REVIEW ARTICLE

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CRITICAL PATIENT'S FAMILY NEEDS IN TERMINALITY OF LIFE: INTEGRATIVE REVIEW

NECESSIDADES DA FAMÍLIA DO PACIENTE CRÍTICO EM TERMINALIDADE DE VIDA: REVISÃO INTEGRATIVA

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RESUME

Objective: to identify in the scientific literature the main needs of the terminally critical patient's family. **Method:** integrative review carried out according to the six proposed steps. Searches were performed in the SciELO, LILACS and PubMed databases, including articles published between 2010 and March 2021. **Results:** from the total sample analyzed (n = 6), clinical trials (50%) and qualitative research (33%). Different needs of family members of terminally ill patients were highlighted, with emphasis on communication needs and emotional, spiritual, psychological and social needs. **Final considerations**: the scientific literature indicates that a family of the terminally ill patient in the intensive care setting presents a variety of needs, and that investing in better communication with the clinical team during the period of hospitalization in the Intensive Care Unit is a urgency. The importance of integrating the health team in the context of terminality to help the family in this delicate moment is perceived, supporting an adequate response to a therapeutic plan. Interdisciplinary work is an alternative, as the needs are of different orders and are not limited to the high technological density common to intensive care.

Keywords: Critical Care; Hospice Care; Family; Nursing; Intensive Care Units.

RESUMO

Objetivo: identificar na literatura científica as principais necessidades da família do paciente crítico terminal. **Método:** revisão integrativa realizada de acordo com as seis etapas propostas. As buscas foram realizadas nas bases de dados SciELO, LILACS e PubMed, sendo incluídos artigos publicados entre 2010 e março de 2021. **Resultados:** do total da amostra analisada (n=6), destacaram-se os ensaios clínicos (50%) e pesquisas qualitativas (33%). Foram evidenciadas diferentes necessidades dos familiares de pacientes críticos na terminalidade, com destaque para as necessidades de comunicação e as necessidades emocionais, espirituais, psicológicas e sociais. **Considerações finais:** a literatura científica aponta que a família do paciente em terminalidade de vida no âmbito da terapia intensiva apresenta uma diversidade de necessidades, e que o investimento na melhor comunicação com a equipe clínica durante o período de hospitalização na Unidade de Terapia Intensiva é uma premência. Percebe-se a importância da integração da equipe de saúde no contexto de terminalidade para auxiliar a família nesse momento delicado, corroborando para uma resposta adequada de um plano terapêutico. O trabalho interdisciplinar é uma alternativa, visto que as necessidades são de ordens diversas e não se limitam à alta densidade tecnológica comum a terapia intensiva.

Palavras-chave: Cuidados Críticos; Cuidados Paliativos na Terminalidade da Vida; Família; Enfermagem; Unidades de Terapia Intensiva.

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INTRODUCTION

Terminality issues in intensive care are linked to therapeutic limitation and humanization, because the intensive care unit (ICU) team, in general, is trained to save lives, using all resources and technologies available to achieve this goal. Thus, to meet all the needs of a terminal patient, which go far beyond those of biological order, it is necessary to organize the dynamics of the unit and constant training of the care team[1].

The dying process in the ICU is still related to the suffering and pain of patients and their families, often linked to the most hostile and stigmatized environment, the ICU[2]. During the proximity of death, the use of complex technologies and mainly the little or no communication between professionals, patients and families, highlight this relationship. Many family members of ICU patients do not have a good understanding of prognostic discussions and often have distorted expectations about survival, functional status and quality of life of their loved ones[3].

Although guidelines from professional societies recommend strategies to support families of critically ill patients, evidence suggests that many families could benefit from, but do not receive, such support [4]. The reasons for this failure of care are commonly related to lack of effective communication, inadequate psychological support to the family members and the ICU team's unpreparedness to deal with terminality, which brings as a consequence for these professionals the feeling of failure in face of the mission to cure the patient, becoming a barrier in the humanized care provided by the health team [5-6].

To understand humanization in complex care environments means to embrace the dynamics of the organization of these units, the management of the professionals' work, and the care provided to users, since the dynamics among these actors (re)feed the human and professional relations/interactions that permeate the care[3].

