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EVALUATION OF THE SATISFACTION OF FAMILIES OF PATIENTS CARED FOR IN INTENSIVE THERAPY UNITS: INTEGRATIVE REVIEW

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ABSTRACT

Objective: to analyze the scientific production related to the evidence on the satisfaction of family members of ICU patients and the instruments used for the evaluation.

Method: An integrative review in which articles published between 2005 and 2015 were analyzed in English, Portuguese or Spanish, in the PUBMED / MEDLINE and LILACS databases and the SciELO library. The following were used as a search strategy: personal satisfaction OR satisfaction AND family. For the purpose of the data collection of articles, an instrument was developed with information such as title, authors, year of publication and journal, study objective, design, participants, research site, main theme and results.

Results: 27 studies met the inclusion criteria. Four instruments were used to evaluate the satisfaction of family members of ICU patients: *Critical Care Family Satisfaction Survey*, *Family Satisfaction in the Intensive Care Unit*, *Critical Care Family Needs Inventory* and the *Quality of Dying and Death*. The studies addressed the satisfaction of family members in relation to their needs and decision making, satisfaction with palliative care, and cross-cultural adaptation studies and the validation of instruments were also evidenced. Regarding the level of evidence, the studies focus on levels II to VI.

Conclusion: the analysis of the scientific production on the satisfaction of family members of ICU patients showed that the factor that contributes most to the promotion of family satisfaction was the quality of care.

DESCRIPTORS: Nursing. Patient satisfaction. Personal satisfaction. Family. Intensive Care Units.

AVALIAÇÃO DA SATISFAÇÃO DE FAMILIARES DE PACIENTES ATENDIDOS EM UNIDADES DE TERAPIA INTENSIVA: REVISÃO INTEGRATIVA

RESUMO

Objetivo: analisar a produção científica relacionada às evidências acerca da satisfação de familiares de pacientes de UTI e os instrumentos utilizados para sua avaliação.

Metodo: revisão integrativa na qual foram analisados artigos publicados entre 2005 e 2015, em inglês, português ou espanhol, nas bases de dados PUBMED/MEDLINE e LILACS e a biblioteca SciELO. Utilizou-se como estratégia de busca: *personal satisfactional OR satisfaction AND family*. Para coleta de dados dos artigos elaborou-se um instrumento com informações como: título, autores, ano de publicação e revista, objetivo do estudo, delineamento, participantes, local da pesquisa, temática principal e resultados.

Resultados: atenderam os critérios de inclusão 27 produções. Foram identificados quatro instrumentos utilizados para avaliar a satisfação de familiares de pacientes na UTI o *Critical Care Family Satisfaction Survey*, *Family Satisfaction in the Intensive Care Unit*, *Critical Care Family Needs Inventory* e o *Quality of Dying and Death*. Os estudos abordaram a satisfação dos familiares em relação às suas necessidades e tomadas de decisão, satisfação quanto a cuidados paliativos, evidenciou-se, ainda, estudos de adaptação transcultural e validação de instrumentos. Quanto ao nível de evidência, os estudos se concentram nos níveis II a VI.

Conclusão: a análise da produção científica sobre a satisfação de familiares de pacientes de UTI permitiu evidenciar que o fator que mais contribui na promoção da satisfação da família foi a qualidade do atendimento.

DESCRITORES: Enfermagem. Satisfação do paciente. Satisfação pessoal. Família. Unidades de Terapia Intensiva.

EVALUACIÓN DE LA SATISFACCIÓN DE FAMILIARES DE PACIENTES ATENDIDOS EN UNIDADES DE TERAPIA INTENSIVA: REVISIÓN INTEGRADORA

RESUMEN

Objetivo: analizar la producción científica relacionada con las evidencias acerca de la satisfacción de familiares de pacientes de UTI y los instrumentos utilizados para su evaluación.

Método: revisión integradora en la que se analizaron artículos publicados entre el 2005 y el 2015 en inglés, portugués o español, en las bases de datos PUBMED/MEDLINE, LILACS y la biblioteca SciELO. Se utilizó como estrategia de búsqueda: *personal satisfactional OR satisfaction AND family*. Para la recoleccion de datos de los artículos se elaboró un instrumento con informaciones tales como título, autores, año de publicación y revista, objetivo del estudio, delineamiento, participantes, lugar de investigación, temática principal y resultados.

