

## UNVEILING FAMILY'S PERCEPTIONS ABOUT THE INTENSIVE CARE UNIT AS A PLACE OF DEATH

### DESVELANDO A PERCEPÇÃO DOS FAMILIARES A RESPEITO DA TERAPIA INTENSIVA COMO LUGAR DE MORTE

### REVELANDO LA PERCEPÇÃO DE LOS FAMILIARES SOBRE LA UNIDAD DE CUIDADOS INTENSIVOS COMO LUGAR DE MUERTE

Efigênia de Souza<sup>1</sup>, Miguir Terezinha Vieccelli Donoso<sup>2</sup>, Eline Lima Borges<sup>3</sup>

#### ABSTRACT

The Intensive Care Unit (ICU) is popularly view of the unit as place destined to die. **Objective:** This study aimed to understand the reasons why people consider the ICU environment as a place of death. **Method:** A meta-synthesis was conducted in order to answer the guiding question: what are the reasons why the families of ICU patients recognize this unit as a place to die? The descriptors used were Intensive Care Units; Death; Qualitative Research; Family and Patients. In the Virtual Health Library, 239 articles were found and, from those, 236 were excluded. This meta-synthesis sample was composed by three studies. **Results:** The results indicate that the reasons for people to perceive the ICU as a place to die are basically: social isolation; frightening environment; painful experience and overload feelings. **Conclusion:** We conclude that, in light of the reasons identified, humanization of the unit and interdisciplinary work may improve this process and contribute to a change of view of the family in relation to the ICU.

**Descriptors:** Intensive Care Units; Death; Qualitative Research; Family; Patients.

#### RESUMO

A Unidade de Terapia Intensiva (UTI) é vista popularmente como um local destinado para morrer e não para sobreviver. **Objetivo:** Este trabalho teve como objetivo compreender motivações das pessoas para considerar a UTI como ambiente para morrer. **Método:** Foi realizada uma metassíntese, para responder a questão norteadora: quais motivos levam a família de pacientes internados na UTI a reconhecer esta unidade como local para morrer? Os descritores utilizados foram Unidade de Terapia Intensiva; Morte; Pesquisa Qualitativa; Família e Pacientes. Obteve-se na Biblioteca virtual em saúde (BVS) um total de 239 artigos, sendo que 236 foram excluídos. Três artigos compuseram a amostra dessa metassíntese. **Resultados:** Os resultados indicam que os motivos que levam às pessoas a perceber a UTI como local para morrer foram basicamente: isolamento social; cenário amedrontador; experiência dolorosa e sentimentos de sobrecarga. **Conclusão:** Conclui-se que, em função destes motivos identificados, a humanização do setor e o trabalho interdisciplinar podem amenizar esse processo.

**Descritores:** Unidade de Terapia Intensiva; Morte; Pesquisa qualitativa; Família; Pacientes.

<sup>1</sup> Enfermeira, especialista em Assistência de Enfermagem de Média e Alta Complexidade, área de concentração em Terapia Intensiva. E-mail: geniasouzanp@yahoo.com.br.

<sup>2</sup> Doutora em Ciências da Saúde pela Faculdade de Medicina da Universidade Federal de Minas Gerais (UFMG), mestre em Enfermagem pela Escola de Enfermagem da UFMG, docente da Escola de Enfermagem da Universidade Federal de Minas Gerais. E-mail: miguirdonoso@uol.com.br.

<sup>3</sup> Doutora em Enfermagem Fundamental pela Escola de Enfermagem da Universidade de São Paulo (USP) de Ribeirão Preto, mestre em Enfermagem pela Escola de Enfermagem da UFMG, estomaterapeuta (TiSOBEST), docente da Escola de Enfermagem da UFMG. E-mail: eborges@ufmg.br.

