

## REVIEW

**Family impact on the recovery of critically ill adults: a review of the literature****Impacto familiar en la recuperación de personas adultas críticamente enfermas: una revisión de la literatura****Impacto familiar na recuperação do adulto criticamente enfermo: uma revisão de literatura**Paula Ceballos-Vásquez<sup>1\*</sup> <https://orcid.org/0000-0002-3804-5146>María Fernanda Campos-Fuentes<sup>2</sup> <https://orcid.org/0000-0002-3101-7070>Valentina González-Alegría<sup>3</sup> <https://orcid.org/0000-0001-6379-9030>Camila Lobos-Lavín<sup>4</sup> <https://orcid.org/0000-0003-1128-462X>

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**Received:** 02/05/2020**Accepted:** 08/03/2021**Abstract**

**Introduction:** Critical care units are described by the families of hospitalized individuals as a secluded place, with restricted access, where the severity and complexity of the patient is paramount. Despite evidence of how important it could be to consider and include family members in the recovery of critically ill persons, this has been undervalued and is difficult to achieve due to the complex conditions of these units. **Objective:** To identify in the literature the impact that the family has on the recovery of hospitalized adults in intensive care units. **Methodology:** Literature review in the CINAHL Complete, Scopus, PubMed and Scielo databases, by searching for the 2014 to 2019 period of time. **Results:** 9 articles were analyzed and based on critical reading the most

relevant aspects were selected for study. Regarding the distribution by years, 33.3% of the articles were published in 2016. Regarding geographical distribution, 44.4% of the selected manuscripts were written in Europe. **Conclusion:** There is a research gap that relates the impact of the family on the recovery of the patient. The identified studies show data with positive trends. However, these trends emerge in an indirect way. Therefore, it is proposed to carry out studies that provide innovative strategies with concrete results to verify these benefits, which can be applied in other intensive care units.

**Key words:** Rehabilitation; Patient; Family; Critical Care (DeCs).

### Abstrato

**Introdução:** As unidades dos pacientes críticos são descritas, pelas famílias, dos hospitalizados como um lugar separado, com acesso restrito, em que a gravidade e a complexidade do usuário é prioridade. Embora, exista evidências que poderia ser importante incluir os familiares na recuperação dessas pessoas, criticamente enfermas, isso é subvalorizado e difícil de acontecer, devido as condições complexas dessas unidades. **Objetivo:** Identificar o impacto na literatura que tem a família na recuperação das pessoas adultas hospitalizadas em unidades de cuidado intensivo. **Métodos:** Revisão de literatura nas bases de dados CINAHL completo, Scopus, Pubmed e Scielo. O período da busca foi de 2014 a 2019. **Resultados:** Foi analisado 9 artigos, os aspectos mais relevantes dos estudos foram descritos. Em relação a distribuição temporal, 33,3% foram publicados no ano de 2016. Quanto a distribuição geográfica, 44% das produções foram realizadas na Europa. **Conclusão:** Existe uma lacuna de estudos que relacione o impacto que as famílias causam na recuperação, os dados favoráveis se obteve de maneira indireta aos estudos encontrados. Se propõe realizar estudos que forneçam estratégias inovadoras, com resultados concretos para verificar os benefícios e que sejam aplicáveis em todas unidades de tratamento crítico.

**Palavras-chave:** Reabilitação; Paciente; Família; Cuidados Intensivos (DeCs).

## Introduction

Intensive care units are described by the families of the patients hospitalized in them as a cold and distant place, with restricted and exclusive access, where the severity and complexity of the ill person is paramount, which is why the family and friends are excluded, with the idea of providing better clinical care to the critically ill person <sup>(1-3)</sup>. Some authors indicate that intensive care units are distinguished from other hospital areas by a high staff-to-patient ratio and access to advanced technological equipment that is not routinely available elsewhere in the hospital <sup>(4)</sup>. Therefore, the complexity of these units could generate objections regarding free access for families; however, extending visiting hours in intensive care units and the participation of the family in planning the care of the critically ill person have been recommended by



international societies and health organizations. As stated by the Italian National Bioethics Committee (INCB), which highlighted the fact that a liberalization of visiting policies is a concrete expression of the principle of respect for the person, and is consistent with the principles of autonomy, beneficence and nonmaleficence <sup>(5)</sup>. According to the INCB and based on scientific knowledge, the presence of loved ones at the bedside in no way constitutes a threat to the patient; on the contrary, it has a beneficial impact on both the patient and the family. In particular, the INCB states that "from an ethical point of view it is unjustifiable not to perform a positive action that can provide benefits for the patient, except in absolutely exceptional cases". Only ethical and clinical reasons of serious health risks can justify the restriction of visits <sup>(5)</sup>.

Despite these recommendations and scientific evidence, visiting hours are still restricted in most intensive care units in many countries <sup>(6)</sup>. There are studies that reveal the importance of involving families in the rehabilitation settings in order to optimize outcomes. The probable benefits include redirecting family psychological distress to a participatory-active role, humanizing the patient's illness and recovery experience, supporting the healthcare system and staff beyond the constraints of therapy time <sup>(7)</sup>.

Given the complexity of intensive care units and the latent need to improve the health of critically ill people, the aim is to identify and demonstrate the impact that the family has on the recovery of patients in these units. By supporting the positivism of such activity, future guidelines and sustainable theoretical evidence can be proposed and established as a strategic tool to provide holistic care. The objective of this work was to identify in the literature the impact that the family has on the rehabilitation and recovery of adults hospitalized in intensive care units.