Resultados: 27 producciones atendieron los criterios de inclusión. Fueron identificados cuatro instrumentos utilizados para evaluar la satisfacción de familiares de pacientes en la UTI o el *Critical Care Family Satisfaction Survey*, *Family Satisfaction in the Intensive Care Unit*, *Critical Care Family Needs Inventory* y el *Quality of Dying and Death*. Los estudios abordaron la satisfacción de los familiares en relación a sus necesidades y la toma de decisiones, satisfacción sobre los cuidados paliativos. Además, se evidenciaron los estudios de adaptación transcultural y la validación de los instrumentos. Sobre el nivel de evidencia, los estudios se concentran en los niveles II a VI.

Conclusión: el análisis de la producción científica sobre la satisfacción de los familiares de pacientes de UTI permitió evidenciar que el factor que más contribuye en la promoción de la satisfacción de la familia fue la cualidad del atendimiento.

DESCRIPTORES: Enfermería. Satisfacción del paciente. Satisfacción personal. Familia. Unidades de Terapia Intensiva.

INTRODUCTION

The hospitalization of a family member in the Intensive Care Unit (ICU) can generate particular feelings in each person who is part of this process (the patient, the family and the health team). ICU hospitalization causes fear and distress mainly in families, since it usually represents the need for complex care due to a critical health condition. Relatives suffer from experiencing feelings that may make them worried and unhappy, generating stress, anxiety and fear, especially when faced with complicated health conditions and the possibility of death.

Assessing the needs and degree of satisfaction of family members of ICU patients becomes an essential part of the care of health professionals, who, among their commitment to care, reduce the pain and suffering of those who have a critically ill family member.[1] Families associate satisfaction with the provision of clear information which enables them to understand the care needs of their family members and the attitude of the medical team. However, the team's ability to offer comfort is the main reason for dissatisfaction. Thus, the adoption of comfort measures in the waiting room, with a harmonious, clean and pleasant environment, can contribute to family satisfaction.[1-2]

Thus, the health team in the ICU needs to understand that the hospital environment may cause unease to the family, and that the willingness to stay longer with the family during the visit, to know how care is performed and the need to participate in the care decisions are expected and natural implications. It is important to emphasize that the family is the one who accompanies the evolution of the patient and it is the family who carries the weight of the decision-making process together with the multidisciplinary regarding the different therapeutic possibilities.[3]

Thus, professionals prepared to support the family are those who are willing to talk, clarify doubts and answer requests, as these factors can interfere in the satisfaction with the care received in the ICU. Therefore the health team has different care tools that can contribute to the knowledge and evaluation in ICU settings. For example, by applying evaluation instruments, the satisfaction of care, or through direct approaches that aim to identify positive and/or negative aspects or potential for better care.

The following guiding question was defined: what evidence is available in the literature regarding the satisfaction of family members of ICU patients and the instruments used for the evaluation?

Thus, in order to contribute to the scientific basis of satisfaction in the ICU, the objective of the present integrative review was to analyze the available evidence in the literature regarding the satisfaction of family members of ICU patients and the instruments used for the evaluation.

METHOD

An Integrative Review (IR) that allows the collection of research results in a systematic and orderly manner. IR assists in the understanding of a certain phenomenon or topic of interest,[4] as it allows the elaboration of an analysis and a synthesis of scientific knowledge produced on a certain subject, allowing the analysis, summary and extraction of general conclusions on a theme.[5]

IR is a feature of the Evidence-Based Practice (EBP) that advocates the use of study results in clinical practice.[6] In addition to providing evidence in practice, EBP allows the use of methods that favor the collection, categorization, evaluation and synthesis of the research results, facilitating their use in practice.[5]

This study was developed in six stages:[7] The 1st step - Identification of the hypothesis or guiding question - elaboration of the research problem in a clear and objective way, definition and search for descriptors or keywords; The 2nd step - Selection of the sampling - definition of the inclusion or exclusion criteria of the studies to be analyzed; The 3rd step - Categorization of the studies - organization of the information of the reviewed articles; The 4th step - Evaluation of the studies - critical analysis of the content of the studies; The 5th step - Discussion and interpretation of the results - comparison of the main results with theoretical knowledge and evaluation as to their applicability; and The 6th step -Presentation of the integrative review and synthesis of knowledge - consideration of the information of each article, in a concise and systematized way, so that the identified evidences are exposed.