## RESUMEN

La Unidad de Cuidados Intensivos (UCI) es vista popularmente como un lugar destinado para morir. **Objetivo:** Este estudio tuvo como objetivo comprender motivos de las personas para considerar la UCI como un ambiente para morir. **Método:** Fue realizada una meta-síntesis para responder a la pregunta de investigación: ¿cuáles son las razones por las cuales la familia de los pacientes internados en la UCI reconocen esta unidad como lugar para morir? Los descriptores utilizados fueron Unidad de Cuidados Intensivos; Muerte; Investigación Cualitativa; Pacientes y Familiares. Se obtuvo un total de 239 artículos, de los cuales 236 fueron excluidos. Tres artículos fueron utilizados en esta meta-síntesis. **Resultados:** Los resultados indican que los motivos que hacen a las personas pensar sobre la UCI como un lugar para morir fueron básicamente: aislamiento social; ambiente espantoso; experiencia dolorosa; sensaciones de la sobrecarga. **Conclusión:** Se concluye que la humanización del sector y el trabajo interdisciplinario puede mitigar este proceso.

**Descriptores:** Unidad de Cuidados Intensivos; muerte; La investigación cualitativa; Familia;

## INTRODUCTION

The Intensive Care Unit (ICU) is a functionally grouped structure with specialized human resources and materials, intended to provide continuous care to severe patients. The first units were installed in Brazil in the 1970s, due to the need for technologies associated with scientific knowledge for the care of highly complex patients.<sup>1</sup>

The experience of hospitalization in an ICU makes patients and their families reflect on life, especially regarding autonomy. The more monitored the patient is, the more distressing it is for the family, who feels the need to be welcomed, needing to receive information about the loved one and seeking empathy in the team. Although the ICU is the ideal place to attend to critical patients, the technological resources available there for patient maintenance and survival and the

work dynamics of the intensive care team cause great stress and distress to patients and families.<sup>2</sup>

In the ICU environment, everything happens in a very intense way, the patient depends on sophisticated machinery and equipment and human relations are impaired to the detriment of advanced technology. When faced with a family member who is naked and invaded by threads and tubes, the family is distressed by the uncertainty of what may happen and the fear of losing the loved one.

Our society is not prepared to cope with human finitude. One is not educated for death, although the anguish related to the possibility of death is present in the daily life of people (patients and relatives) because of being in an ICU, medicine itself is linked to healing in a high-tech unit.<sup>3</sup> The relationship between the ICU and imminent death figures as a harmful

component of patient treatment and of the family members' reaction.

Being hospitalized at the ICU entails a cultural meaning. The patient and family believe that ICU hospitalization is a synonym of imminent death.<sup>2</sup> Thus, the research problem was established: relatives of patients admitted to the ICU consider this unit an environment to die.

Thus, the objective of this study was to identify in the literature reasons that lead the family of patients hospitalized in ICU to consider this unit as an environment to die. Understanding the reasons that made the family of ICU patients perceive this place as a place to die becomes fundamental to clarify the process of being hospitalized at the ICU.

This work will favor reflections for nursing on ways to present to the user and family the ICU as an advanced place of treatment and, therefore, of life expectancy, not a place destined for the person to die.

## **METHOD**

This work used the metasynthesis as a methodological framework, as it allows us to analyze primary studies with different types of design on the subject of interest.

Qualitative research involves an interpretive and naturalistic approach to the world. It seeks to explore how people give meaning to the world around them, who they are, and how they present this and respond to others. The complexity of qualitative research stems from the fact that there is no single strategy for its methodological and interpretive development. The possibilities of qualitative research are recognized in the investigation of attitudes, beliefs and preferences of professionals and patients.<sup>4</sup>

Why the metasynthesis? Because this study involves meanings, which are explained through qualitative research, being a subject linked to subjectivity. Qualitative research originated in anthropology and sociology and seeks answers to questions that are not easily found in the experimental methodology. It is defined as an activity that places the observer in the world and brings an interpretative approach.<sup>4</sup>

The metasynthesis is an interpretive integration of qualitative results that are by themselves the interpretative synthesis of data, including phenomenology, ethnography, grounded theory, as well as other theoretical, coherent and integrated frameworks or explanations of certain phenomena, events, or cases that are the hallmarks of qualitative research. These

integrations go beyond the sum of the parts, offering a new interpretation of the results. These interpretations cannot be found in any research report, but are inferences derived from considering all the articles in a sample as a whole.<sup>5</sup>

The goal of meta-synthesis is to take into account all important similarities and differences in language, concepts, images and other ideas surrounding a given experience; broadening the interpretative possibilities of the results and constructing extended narratives or general theories. Metasynthesis can broaden the scope of results deriving from the subjects' perception, feelings, vision and experiences.