It is necessary to know the various difficulties faced by the family of the terminal critically ill patient facing the current situation, whether in the psychosocial, economic, spiritual and communication with the health team[7]. Considering the terminality process as a stage of difficult acceptance, pointing out these needs serves to clarify prognoses, besides allowing the family members to express their anxieties and fears, feeling supported by the assisting team [8].

Once it was pointed out that there is still a need to increase the terminality process in the ICU and that identification of family needs in this process may contribute to more humanized care practices that are closer to

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integral care, this study aimed to identify in the scientific literature the main needs of the family of the terminally ill critically ill patient.

METHODS

This is an integrative review, which was developed according to the six steps proposed by the chosen referential: (1) elaboration of the guiding question; (2) establishment of inclusion/exclusion criteria and literature search/sampling; (3) data collection and information categorization; (4) critical assessment of the included studies; (5) interpretation of results; and (6) presentation of the integrative review, with the synthesis of knowledge [9].

1st step - the development of this review occurred through the formulation of the following guiding question: what are the main needs demanded by the family of the terminally ill adult patient admitted to an Intensive Care Unit, as verified in the scientific literature?

2nd step - the search for articles was carried out in the following databases: Latin American and Caribbean Health Sciences Literature (LILACS), Scientific Eletronic Library Online (SciELO) and MedLine, via PubMed.

The descriptors used were: "critical care", "hospice care" and "family". Combinations of the descriptors "critical care" AND "critical care" AND "family" were used.

The literature search occurred in April 2021. Inclusion criteria were: articles published between 2010 and March 2021; articles with abstract and full text, freely available in online databases; and written in English, Spanish or Portuguese. The exclusion criteria were studies that did not answer the research question; theses, dissertations, and editorials, as well as publications classified as literature review articles of any nature.

3rd step - with the data search done, the abstracts of all the recruited texts (n=37) were read. By applying the eligibility criteria, six articles were included in the review. From these, the following information was extracted and summarized: title of the article, periodical and year of publication, database from which the article was extracted and summarized.

4th step - the selected articles were assessed in an interpretative manner, aiming to extract from the texts the main needs of family members of terminally ill patients assisted in the ICU context. This information was summarized in order to systematize knowledge.

5th step - interpretation of findings occurred in the discussion, linking the data surveyed/extracted in the previous steps with pertinent literature and authorial inferences.

6th step - the synthesis of knowledge occurred in an illustrative way, using synoptic

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tables that summarize the information extracted in the integrative review.

It is noteworthy that this study does not violate the ethical principles in research involving human beings, since it is a secondary research. All primary research articles had their ethical issues checked upon reading.

RESULTS

Using the descriptors cited, 12 articles were found in SciELO, none in LILACS, and 25 in PubMed, totaling 37 articles in the databases. After a rigorous reading, 06 articles fit the question under study for analysis and synthesis of knowledge (Chart 1).

Chart 1 - List of selected articles according to title, journal, year, database, study origin, type of study and conclusions

Code and title	Journal and year	Database Study origin	Study origin	Study type	Conclusions
I) A brief intervention for preparing ICU families to be proxies: a phase I study[10]	PLoS One 2017	SciELO	United States	Clinical trial with 122 health representatives and 111 patients	This intervention of family communication with the clinical team was considered positive
II) Support group as a strategy to receive family members of patients in Intensive Care Unit [11]	Journal of USP's School of Nursing 2010	SciELO	Brazil	Descriptive research with a qualitative approach, of the convergent care type, with 51 participants	We recommend a reflection on the reorganization of care practice to include a "support group" to meet the needs of family members
III) Death on stage in the ICU: the family facing terminality [12]	Trends in Psychology 2017	SciELO	Brazil	Clinical-qualitative research with 6 participants	The resilient behavior of family members regarding the terminalit
IV) A novel Family Dignity Intervention (FDI) for enhancing and informing holistic palliative care in Asia: study protocol for a randomized controlled trial[13]	Trials 2017	PubMed	Singapore	Open-label randomized controlled clinical trial with 126 participants	Addressed psycho-spiritual care to p successfully facing mortality
V) A randomized trial of a family-support intervention in Intensive Care Units[14]	New England Journal of Medicine	PubMed	United States	Cluster randomized clinical trial involving patients	Presented satisfactory evaluation about the quality of

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	2018			at high risk of death and their caregivers in five ICUs	communication of the health team and the patient and family
VI) Shared decision-making in end-stage renal disease: a protocol for a multi-center study of a communication intervention to improve end-of-life care for dialysis patients[15]	BMC Palliative Care 2015	PubMed	United States	Multicenter cohort study that implemented intervention to improve communication for end-of-life hemodialysis patients	Assisting the healthcare team in advance care planning for caregivers and patients at the end of life

Source: The authors

The main needs encountered by the family of the terminally ill patient are described in Table 2.