In the first stage the research question was elaborated which directed the integrative review: "What evidence is available in the literature regarding the satisfaction of family members of ICU patients and the instruments used for the evaluation?". Data were collected in March 2015 in the databases: Latin American and Caribbean System of Health Sciences Information (LILACS), National Library of Medicine (PUBMED) and Virtual Library Scientific Electronic Library Online (SciELO). The descriptors used were previously consulted in the Medical Subject Headings (MeSH) and Descriptors in Health Sciences (DeCS) dictionaries which defined the search strategy: Personal satisfaction OR satisfaction AND family, for the three research sources. In PUBMED, the following filters were used: Clinical trial; free full text; 10 years; English; Spanish; English. In LILACS the search was designated by the search filters: published in the last 10 years; Spanish; English and Portuguese and full text; and, in the SciELO library, the filters were: health sciences, English, Spanish, Portuguese and published in the last 10 years.

The second stage consisted in the selection of the sampling with the following inclusion criteria: original articles published between 2005 and March 2015; available in full; which addressed the subject of satisfaction, family and adult ICU; published in Portuguese, Spanish or English. For all the sources of information consulted, we chose not to use the descriptor Intensive Care Unit, since it could give rise to restrictions in the searches of the studies. However, this was part of the inclusion criteria in the selection and reading process of the articles.

Literature reviews, letters to the editor, opinion of authorities and/or report of expert committees or studies that did not represent results of primary studies; publications that did not fall within the established search period; whose target audience were relatives of children; which did not answer the previously established research question; and those found in more than one database (duplicity) were excluded.

An instrument for the data collection of the articles was elaborated with information such as: Title, authors, year of publication and journal, study objective, outline, participants, research site, main theme and results. A total of 27 publications were analyzed,[1,8-33] classified according to the approach, design[34] and in relation to the level of evidence (LoE).[35]

675 studies were identified: 138 in total were identified in PUBMED, but only six met the inclusion criteria, 349 were identified in SCIELO, from which only two were selected; and, 188 in LILACS, with only 19 being chosen (Figure 1). Duplicated articles were aggregated into the base containing the largest number of articles. The process of reading and analyzing the articles in their entirety was performed by two reviewers, and a third reviewer was consulted for cases in which doubts were raised regarding the inclusion of the studies.

For the treatment of bibliographical data, justice, integrity, impartiality and respect to the original authors of the publications that composed this study was maintained . In addition, some articles belong to the literature review of the dissertation of the Postgraduate Program of the Faculty of Nursing of the Federal University of Pelotas (UFPel) entitled "Cross-cultural adaptation and preliminary validation of the Family Satisfaction with Care in the Intensive Care Unit (FS-ICU 24) for Brazilian Portuguese ", which obtained the approval of the Ethics Committee of the Faculty of Nursing of UFPel under the opinion 1,104,124.

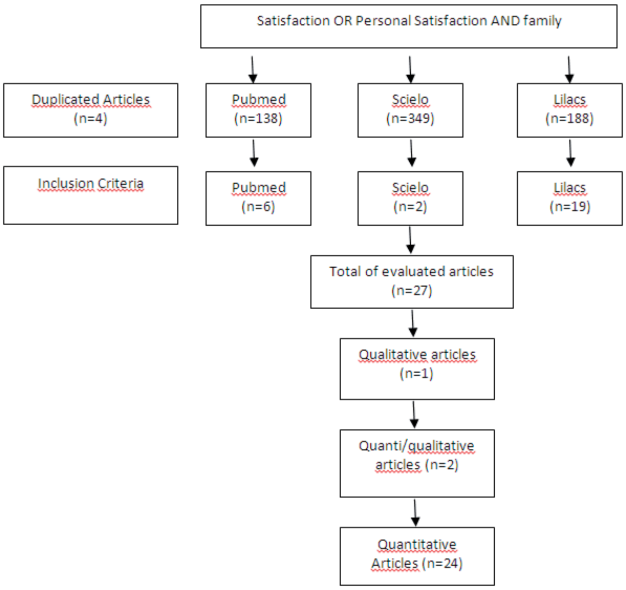

Figure 1 – Articles included in the integrative review, 2015

RESULTS

From the 27 publications, three thematic categories for the discussion were identified: 1) family satisfaction in relation to palliative care and their perception about the quality of their family member's death process; 2) different aspects related to family satisfaction, needs and decision making; and 3) satisfaction evaluation instruments (application, adaptation and validation of scale).

The description of the themes was presented with the level of evidence preceded by the characterization of the studies. In the first two themes the results of the surveys analyzed and the instruments that were used to evaluate the satisfaction are presented.