The research problem gave rise to the following guiding question: what are

the reasons that make family members of ICU patients acknowledge this unit as a place for the patient to die? To compose the sample, the studies should comply with the following criteria: qualitative studies in Portuguese, English or Spanish; published between 2004 and 2013 in scientific journals and which discussed the link people (patients and family members) establish between death and ICU hospitalization. An advanced research was undertaken, crossing the descriptors "Intensive Care Units; Death; Qualitative Research; Family; Patients". To combine the descriptors, the Boolean operator AND was used.

### Chart 1: Search strategy

Database	Descriptors	Number of articles found	Number of articles selected
<b>Lilacs</b>	<i>Unidade de Terapia Intensiva AND Morte AND Pesquisa Qualitativa .</i>	11 articles	03 articles
	<i>Unidade de terapia intensiva AND Morte AND Família</i>	24 articles	zero articles
	<i>Unidade de terapia intensiva AND Morte AND Pacientes</i>	204 articles	zero articles
	<b>Total Lilacs</b>	<b>239 articles</b>	<b>03 articles</b>
<b>MEDLINE</b>	<i>Unidade de Terapia Intensiva AND Morte AND Família e Pacientes</i>	zero articles	zero articles
	<i>Unidade de Terapia Intensiva AND Morte AND Pesquisa Qualitativa</i>	zero articles	zero articles
<b>Total MEDLINE</b>		<b>Zero articles</b>	<b>Zero articles</b>

The databases consulted were Medline and Lilacs. In total, 239 articles were obtained from the VHL Virtual Health Library. After reading the titles, 57 articles were obtained. These were subjected to a careful reading of the abstracts, aiming for a global understanding and discovery of the approach the authors had used and the identification of the central ideas of each article.

Of the 57 articles obtained, 54 were excluded for the following reasons: eight were repeated, 17 were publications prior to 2004, one was a reflective instead of a research article, one was an article resulting from the same research that produced one of the articles already selected, and the other 28 did not address the research question, that is, "what are the reasons why the family members of ICU patients recognize this unit as a place for the patient to die?"

On the whole, three articles were selected that corresponded to the guiding question and will be presented and discussed in the development of this study in the form of synoptic tables.

To conduct the study, a data collection instrument was developed, which was completed for each article to facilitate the subsequent analysis of the data obtained. The instrument permitted

the identification of the publications' methodological design, sources, year of publication, profession and degree of the authors and the conclusion of the authors about the reasons that made the family members of ICU patients recognize this unit as a place for the patient to die. To evaluate the quality of the articles, the Critical Appraisal Skills Program (CASP) tool was used.<sup>6</sup>

A qualitative analysis of the selected articles was carried out in the framework of the research problem. The analysis was carried out in two stages: in the first, the identification data of the publication and the author were evaluated. In the second, the question of interest was analyzed: reasons that made people to recognize the ICU as a place for the patient to die. The results are presented in the form of synoptic tables. For the sake of easy reading, the papers were coded as Article 1, Article 2 and Article 3.

## RESULTS

The selected articles were published in the following journals: *Revista Brasileira de Terapia Intensiva* (Article 1), *Revista de Pesquisa: Cuidado e Fundamental* (Article 2) and *Revista Gaúcha de Enfermagem* (Article 3).

From the three articles obtained, two used phenomenology as the theoretical

framework (Articles 1 and 3) and one used Bardin's content analysis (Article 2).

Phenomenology seeks to understand the research phenomenon, without worrying about explanations and generalizations. The researcher is not part of a specific problem, but conducts the research based on an inquiry about a phenomenon, which needs to be situated, that is, being experienced by the subject. Phenomenology originated as a movement in philosophy, being later applied to the human sciences. In nursing, the use of phenomenology also represented a search for an alternative research method.<sup>7</sup>

Content analysis is defined by Bardin as a tool for the study and analysis of qualitative material, which permits the understanding of a communication or discourse, extracting the most relevant aspects.<sup>8</sup>

Regarding the authors' educational background, this varied, the authors being nurses, physiotherapists, medical students (Article 1) and nurses (Articles 2 and 3).

The degree of the main author varied among Ph.D., M.Sc. and B.Sc. In one article, undergraduate students (nursing and medicine) participated.