Table 2 - Needs explored in each article

Articles	Main family needs
I, II, V e VI	Communication needs
II	Emotional needs
III, IV	Spiritual needs
IV, V	Psychological needs
III, IV	Social Needs

Source: The authors

DISCUSSION

In articles I, II, V and VI the family of the terminally ill critically ill patient reports that communication is one of the main needs to be improved. Communication is an anchor of health work and is considered a soft technology of care [16]. It needs to be developed by the workers for a better articulation of care, and this, undeniably, must incorporate patients a families at all levels of complexity and life stages, including terminality [17].

A qualitative study on the facing of the assistance team to care for critically ill patients at the end-of-life raised three themes: academic-cultural barriers, related to the ICU assistance orientation to patients and caregivers and lack of training in end-of-life care; architectural-structural barriers, related to lack of space and privacy for the patient and family in the last moments of life; and psycho-emotional barriers, related to the use of emotional distancing as a strategy applied by the nursing team. As possible solutions to these challenges, the authors pointed out the

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training of the nursing team on end-of-life care through the use of guidelines or protocols and the development of strategies for coping with assistance and effective communication to family members [18].

A multicenter study, conducted to assess family satisfaction regarding the care of patients and their family, applied a satisfaction questionnaire between January 2015 and February 2016 in ICUs of three tertiary university hospitals in South Korea [19]. The findings pointed out the main factors affecting satisfaction identified through quantitative and qualitative analyses. Families reported the lowest satisfaction with the waiting room environment, communication, and management of patient agitation. The decision not to resuscitate, ICU mortality, and ICU culture were also associated with family satisfaction with intensive care. In this sense, the authors believe that the efforts to improve the quality of care should be directed on the intervention of the factors that cause dissatisfaction of the family of the critically ill patient, and this includes improvement in the communication processes.

A cohort study conducted in Spain assessed the quality of clinical care provided to patients dying in the ICU[20]. Criteria for excellence in intensive care were assessed by indicators and quality measures related to end-of-life care. A total of 282 patients from 15 Spanish ICUs were included. Almost all records evaluated both the patient's decision-making capacity and the clinical staff's communication with family members. Only two ICUs had open visitation policies. The absence of protocol for withdrawal of life support treatments was observed in 13 units. The study concluded that the quality of end-of-life care in the participating ICU needs to be improved and that, despite the existing gaps, a gradual improvement plan can be designed, adapted to the situation of each hospital and ICU.

To determine perspectives on how prognostic information should be conveyed in critical illness, a multicenter study was conducted in three academic medical centers in California, Pennsylvania, and Washington[21]. There was broad support among family members for existing expert recommendations, including disclosure of truthful prognoses, emotional support, tailoring the disclosure strategy to each family's needs, and checking for understanding. In addition, participants added more specific suggestions, such as improving communication about the patient's health condition to family members. In addition to conveying prognosis estimates, physicians should help families "see the prognosis for themselves" by showing families radiographic images and explaining the clinical significance of physical manifestations of serious illness at the bedside.

For the participants of the aforementioned study, physicians should conceptualize prognostic communication as

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an interactive process that begins with a preliminary mention of the possibility of death at the beginning of ICU admission and becomes more detailed as the clinical situation develops [21].

Articles II, III, IV and V emphasize the need for psychological, spiritual and emotional support to family members facing the intensive care admission and terminality. The health team must calm, welcome and value the feelings and expectations of the patient and family members [22]. This welcoming process often permeates touch, conversation and knowing how to listen, care that may be neglected due to the complexity of intensive care and culture.

Authors reinforce the importance of the participation of psychology in welcoming and listening to the family members of patients in the ICU, since the assistance of this team provides a more professionalized opportunity to talk about the terminality, being able to express what they feel, such as anger, guilt, sadness and stimulate them to say an appropriate goodbye. Thus, post-death reactions may become milder and, consequently, favor a better elaboration of mourning [23].