Characterization of the evaluated articles

All the analyzed studies used ICU family assessment instruments with different approaches. From the total amount of studies, 62.9%,[1,14-17,19-20,22,24-27,29-33] had the objective of evaluating satisfaction with regard to decision-making, 25.9% [8-13, 28] aimed to evaluate satisfaction regarding the care of patients in palliative care in the ICU, and 11.1% [18,21,23] had the objective of adapting and validating instruments.

Table 1 - Characterization of the studies that compose the integrative literature review in relation to the methodological approach and the level of evidence, 2015

Authors	Approach	Delimitation		LoE*
		Observational	Experimental	
Kross EK, Engelberg RA, Downey L, Cuschieri J, Hallman MR, Longstreth Jr WT, et al.[8]	Quantitative		Clinical trial with groups	III
Gries CJ, Curtis JR, Wall RJ, Engelberg RA[9]	Quantitative	Cohort		IV
Gerstel E, Engelberg RA, Koepsell T, Curtis JR[10]	Quantitative		Randomized Clinical Trial	III
Neves FBCS, Dantas MP, Bitencourt AGV, Vieira OS, Magalhães LT, Teles JMM, et al.[1]	Quantitative	Transversal		VI
Kross EK, Nielsen EL, Curtis JR, Engelberg RA[11]	Quantitative		Clinical trial with groups	II
Osborn TR, Curtis JR, Nielsen EL, Back AL, Shannon SE, Engelberg RA[12]	Quantitative	Transversal		IV
Curtis JR, Nielsen EL, Treece PD, Downey L, Dotolo D, Shannon SE, et al.[13]	Quantitative		Clinical trial with groups	II
Dodek PM, Wong H, Heyland DK, Cook DJ, Rocker GM, Kutsogiannis DJ, et al.[14]	Quantitative	Transversal		II
Khalaila R[15]	Quantitative	Transversal		IV
Johnson JR, Engelberg RA, Nielsen EL, Kross EK, Smithe NL, Hanada JC, et al.[16]	Quantitative	Cohort		IV
Puggina AC, Ienne A, Carbonari KFBSF, Parejo LS, Sapatini TF, Silva MJP[17]	Quantitative	Transversal		VI
Brown A, Mohammed H[18]	Quantitative	Transversal		II
Stricker KH, Kimberger O, Schmidlin K, Zwahlen M, Mohr U, Rothen HU[19]	Quantitative	Transversal		III
Fumis RR, Nishimoto IN, Deheinzelin D[20]	Quantitative	Prospective		II

Hickman RL Jr, Daly BJ, Douglas SL, Burant CJ[21]	Quantitative	Transversal		III
Schwarzkopf D, Behrend S, Skupin H, Westermann I, Riedemann NC, Pfeifer R, et al.[22]	Quanti/ qualitative	Cohort		IV
Huffinesishel M, Johnson KL, Smitz Naranjo LL, Lissauer ME, Fishel MA, D'Angelo Howes SM, et al.[23]	Quantitative	Prospective		III
Jongerden IP, Slooter AJ, Peelen LM, Wessels H, Ram CM, Kesecioglu J, et al.[24]	Quantitative	Prospective		III
Yousefi H, Karami A, Moeini M, Ganji H.[25]	Quantitative		Clinical trial with groups	IV
Henrich NJ, Dodek P, Heyland D, Cook D, Rocker G, Kutsogiannis D, et al.[26]	Qualitative	Transversal		VI
Karlsson C, Tisell A, Engström A, Andershed B[27]	Quanti/ qualitative	Retrospective		II
Lewis-Newby M, Curtis JR, Martin DP, Engelberg RA[28]	Quantitative	Prospective		VI
Shelton W, Moore CD, Socaris S, Gao J, Dowling J[29]	Quantitative		Quase-experimental	III
Kodali S, Stametz RA, Bengier AC, Clarke DN, Layon AJ, Darer JD[30]	Quantitative	Cohort		IV
Hwang DY, Yagoda D, Perrey HM, Tehan TM, Guanci M, Ananian L et al.[31]	Quantitative	Transversal		III
Gerasimou-Angelidi S, Myrianthefs P, Chovas A, Baltopoulos G, Komnos A[32]	Quantitative	Transversal		III
Tastan S, Iyigun E, Ayhan H, Kılıckaya O, Yılmaz AA, Kurt E[33]	Quantitative	Transversal		III

*LoE=Level of evidence.