In qualitative research, the definition of the sample is not numerical, based on statistical data, like in quantitative research. In this

metasynthesis, in all articles, the sample was defined by the saturation criterion. Saturation sampling is a conceptual tool often used in qualitative research reports in different areas in the health field, among others. It is used to establish or close the final size of a study sample, interrupting the capture of new components.<sup>9</sup>

All articles were published in Brazilian journals, and the Qualis levels were B1 (Article 3) and B2 (Article 1 and Article 2).

The participants in the three studies, that is, the research samples were composed of relatives of ICU patients.

For a better understanding, the articles are presented in the form of synoptic tables (Chart 1):

**Chart 2: Description of the publications included in the metasynthesis**

Title	References	Design	Thematic categories produced
<b>Article 1</b> Experiences of family members of ICU patients	Urizzi, Fabiane et al. Vivências de familiares internados em Unidade de Terapia Intensiva. Rev. Bras. Ter. Intensiva [online]. 2008; 20(4):370-5.	Phenomenology	<b>At ICU of private hospital:</b> <ul style="list-style-type: none"> <li>• Difficult, painful, wordless experience;</li> <li>• Putting oneself in the other's place and perceiving the other; approximation of the patient's suffering;</li> <li>• Rupture of the relation with the family's daily life;</li> <li>• Fear of the family member's death;</li> <li>• ICU: feared, but necessary environment;</li> <li>• Concern with care for the family member.</li> </ul> <b>At ICU of public hospital:</b> <ul style="list-style-type: none"> <li>• Difficult, terrible and painful experience;</li> <li>• ICU – environment that offers fear and care;</li> <li>• Change in family's daily life;</li> <li>• Possibility of death.</li> </ul>
<b>Article 2</b> Perceptions and needs of family members of ICU patients	Camponogara S, Santos TM, Rodrigues IL, Frota L, Amaro D, Turra M. Percepções e necessidades de familiares de pacientes internados em UTI. J. Res.: Fundam. Care. Online, 2013.	Content analysis	<ul style="list-style-type: none"> <li>• Perceptions of family members about ICU: contradictory feelings;</li> <li>• The family's needs: care demands;</li> <li>• Communication between family members and health team.</li> </ul>
<b>Article 3</b> Phenomenon experienced by Family members of ICU patients	Comassetto I, Enders BC. Fenômeno vivido por familiares de pacientes internados em Unidade de Terapia Intensiva. Rev Gaúcha Enferm. 2009; 30(1):46-53.	Phenomenology	<ul style="list-style-type: none"> <li>• Fear of family member's death;</li> <li>• Absence of humanization;</li> <li>• Social isolation;</li> <li>• Trust in ICU;</li> <li>• Burden in personal life.</li> </ul>

**Chart 3: Articles and respective scores on the Critical Appraisal Skills Program – CASP tool**

Article	CASP
Article 1	A
Article 2	A
Article 3	A

## DISCUSSION

The separation of the family emerged in Article 1, and was also referred to in Article 3 as social isolation. The hospitalization period at the intensive care unit requires the family's separation from the loved one, as visits take place at predetermined times and a companion is not allowed in the sector.<sup>10</sup> The complexity of the unit may make it impossible for the family to stay constantly, restricting their stay to visiting hours. The expansion of the time for visiting family members could be optimally increased so that care would not be adversely affected, to the detriment of a companion, who obviously questions, speaks up and demands more time from the professionals.

As noticed in the three articles, the ICU figures in the people's imaginary as something complex, frightening, which isolates and

differentiates patients as potentially "moribund". But the literature presents alternatives, especially with regard to humanization. It is recalled that implementing a humanization process in the interdisciplinary field of health, based on ethics, implies the rescue of the human dimension in work relations and its permanent problematization.<sup>11</sup> The same literature states that ethics requires the implementation of a reflective process about the principles, values, rights and duties that govern the health professionals' practice, including the dimension of care considered as humanized. Thus, one can no longer conceive care without reflecting on the humanization process, not only in the ICUs, but in any hospital service.

The rigorous routine of the sector appears in nuances in Articles 1 and 3, the former referring to the intensive care environment as a feared scenario.



