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NOTE PREVIEW ARTICLE

FAMILY MEMBERS OF PATIENTS IN PALLIATIVE CARE IN INTENSIVE CARE

FAMILIARES DE PACIENTES EM CUIDADOS PALIATIVOS NA TERAPIA INTENSIVA

FAMILIARES DE PACIENTES EN CUIDADOS PALIATIVOS EN LA TERAPIA INTENSIVA

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ABSTRACT

Objective: to investigate the existence of the relationship between the needs and the social support perceived by the relatives of patients in palliative care in the ICU. **Method:** this is a quantitative, cross-sectional study. The research will be done with 52 relatives of patients who are in palliative care in the ICU, in a private referral hospital. The following instruments will be proposed for this research: clinical and sociodemographic questionnaire, Social Support Scale and Inventory of Needs and Stressors of Families in Intensive Care. Data analysis will be based on descriptive and inferential statistics. **Expected results:** it will be hoped to contribute to the advancement in the thematic and to the development of professional practices that meet the demands of this clientele, so that they can be supplied. **Descriptors:** Family; Palliative Care; Critical Care; Hospitalization; Intensive Care Unit; Social Support.

RESUMO

Objetivo: investigar a existência da relação entre as necessidades e o apoio social percebidos pelos familiares de pacientes em cuidados paliativos na UTI. **Método:** tratar-se de um estudo quantitativo, de caráter transversal. Realizar-se-á a pesquisa com 52 familiares de pacientes que estejam em cuidados paliativos na UTI, em um hospital privado referência. Propor-se-ão os seguintes instrumentos para a realização desta pesquisa: questionário clínico e sociodemográfico, Escala de Apoio Social e Inventário de Necessidades e Estressores de Familiares em Terapia Intensiva. Basear-se-á a análise dos dados nas estatísticas descritiva e inferencial. **Resultados esperados:** esperar-se-á contribuir para o avanço na temática e para o desenvolvimento de práticas profissionais que venham ao encontro das demandas desta clientela, para que possam ser supridas. **Descritores:** Família; Cuidados Paliativos; Cuidados Críticos; Hospitalização; Unidade de Terapia Intensiva; Apoio Social.

RESUMEN

Objetivo: investigar la existencia de la relación entre las necesidades y el apoyo social percibidos por los familiares de pacientes en cuidados paliativos en la UTI. **Método:** se tratar de un estudio cuantitativo, de carácter transversal. Se realizará la investigación con 52 familiares de pacientes que estén en cuidados paliativos en la UTI, en un hospital privado referencia. Se propondrán los siguientes instrumentos para la realización de esta investigación: cuestionario clínico y sociodemográfico, Escala de Apoio Social e Inventario de Necesidades y Estresores de Familiares en Terapia Intensiva. Se basará el análisis de los datos en las estadísticas descriptivas e inferencial. **Resultados esperados:** se esperará contribuir al avance en la temática y al desarrollo de prácticas profesionales que vengan al encuentro de las demandas de esta clientela, para que puedan ser suplidas. **Descriptores:** Familia; Cuidados Paliativos; Cuidados Críticos; Hospitalización; Unidades de Cuidados Intensivos; Apoyo Social.

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INTRODUCTION

It is known that the process of sickness can provoke emotional fragility in the patient and his family, since they do not expect, nor are prepared, to deal with such reality. This fragility can be exacerbated by the need for hospital admission, especially if it is in the Intensive Care Unit (ICU), since this environment has a paradox as regards its function: for some, it is a place to dying, while for others it provides the best assistance by virtue of the technological apparatus offered.¹ It is pointed out that the permanence of a family member in the unit can also be interpreted as a threat to life, in addition to the physical distance between the parties.²

When a family member becomes ill and is hospitalized, a crisis is marked by severe illness and this may lead to a disorganization of the relationships between these members, as well as an imbalance in the roles occupied by each one. It is understood in this context that the family also needs support in facing and adapting to the new phase of life, as well as the search to maintain the balance or recover what was lost with the crisis.³⁻⁵

It is verified that when the person receives the diagnosis of illness outside the possibility of cure, the family suffers with it, experiencing the emotional impact with fears in the face of the new condition of life.⁶ Different reactions are observed, therefore, between the family groups, generating the need to understand them for better care. It is pointed out, in this sense, when it comes to patients in a palliative care situation (PC) or in a context in which the prospect of recovery is very small, that care is of the utmost importance since family members have specific needs and present high levels of stress, mood disorders and anxiety, as well as feelings of impotence and uncertainty about the unknown, during the follow-up of the family member admitted to the ICU.⁷⁻⁸

PCs are defined as actions aimed at alleviating unpleasant symptoms, caused by illness or by treatment. It is known that, according to the World Health Organization, PCs are active and total patient care, through the multiprofessional approach, when the disease does not respond to curative therapies and when the control of pain and psychological, social and spiritual symptoms is a priority. The objective of this type of care is to improve the patients' quality of life, including care for the family.⁹