Aspects related to family satisfaction

As the first two thematic categories include the family satisfaction of patients hospitalized in the ICU as the main theme, a joint analysis of the results was carried out. Among them, aspects that appear as positive or favorable and / or as negative or unfavorable are highlighted (Table 1).

To improve end-of-life experiences, we investigated family satisfaction with the care of patients who died in ICUs in the United States. In order to assess the quality of death, the authors applied the Family Satisfaction in the Intensive Care Unit (FS-ICU) and Quality of Dying and Death (QODD) questionnaire in order to evaluate family satisfaction. The highest levels of satisfaction were related to nursing ability and competence, family support in decision making, and direct family participation in patient care (LoE IV).[12]

In the United States, the QODD questionnaire was used to identify the satisfaction of families and nurses with end-of-life palliative care. Both highlighted that patients whose physician was a neurosurgeon had better quality of attention at the time of death. On the other hand, those treated by surgeons presented worse classification in relation to palliative care and quality of care at the moment of death (LoE III).[8]

In order to evaluate family satisfaction regarding decision making at the end of the ICU patient's life, using the FS-ICU, conditions considered important were identified, such as medical recommendations for withdrawal of life support, wishes expressed by patients, family discussions and spiritual needs (LoE IV).[9]

In the search for knowledge regarding aspects that would be relevant to the satisfaction of families with patient care in the last five days of life, also in the United States, the results indicated that withdrawal of all life-sustaining interventions in younger patients was prolonged and resulted in remaining in the ICU for longer periods of time. This was associated with increased family satisfaction; in addition, those diagnosed with cancer had the opportunity to have more family members participating in decision making (LoE III).[10]

Regarding the aspects related to family burden in relation to the care of the patient who died in the ICU, the QODD and FS-ICU instruments were applied, identifying that when younger patients died, the family members living with the patient were vulnerable to suffering. (LoE II).

Accordingly, a Canadian study evaluated the effectiveness of the quality of intervention to optimize end-of-life care in the ICU and that, even when responding to the research instruments, relatives of elderly people in palliative care and relatives of those who had died, presented better acceptance and greater participation (LoE II) .[13]

However, no variation in response rate was identified by age group in the application of the FS-ICU and QODD instruments. It was concluded that both questionnaires evaluated satisfaction with end-of-life care and quality of death, and the results differed with the patient's age. The families of the elderly patients reported high levels of satisfaction with ICU care and better quality of care in the experience of death (LoE VI) [28]. In the evaluation of the degree of satisfaction of the family in relation to ICU patient care using the Critical Care Family Needs Inventory (CCFNI), the results indicated higher satisfaction rates in relation to the care offered to the hospitalized relative and to the honesty of the information received. However, the lower indexes were related to the fact that the families believed that there was a lack of interest of the professionals in offering information about the equipment used (LoE VI).[1]

Although most families declare being satisfied with the care provided to the family member, some factors may increase or decrease satisfaction. Such factors are those related to the clarity of information, as a positive aspect; and the low accessibility of physicians, as negative. In addition, families indicated the type of assistance they would like to have received: 49.4% would have liked to have received more technical information and 45.1%, would have liked to have received psychological help (LoE II).[20]

Aspects considered favorable for the promotion of satisfaction included courtesy and respect for the patient (LoE III),[19] the offer of greater emotional support and the promotion of family participation in making decisions regarding care (LoE IV).[22]

In Canada, during the application of FS-ICU, factors related to the satisfaction and dissatisfaction of relatives of survivors and non-survivors in the ICU were identified. Positive factors include: quality of professionals; competence and professionalism of the team; respect to family and patient; and, compassion at the moment of death through the kindness of the officials. Negative points included: interpersonal skills; characterization of physicians as rude, aggressive and insensitive; and loud and inappropriate conversations among professionals, such as jokes, especially by the nursing team (LoE VI).[26]

In the United States, which have the average FS-ICU scores, in comparison between the satisfaction of the families of patients in a General ICU and a Neurological ICU, it was identified that the satisfaction was lower in relation to the waiting room. Less than 60% of the families of the neurological ICU were dissatisfied with the domains: physicians' communication frequency, inclusion and support in decision making and family control over the care of their relative. In addition, the study concluded that the families of the neurological ICU presented less satisfaction with the team's concern and care for their needs than those of the General ICU (NE III).[31]

Another factor that interferes with family satisfaction with ICU care in the United States is the acceptance of the development of spiritual activities performed by professionals to support patients and families. These activities are particularly related to the support of religious and spiritual needs and emotional support (LoE IV).[16]