It is believed that the equipment contributes to a mechanized environment. Due to its specificity and the great technological diversity of nursing care, the ICU contains many peculiarities that distinguish it from other services. The ICU contains qualified personnel and offers continuous care, using sophisticated devices capable of maintaining the patient's survival.<sup>12</sup> This fact may be "mechanizing" the ICU. In addition, there is the aspect of the ICU as a place for quick and effective decision-making and action (if possible). On the one hand, there is the apparatus necessary to save lives and the strict routines of the patient care teams. On the other hand, there is the possibility of death, the severity of the critical patient and the suffering of his family.<sup>13</sup> Again, the need for humanization appears between the lines, as the strict routines and apparatus could coexist in a systematized manner, without mechanizing the care though.

The patient's isolation was recurrent and emerged in Articles 1 and 3. The family's participation in the ICU is more delicate, as the environment itself restricts the presence of visitors and companions. Nevertheless, there is an ongoing trend to reduce this aspect

of ICU hospitalization. At least in the pediatric intensive care units, this reality has been modified and changes are observed in the daily life of these units in the behavior of the professionals involved in the care, who have been adopting a care model centered on patients and their families.<sup>14</sup>

The emotional burden emerged in all three articles in various ways: suffering, fear and anxiety, among others. The relationship with the hospital staff may evolve towards a tighter bond though, as soon as the family feels understood and attended in its needs.<sup>15</sup> Thus, interdisciplinarity is once again an alternative to alleviate the suffering of patients and families.

The lack of humanization emerged in Article 3. The "non-humanized" dimension of science and technology occurred as the use of depersonalized objects and an investigation that was proposed as cold and objective increased.<sup>16</sup> The environmental issue itself makes the unit "cold". This can be mitigated by the humanization of care. The complexity of care, however, cannot de-characterize the human dimension that needs to be the basis of any health intervention process, mainly with regard to the intended humanization of a hospital.

The following question is raised: how can one speak of care humanization if the workers themselves are often treated in an inhumane way?<sup>11</sup> Thus, the adaptation of the ICU to a humanized unit, to the detriment of the "coldness" transmitted by the characteristics of the structure and dynamics of the sector deserves reconsideration and re-elaboration.

The term "cold environment" also emerged in all three articles, although this term has not been reported as a category. In a study about the use of colors in the intensive care setting, the authors discuss the aspect of aesthetics as a route to consider in the ICU and that advocates the care attributed to the environmental conditions. According to the authors, health professionals should seek and implement measures that promote their own physical and emotional wellbeing and that of their staff, patients and families.<sup>17</sup> The ICU environment is naturally cold, favoring even the discomfort of the people circulating in the unit. A humanized environment, making use of colors, for example, could promote a less cold aspect of the ICU.

Finally, it is recalled that the word death encompasses many

attributes and associations: pain, rupture, interruption, ignorance, sadness.<sup>18</sup> The severity of the patients in the intensive care unit implies the possibility of death. Nurses should know when and how to address the issue of finitude. The ICU is not synonymous with finitude though, but with a unit with greater resources to treat and take care of people. Keeping the patient - when possible - informed about the care plan and the evolution of the disease through interdisciplinary work facilitates the understanding of the process, i.e. the patient is fragile, but this is not a synonym of death. In a reflective article on this theme, the authors show the evolution in the meaning of death, while the aim is to understand the patients' and their relatives' feelings towards the ICU hospitalization. They reflect on the concerns that permeate their experiences with families of patients hospitalized in the ICU, being a nurse and a psychologist. The authors further point out the need for interdisciplinary work, systematizing and individualizing care.<sup>13</sup> Perhaps this triad (interdisciplinarity, systematization of care and individualized care, considering the individual as singular) can ease the trauma of the patient, and

consequently of the family. The nursing professional is essential in the training and monitoring of this triad, recalling that the hospital needs to improve and monitor its processes.<sup>19</sup>

## CONCLUSIONS

As a result of the technical and scientific process in the context of care at the intensive care unit, human dignity and interpersonal relationships seem to have been relegated to the background. Nevertheless, the health professionals' awareness and concern with the emotional and spiritual aspect of patient care is noticed. In the articles analyzed, the importance of family involvement and clarification to the patients about

injuries and propaedeutics - whenever possible - is perceived.

Interdisciplinarity in harmony and humanization are aspects that appear, even though between the lines, as alternatives to demystify the ICU as being a place for critical patients to die. This conception starts to transform itself based on health professionals' simple behaviors, and nursing plays a fundamental role in this process. Clarification can be obtained through conversations and greater attention to the emotional aspect of those involved. A mere look can simply comfort the patient and his family.