Another indispensable professional category in the welcoming and humanization of care in the ICU is nursing, because this team is in daily contact with the patient, experiencing the fears and anxieties of patients and their families [24]. The nurse, in particular, has a fundamental role in the sense of articulation of the interdisciplinary team, once his characteristic/position as care manager is recognized. From the author's experience, it is believed that the interprofessional articulation favored by the nurse's work tends to culminate in better care results, and also in greater participation and autonomy of the family in the care process.

Autonomy of the family members and of the patients themselves in the ICU, although not necessarily expressed in the synthesis of the exposed knowledge, probably permeates the identified needs, perhaps especially for the greater quality and/or amplitude in the communication of the intensivist professionals with the family members. This is an important subject to be addressed in the critical care setting, even because the possibility of becoming a subject with power of decision about his health has already been referred to as fragile in this setting[25].

Regarding the identified spiritual needs, a research described the timing and nature of meetings with chaplains in ICUs [26]. The findings point out that chaplain visits are uncommon and usually occur shortly before death among ICU patients. Communication between chaplains and physicians is rare. The chaplaincy service is primarily reserved for terminally ill patients and their families, rather than providing proactive spiritual support. These observations highlight the

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need to better understand the challenges and barriers to optimal chaplain involvement in ICU patient care.

Recently, Brazilian nursing researchers, with the objective of understanding spirituality and the practice of euphemia experienced by nursing professionals in the hospital setting, concluded that the workers perceive spirituality and the practice of euphemia as a motivational tool for the team to face the difficulties experienced at work and to increase the faith of the hospitalized patient [27]. Added to this, another national study carried out in southern Brazil with hospitalized patients referred to spirituality, religiosity and euphemia as a biopsychosocial triad, capable of attributing meaning, foundation and balm to human life [28].

In ICU, respect to the proposition of conducts based on spiritual values of the critically ill patient has already been referred by more than 88% of a sample (n=42) of nurses, in the state of São Paulo, Brazil. The authors of this study still believe that there is a taboo that permeates the spiritual and religious dimension, which makes it difficult for healthcare professionals to understand their own spirituality and how it can contribute to the integrality of nursing care given to critically ill patients in the ICU [29].

Notwithstanding the relevance of the allusions expressed, it is noteworthy that the aforementioned study is anchored on the spirituality of patients and, with this review, one notices that there is also a need to expand the view about the spiritual needs of family members of these individuals. This broadening, possibly, can contribute to the effectiveness of care and transposition of this care to the sick being, since he/she is part of a family social environment.

Studies III and IV highlight the need for a social support network for family members and patients. The authors of a study conducted in four ICUs in the United States state that in order to make the family decision making process effective, it is important to recognize and understand the informal roles that various family members may play in the end-of-life decision making process [30]. The authors concluded that the family's informal roles reflect the diverse responses to the family's decision-making demands, which is often a new and stressful situation. Identifying these roles can help professionals understand the roles of each family member in addition to guiding the development of strategies to support and facilitate increased effectiveness of decision-making processes at the time of a loved one's illness and death.

It is prudent to assume that there are limitations to this study, which are mainly related to the lack of more advanced search strategies and in a larger number of databases, besides the fact that the search in the databases was made by a single researcher. However, it is believed that the study

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contributes in the sense of clearly defining some needs that are demanded by the family member of the terminally ill patient in the ICU. This certainly may give rise to debates and planning on actions for a more sensitive and integral care in this phase of life, and that surpasses the clinical-assistance barriers of the critically ill. Finally, it is known that it is important that future research be developed on the importance of the presence and autonomy of the family in terminality situations**.**

FINAL CONSIDERATIONS

It is concluded that the scientific literature points out that the family of the terminally ill patient in intensive care presents a diversity of needs. The synthesis of knowledge allowed by this study points out that such needs are related to: communication needs and emotional, spiritual, psychological and social needs.

In view of the above, considering that the needs are eminently relational, it is considered that investment in better communication with the clinical team during the period of hospitalization in the Intensive Care Unit is an urgency. In this effective communicative process, it is expected that the family is welcomed, listened to, and its needs systematized in order to be solved and/or attenuated.

The importance of the health team's integration in the terminality context is perceived in order to help the family in this delicate moment, corroborating for an adequate response to a therapeutic plan. Interdisciplinary work is an alternative, since the needs are diverse and not limited to the high technological density common to intensive care.

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