Based on the application of the CCFNI instrument, a Brazilian study identified and compared the perception of nonverbal communication expressed during the hospital visit and the degree of satisfaction of the relatives in relation to their needs in the ICU. It was verified that the families are not completely satisfied with the ICU team or the dynamics of the ICU, highlighting the need to improve the relationship with the family and offering clear information about the clinical picture (LoE VI).[17]

In Sweden, in assessing satisfaction related to the needs of safety, information, proximity, support and comfort, through the Critical Care Family Satisfaction Survey (CCFSS) instrument, participants were found to be more satisfied with the support, team and the quality of treatment; and less satisfied with comfort, the availability of doctors for normal conversations, and the preparation for transferring the patient to the ICU (LoE II).[27]

North American authors assessed satisfaction by using the CCFSS after an intervention related to the inclusion of a family support coordinator to help families in the ICU setting, clarifying complex medical information, acting as a link between the family and staff, and promoting family-centered decision making. The results showed a significant increase in family satisfaction after this intervention as a result of improved communication with physicians (LoE III).[29] In Iran, through the use of the Johnson questionnaire it was identified that the use of nursing interventions based on family needs, in relation to trust, support, information, closeness and convenience had a significant and positive impact on satisfaction (LoE IV).[25]

In Greece, family satisfaction with care in the ICU and its association with nursing workload was assessed through the Nursing Activities Index. The results identified the lack of nurses in a work shift (which may interfere with satisfaction) and the need to include family members in the decision making process. Nevertheless, the average level of family satisfaction with care was 80.7% (LoE III).[32]

Studies that addressed the satisfaction of families in the ICU with decision-making indicated the need for a greater participation of these families.[23-24,30] Families who attend family meetings are more satisfied with decision-making, as it is necessary to look at family dissatisfaction as a way to improve the relationship between staff and family (LoE IV) .[30] Another strategy is the adoption of a checklist by the ICU team to assess the need for care every 24 ,72 and 96 hours, which contributed to the change in the work process.[23] In addition, the satisfaction of the relative was greater when the patient remained in a single room, compared to being in a ward, which showed the importance of the environment in the satisfaction of the patient and family member (LoE III).[24]

A study using the CCFNI performed in Israel with professionals and patients' families, discovered positive relations for most domains of organizational culture and security with regard to satisfaction, related to the care of relatives of non-survivors who had spent at least 14 days in the ICU. This concludes that organizational culture is more easily perceived by those who interact frequently with the team (LoE IV).[15]

The main aspects highlighted in the literature, such as positive or negative, for family members to feel satisfied with the environment, health team and care received, are described in Table 2.

Table 2 - Aspects that contribute positively and negatively to the satisfaction of the family of patients attended in Intensive Care Units. 2015

Positive Aspects	Negative Aspects
Professionals	
Quality of professionals: competence and professionalism.[26-27] Nursing skill and competence [12] Specialty (doctors neurosurgeons) suggests greater sensitivity.[8] Honesty in the information given to the family.[1] Clear and complete information given by the responsible doctor.[17,20] The inclusion of a family support personal coordinator in the team.[29] Nursing interventions aimed at trust, support, information, proximity and familiarity with the family.[25]	Specialty (medical surgeons) suggests less sensitivity.[8] Low accessibility.[20] Lack of interpersonal skills.[26] Rude, aggressive and insensitive treatment.[26] Inappropriate conversations on the part of the members of the health team, mainly the nursing professionals. Inadequate communication from doctors.[31] Specific ICU team would bring lower satisfaction with care (lack of interest).[1] Professional posture and non-verbal language in front of the patient and the family.[17] Lack of available caregivers for regular conversations with family members.[27] Lack of team relationship with family.[17]
Family	
Family support in decision-making, direct participation in patient care.[12] Emotional support.[22] Most prolonged withdrawal of life support.[10] Extubation near the time of death.[10] Promote family participation in the decisions regarding care and therapy.[22-24,30,32] Respect for the family and the patient.[26] Compassion at the time of saying goodbye (moment of death).[26] Care and attention to spiritual and/or religious needs.[16] Single room for the family.[24] Participation in family groups.[30]	Relatives who live directly with the patient.[13] Perception of professionals' lack of interest in providing information.[1] Non-inclusion and lack of support in decision-making.[31] Lack of preparation for transfer of family member to ICU.[27] Lack of comfort.[27]
Patient	
Improvement of quality of care at the end of life.[1,13,32] Older patients.[28] Courtesy and respect for hospitalized patient.[19]	Young patients.[28]
Institution	
Institutional culture in relation to end-of-life care.[15]	

Adaptation, validation and evaluation of the psychometric properties of scales

Three studies related to the process of adaptation and/or study of the metric properties of instruments proposed to evaluate the satisfaction of family members of patients attended at the ICU were identified. The Critical Care Family Satisfaction Survey (CCFSS) and Family Satisfaction in the Intensive Care Unit (FS-ICU) instruments were used.