## REFERENCES

1. Ferreira PD, Mendes TN. Família em UTI: importância do suporte psicológico diante da iminência da morte. *Rev SBPH*. 2013; 16(1):88-112.
2. Marques FRD, Botelho MR, Matos PCB, Waidman MAP. Morte em uma unidade de terapia intensiva: a visão da equipe multidisciplinar em relação ao paciente e ao corpo. In: VII Encontro Internacional de Produção Científica CESUMAR; 2011; Maringá. Maringá: Centro Universitário de Maringá; 2011.
3. Kovács MJ. Desenvolvimento da tanatologia: estudos sobre a morte e o morrer. *Paidéia*. 2008; 18(41):457-68.
4. Lopes ALM, Fracolli LA. Revisão sistemática de literatura e metassíntese qualitativa: considerações sobre sua aplicação na pesquisa em enfermagem. *Texto & Contexto Enferm*. 2008; 17(4): 771-8.
5. Sandelowski M, Barroso J, Corrine I. Using qualitative Metasummary to Synthesize Qualitative Descriptive Findings. *Res Nurs Health*. 2007;30(1):99-111.
6. Critical Appraisal Skills Programme (CASP): making sense of evidence. Public Health Resource Unit. England; 2006 [cited 19 set 2018]. Available in: [www.cfkr.dk/images/file/CASP%20instrumentet.pdf](http://www.cfkr.dk/images/file/CASP%20instrumentet.pdf)
7. Correa AK. Fenomenologia: uma alternativa para pesquisa em enfermagem. *Rev Latinoam Enferm*. 1997; 5(1):83-8.
8. Bardin L. *Análise de conteúdo*. 70ed. Lisboa: Edições 70; 2009.
9. Fontanella BJB, Ricas J, Turato ER. Amostragem por saturação em

- pesquisas qualitativas em saúde: contribuições teóricas. *Cad Saúde Pública*. 2008; 24(1):17-27.
10. Vieira CAL, Marques GH. Morte, angústia e família: considerações psicanalíticas a partir da Unidade de Terapia Intensiva. *Psicanál Barroco Rev*. 2012; 10(1):97-108.
11. Backes DS, Lunardi VL, Lunardi Filho WD. A humanização hospitalar como expressão da ética. *Rev Latinoam Enferm*. 2006; 14(1):132-5.
12. Aguiar ASC, Mariano MR, Almeida LS, Cardoso MVLML, Pagliuca LMF, Rebouças CBA. Percepção do enfermeiro sobre promoção da saúde na Unidade de Terapia Intensiva. *Rev Esc Enferm USP*. 2012; 46(2):428-35.
13. Millani HFB, Valente MLC. A família e a internação em UTI: a doença e a morte no Hospital Regional de Assis – SP. *Nursing*. 2008; 11(120):235-42.
14. Molina RCM, Fonseca EL, Waidman MAP, Marcon SS. A percepção da família sobre sua presença em uma Unidade de Terapia Intensiva Pediátrica e Neonatal. *Rev Esc Enferm USP*. 2009; 43(3):630-8.
15. Pinto JP, Ribeiro CA, Silva CV. Procurando manter o equilíbrio para atender a demanda e cuidar da criança hospitalizada: a experiência da família. *Rev Latinoam Enferm*. 2005; 13(6): 974-81.
16. Marques IR, Souza AR. Tecnologia e humanização em ambientes intensivos. *Rev Bras Enferm*. 2010; 63(1):141-4.
17. Boccanera NB, Boccanera SFB, Barbosa MA. As cores no ambiente de terapia intensiva: percepções de pacientes e profissionais. *Rev Esc Enferm USP*. 2006; 40(3):343-9.
18. Medeiros LA, Lustosa MA. A difícil tarefa de falar sobre morte no hospital. *Rev SBPH*. 2011; 14(2):203-27.
19. Silva LGC, Haddad MCFL, Vituri DW, Jodas DA, Otrenti E. Dez anos buscando a melhoria da qualidade do

cuidado de enfermagem em um hospital universitário. *Rev Enferm Atenção Saúde*. 2012; 1(1):44-56.

RECEIVED: 08/08/14  
APPROVED: 20/08/18  
PUBLISHED: 09/18