Human acts are involved in caring for the individual, family and community,

encompassing both humanitarian and scientific values;¹⁰ in this way, the PCs extend the perspective of care, in a continuous and specific way, with focus in pain control and understanding the various biopsychosocial aspects of the patient and his/her family.^{6,11}

In relation to the hospital context, it is worth noting that PCs can occur in the various sectors where the patient is hospitalized, such as in the ICU, where it is relevant to provide a specific and continuous attention to the patient and his/her family.¹¹⁻² It is proposed by some authors that PCs may be used, as a form of assistance with curatives, with a focus on the prevention and treatment of patient and family suffering.¹³⁻⁵

It should be considered, with a view to promoting the quality of life of those involved, their needs.¹⁶ It is noticed that, among the evidenced demands, the information emerges as one of the priority aspects in the needs of the family members.¹⁷⁻⁸ Other needs assessed as important for the family in the ICU are listed, such as support, comfort, safety and proximity, evidenced in studies in which an evaluation instrument was used in the survey.¹⁹⁻²¹

It is understood that, in the family's experience with a PC member, social support can help in coping with the stress caused by the experience, so that those involved feel supported and have their demands met.²² It is necessary, considering the above, to understand the aspects related to the needs and social support perceived by the relatives of patients in PC in the ICU.

OBJECTIVE

To investigate the existence of the relationship between the needs and the social support perceived by the relatives of patients in palliative care in the ICU.

METHOD

This will be a quantitative cross-sectional study of the survey type, which aims to collect data about a particular phenomenon in a specific sample. The research will be carried out at the ICU of the Casa de Saúde São Lucas hospital, a private institution located in the city of Natal, Rio Grande do Norte.

The sample will be sampled for convenience, with 52 family members of patients admitted to the ICU who are in palliative care. The number of participants were defined from the specific calculation for the construction of this sample group, based on the survey of the number of patients

admitted to the ICU in the last two years, in this same hospital. It will be required that at least one family member of these patients attend the ICU to follow the clinical condition of the boarding school.

The project was submitted and approved by the Research Ethics Committee of the Federal University of Rio Grande do Norte (UFRN) under number 1,618,239, CAAE: 56191216.5.0000.5537, following, therefore, all recommended procedures for studies involving in accordance with Resolutions N. 466/12 and N. 510/16 of the National Health Council.

It will be ensured that the participation of family members occurs voluntarily, by signing the Informed Consent Form. The research will initially be presented to the relatives of patients in PC at the moment they are at the collection site. The invitation to participate and the collection of data in the ICU will be made, before or after the visiting hours.

The instruments proposed for this research will be used, translated and validated for the Brazilian reality and that allow to evaluate the aspects mentioned in the objectives of this study: sociodemographic and clinical questionnaire, Inventory of Needs and Stressors of Families of Intensive Care and Scale Social Support.

The purpose of the sociodemographic clinical questionnaire is to obtain sociodemographic, psychosocial and health information. It will be a semi-structured interview script prepared for this study.

It is pointed out that the Inventory of Needs and Stressors of Intensive Care Family Members (NSICFM) is an instrument derived from the Critical Care Family Needs Inventory, adapted and validated for the Brazilian culture, which evaluates the importance of the needs of the relatives of patients in the ICU and satisfaction with the service in this unit. The version available in Portuguese is composed of 43 Likert items and addresses the needs related to five dimensions: information, safety, proximity, support and comfort.²³

The Social Support Scale (SSS) shows the frequency with which the individual perceives that he or she can rely on people who support him in different situations. The scale is constituted by 19 items, each containing five alternatives ranging from one to five points, divided into five dimensions of support: material, affective, emotional, information and social interaction.²⁴

Data analysis will be based on descriptive and inferential statistics. The data will be

tabulated in a spreadsheet (Microsoft Excel) to be analyzed with the aid of data-processing software for social sciences, the Statistical Package for the Social Sciences (SPSS).

The inclusion criteria of this study will be: family members of PC patients who are hospitalized for at least 24 hours in the ICU; aged between 19 and 59 years, the adult population being considered according to the World Health Organization; who must accept to participate in the research, by signing the Free and Informed Consent Term. As an exclusion criterion, elderly relatives will be selected as of the age of 60, depending on the cognitive peculiarities of this period of development.²⁵

EXPECTED RESULTS

It will be sought, through this research, to give visibility to the topic, since the needs of the relatives of patients in PC in the ICU can not be ignored, since care should promote the integrality of the care to the patient and his family, within the biopsychosocial model to understand health, as well as the relevance of obtaining information about the social support perceived by the family, which may influence the confrontation of the critical reality in question.

It is hoped that the data coming from this research may also be relevant to scientific and academic knowledge, since, increasingly, sick people are being referred to the ICUs in the search for the promotion of better care, a place that has also been receiving patients in PC and, consequently, their family, with all the subjectivity involved in the hospitalization process. It is necessary to develop professional practices that meet the demands of this clientele, so that they can be met.

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