The CCFSS instrument is used to measure satisfaction with intensive care. It is composed of 20 items related to satisfaction, each uses a Likert scale with five points (very satisfied to very dissatisfied), which form five subscales: guarantee, proximity, information, support and comfort, which includes quantitative data and qualitative characteristics of family members.[21]

The FS-ICU instrument is composed of 24 items that provide scores for overall satisfaction with care and decision making to evaluate the satisfaction of ICU care, regardless of the clinical outcome of the patient, and proposes the evaluation of the decision-making process and family-centered attention.[21]

A study developed in Turkey tested the FS-ICU, it evaluated the measurement properties of the instrument, which were applied to the relatives of patients who were in the ICU and presented high internal consistency (Cronbach's alpha 0.95) for the full scale, and showed to be reliable and was identified as a valuable evaluation tool (LoE III).[33]

In Saudi Arabia, the CCFSS was adapted and the reliability of the instrument was studied when it was applied to seven ICUs. Internal consistency was tested using the Spearman correlation coefficient and had scores of between 0.52 and 0.81. The overall mid-scale score was 20.5 indicating that the majority of respondents were satisfied with the care received in the ICU (LoE II).[18]

In order to evaluate the metric properties of the CCFSS with family members in Brazil, the internal consistency analysis was performed using Cronbach's alpha (0.91) and it was identified that the modified version of 14 items of CCFSS is reliable and valid and that the measures did not differ among family members of patients who received intensive care and who were exposed to the intervention compared to those who received usual care, even when given to family members at the onset of chronic illness, as well as at the time of ICU discharge (LoE III).[21]

DISCUSSION

When analyzing publications regarding the evidence on the satisfaction of family members of patients cared for in Intensive Care Units and the instruments used for the evaluation, diverse information on the subject was identified. Among the studies that aimed to evaluate family satisfaction, the objective of the present review, in relation to patient care in palliative care and the quality of death in the ICU, highlights the sum of evaluation strategies, that is to say, the application of instruments which can extend the study of the subject with the application of QODD and FS-ICU.[8-13, 28]

Faced with the variety of instruments, it is up to the professionals to understand each one and the need for evaluation, so that they can choose the one that would respond to their needs. Using strategies such as the application of more than one evaluation tool can complement existing information: for example, the use of an instrument to assess family satisfaction on care that a family member received in the ICU and an instrument to evaluate the quality of care at the time of death would contribute as a process of evaluation of actions/care offered in the ICU.

In a study[36] performed in a teaching hospital in the South of Brazil, with the objective to understand how nurses perceive the care provided to the terminal patient in a hospital setting, the authors highlight the need for an open dialogue with patients and their families in order to respect their desires, avoiding greater suffering, including the family in the care, offering support and comfort, especially in the dying process.

A survey carried out to identify the care of relatives of terminally ill patients considered the importance of honest dialogue, with understandable information as a tool to improve satisfaction. Emphasizing that the family of the patient in palliative care should have flexible visiting times, which could increase satisfaction, even if the patient is in the final stages of the dying process.[37]Accordingly, there is a greater family satisfaction with the care provided to those who died when compared to those whose clinical status improved.[38]

The satisfaction of family members with ICU care for patients who died was more satisfactory than those who improved and were discharged from the ICU.[38] It can be assumed that the families of severe patients in palliative care are more fragile and, therefore, would receive more attention from the professionals.

It is necessary that the health team understands that the hospital environment causes unease to the family, arousing feelings such as insecurity, helplessness and an immense desire to remain with the family member most of the time. At the same time, there is a need to understand and follow the changes in the clinical status of the hospitalized relative, as well as to participate in decision-making regarding treatment.[3]

Another study[37] which selected articles on the care of relatives of terminally ill patients in the ICU considered the importance of honest dialogue, with understandable information as a tool to improve family satisfaction. They also emphasize that, in relation to patients in palliative care, there should be differential treatment to family members, such as flexible visiting times, which could increase satisfaction even if the patient is in the final stage of the dying process.

