professionals to host the family.9

In a qualitative research aimed at identifying the main needs of relatives of patients hospitalized in ICU, one of the aspects pointed out by the relatives was the lack of information, including difficulties in accessing the diagnosis and prognosis of the patient. This fact shows that information was one of the main forms of help that the health team could provide to family members. The study also pointed out that the nurse is the professional who must bring clear and objective information about what is happening to the patient, the behaviors being taken, the prognosis and what it means “being stable”.17

A review study found that nursing plays an essential role in the preparation of the family member for the experience to be experienced within an ICU. The patient’s condition should be described in terms appropriate to his level of understanding, any equipment should be explained before the family sees the patient and the nurse must accompany the family member to the bed to explain and clarify any information needs that arise.6

Through the assessment of family needs, it is possible to identify the aspects related to the care given to the patient and the family, which in turn subsidizes the planning and implementation of actions aimed at serving them, as well as the redirection of the care approach for situations considered relevant by family and patients.9

The focus of the nursing/family relationship should be the patient’s well-being and the relationship should allow the family to perceive in the team possibilities for support. To do so, the nursing must be receptive, accessible and prepared to meet their needs. In this way, the family should be seen as the focus of care and not as an appendix to their sick family member.18

Being present, building relationships, and creating a bond with the relatives, are forms of establishing the relations of welcome. So, reorganizing the work scenario whose actions are still centered and focused, almost exclusively, on the hospitalized person, and considering their relative, is a challenge for nursing, especially for the teams that work in high units complexity, such as ICUs.18

It should be emphasized that the implementation of interventions with the family and the patient is not an individual responsibility of the professionals who work in the ICU, but must be undertaken jointly with the managers of the institutions. Recognition and inclusion of the patient’s family as the focus of care requires fundamental changes in the vision and organization of health institutions as a whole.9

The ICU environment should be perceived by the family as a place where they feel safe, welcomed, confident and with broad access, with a right to information about their patient’s health status, their prognosis and how they are being provided the care. It should be ensured, through dialogue with the team and clarification in their concerns, so that families feel supported, comforted and participatory in the treatment process.19

Deeper considerations about the processes that involve nursing care to the family in the ICU environment should be recurrent for the direction of actions. This enables the understanding of their needs and feelings that favors a more humanized care.20

CONCLUSIONS

Herein, the findings point out the main factors capable of contributing to the adequate attendance of the needs of the relatives of patients hospitalized in ICU. The needs with higher average scores are related to the adequate emotional support from the professionals and greater clarification about the care given to the patient.

Involving the family in care requires health professionals, especially nursing professionals, to adopt an open posture for dialogue and the exchange of knowledge. The family member should not be treated only as a recipient of information, since when the family participates actively in the care process, the negative factors that permeate this moment are minimized.

It is believed that the results of this study can contribute to the planning of nursing interventions aimed at the improvement and quality of care provided to patients hospitalized in ICU and their families. It is suggested that more studies should be performed in this framework but with different methodological approaches aiming to broaden the knowledge about this matter.

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*Corresponding Author:
Vanessa Carla Batista
Rua Sueo Toda, 163, Apto 404
Vila Esperança, Paraná, Brazil
E-mail address: vane.vcb@hotmail.com
Telephone number: +55 42 9 99597260
Zip Code: 87.020-410

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