Regarding the quality of care at the end of life, the QODD identified the desire of the family to participate in decision-making regarding orthothanasia (desirable death without anticipating or prolonging death).[39]

The association of satisfaction with care is clearly evident among the relatives, such as receiving clear information about the health conditions of the family member hospitalized in the ICU and regarding the attitudes and attention that the professionals give. Due to the need for family members to be informed, they are sensitive to the way they are received. Thus, if family members feel supported and have their needs fulfilled - by means of sincere dialogue and have their frailties considered - their satisfaction would be better, since it is suggested that the patients would also receive qualified attention, which could influence the satisfaction with the quality of death.

Seven studies were identified (25.9%)[8-13,28] that aimed to assess family satisfaction regarding patient care in palliative care and the quality of death in the ICU. Among them, five (18.5%) of the variables of interest (death quality and family satisfaction)[8,11-13,28] applied the QODD and FS-ICU.

The QODD has items arranged to more accurately measure the satisfaction of care in the process of death and dying.[8,11,13,28] In turn, the FS-ICU instrument, divided into two parts - satisfaction with care and satisfaction with decision-making - has specific items that assess the opinion regarding terminal patient care, as well as satisfaction and decision-making items.[8-9,11,13] The association of these instruments are strategies used by authors in order to obtain more reliable data. Thus, for greater precision and data reliability, similar instruments capable of evaluating variables that have similarity were sought.

The wide use of structured research instruments in different countries, adapted and evaluated for the metric properties of scales for subsequent application was evidenced.[18,21,35] These instruments present reliable and valid results, allowing comparisons of results in different populations.

The lack of a valid and reliable instrument to evaluate family satisfaction in Brazil is noted, which may contribute to the process of evaluating the quality of care offered to patients and their families in the ICU environment in Brazil. Also, it is necessary to improve the knowledge regarding the evaluation of family satisfaction with the care received by a family member and regarding the validation process of instruments proposed in different languages that can be applied in Brazil. The assessment of satisfaction among the family members, in an initial stage of hospitalization, would allow the health team working in the ICU, principally the nursing team, to plan and/or reformulate more targeted care actions, aiming at better results for both patients treated in the ICU, as well as for the accompanying family member.

It is also worth mentioning a study which was performed with the objective of identifying the degree of satisfaction of the relatives of patients hospitalized in intensive care units. The results indicate that the family members presented a high degree of satisfaction regarding general care, mainly associated with communication, attitude and care with the patient. The lowest satisfaction rates were related to the ability of ICU professionals to value the feelings of family members and to provide sufficient information about the equipment used by the patient.[1] On the other hand, another study which sought to describe the evaluation of the visitors regarding the quality of care provided in a general intensive care unit of a tertiary-level teaching university hospital, identified that, according to the family, communication failures represent the main factor that negatively interferes with the quality of service.[3]

Thus, the studies awaken the need to expand the communication possibilities established with the relatives, since it is a resource that brings them closer to the health professionals and facilitates the understanding of the clinical conditions of hospitalized patients, resulting in relief from suffering and comfort.

The lack of instruments validated in Brazil on family satisfaction in intensive care is identified as a limitation in this study, which results in a lower production of articles on the subject, in addition, it is estimated that if the search period was amplified for more than 10 years and if more databases were included, there would have been more articles to add to the discussion.

CONCLUSION

The results allowed to analyze the available evidence in the literature about the family members' satisfaction in ICU patients and the instruments used for the evaluation. In order to evaluate satisfaction, the authors used the following instruments: CCFS, FS-ICU, CCFNI and QODD, some authors used instruments as a strategy to better respond to the research objectives and to complement the study in a certain hospital institution. It was verified that all developed studies aimed at improving the quality of care, either through validated instruments or the use of instruments to test their metric properties for application at a later date.

The majority of the studies aimed to evaluate the family in relation to their satisfaction and needs, as well as the satisfaction with making decisions regarding procedures and patient care. Studies that evaluated satisfaction of family members of patients in palliative care had different methodologies, but all emphasized the need for improvements in the quality of care and patient comfort.

In addition, other relevant aspects referred to the skill and competence of nursing; withdrawal of life support and indicators of palliative care; and the caregiver at the end of life. It should be emphasized that family members who experience palliative care and participate in decision-making at the end of life may suffer from emotional stress, thus requiring the support of the nursing staff and other members of the ICU team.

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