## **Methodology**

A review of the literature was carried out to answer the question: What impact does the family have on the rehabilitation of adults hospitalized in the intensive care unit? The PICOT strategy was used to structure



the question <sup>(8)</sup>. The CINAHL Complete, Scopus, PubMed and Scielo databases were used for the review, with 4 descriptors consulted in Spanish and English in the Health Sciences Descriptors (DeCS) and Medical Subject Headings (MeSH). First, the descriptors listed in Table 1 were selected. It should be noted that for a broader search "Rehabilitation" was used as a synonym for "Recovery".

Table 1: DeCs and MeSH descriptors:

Descriptors	MeSH	Descriptors	DeCs
<i>Rehabilitation</i>	Indexed	Rehabilitación	Indexed
<i>Patient</i>	Indexed	Paciente	Indexed
<i>Family</i>	Indexed	Familia	Indexed
<i>Critical Care</i>	Indexed	Cuidados Críticos	Indexed

*Source: Own development.*

The aforementioned databases were used with the Boolean AND, including the 4 keywords in the following order: rehabilitation AND patient AND family AND critical care, in order to perform a general search. The search was limited by the following items: published between 2014 and 2019, original research, adult and nursing category, excluding the pediatric category. The stages of this manuscript were: formulation of the question, search for information in the literature using search engines and electronic databases, analysis of the literature and reporting of the results. For data collection we used an instrument developed by us that included the following items: identification of the authors, title of the article, objectives of the manuscript, and results or conclusions relevant to the review and conclusions.

Thus, a total of 46 articles were obtained in CINAHL Complete, 353 articles in Scopus, 632 articles in PubMed and 13 articles in Scielo. Based on this, we narrowed down the searches through the selection criteria (inclusion and exclusion) and changed the order of the keywords. Four articles were selected from CINAHL Complete, 7 from PubMed, 5 from SCOPUS and 2 from Scielo. The 18 selected articles were thoroughly reviewed in order to obtain information regarding the objective of the review, in which a



critical analysis and confirmation of the inclusion and exclusion criteria were carried out, so that 9 articles were selected for this review.

## Results

Regarding the distribution by years of the selected articles, it is highlighted that 33.3% of them were published in 2016 and 22.2% in 2019. Regarding the geographical distribution, 44.4% of the selected manuscripts were produced in Europe, while 33.3% of the articles were produced in Australia and only 11.1% were produced in Latin America. The Table 2 lists in chronological order of publication each article selected for this review, which allowed a comparative reading between them, comparing the objectives and conclusions obtained by each author.

Table 2: Summary of articles selected for the narrative review after the application of inclusion criteria and critical reading (n=9).

<b>Name of study/ Place and year of publication</b>	<b>Objectives</b>	<b>Conclusions and/or results</b>
<b>E.1</b> From spouse to caregiver and back: a grounded theory study of post-intensive care unit spousal caregiving/ Denmark, 2015 <sup>(9)</sup> .	To explore the challenges and caregiving activities that spouses must perform and cope with during the first year of recovery of patients hospitalized in intensive care units.	The informal caregiver (spouse) addresses the primary concerns and needs of their loved one to promote recovery while maintaining couple and social life. This study shows that the caregiver engages in a dynamic process consisting of 4 elements: committing to the patient's care, acquiring caregiving skills, negotiating the level of care, and gradually abandoning the caregiving role in the advanced process of recovery. The vital support provided by informal caregivers and their active role in the entire recovery process is emphasized. However, it is necessary for health personnel to provide support to family members and spouses after the patient's discharge. Healthcare professionals, both in and out-of-hospital, are encouraged to provide information and support from admission to post-discharge recovery.



- E.2** Restrictive visiting/non-restrictive visiting for adults in an intensive care unit/Chile, 2016 <sup>(10)</sup>. To demonstrate the impact of restrictive and non-restrictive visiting for the family and healthcare personnel, on the health of patients in intensive care units. Visiting in intensive care units continues to be a topic of global debate and is left to the criteria of each healthcare institution. This study concludes that non-restrictive visiting generates numerous benefits, favoring the patient's physical and emotional recovery. Likewise, the family shows greater satisfaction with the personnel and the healthcare system by having a flexible visiting schedule, always respecting and giving priority to the patient's medical treatment. As already mentioned, the system of visiting in the units will depend on the internal protocols of each hospital and its culture, so it is necessary to generate new evidence to concretely validate the benefits of families in the recovery of critically ill patients.
- E.3** What factors affect the implementation of early rehabilitation into intensive care unit practice? - A qualitative study with clinicians/ Australia, 2016 <sup>(11)</sup>. To identify factors (barriers and facilitators) that influence the implementation of early rehabilitation in patients in intensive care units. Early rehabilitation applied to people hospitalized in intensive care units has benefits that lead to a safe, prompt and effective recovery. The study exposes factors that act as barriers and facilitators for the application of early rehabilitation, among which the expectations of the health team and the previous knowledge they have stand out, as well as the patient's factors. Both are united in the importance of transmitting to family members the importance of rehabilitation as a vital process in recovery, being the family a central element that has an impact on prognosis, motivation, sedation, delirium and the family relationship. Physicians recognize the need to educate the health care team as a strategy to level knowledge and thus recognize family members as a positive factor in the recovery of patients. On the other hand, barriers such as lack of time, personnel and resources are mentioned; these factors must be changed for a future improvement plan. Finally, it is recognized that rehabilitation is not the responsibility of a single discipline but rather of a multidisciplinary team.
- E.4** Building bridges between healthcare professionals, patients and families: A coproduced and integrated approach to self-management support in stroke/ London, 2016 <sup>(12)</sup>. To deepen understanding of how self-management support to the family can become an integral part of daily care and rehabilitation. Family self-management in the Intensive Care Unit (ICU) implies that professionals must develop skills and supportive relationships with the family of critically ill persons in order to carry out efficient practices that respond to their needs. This type of approach has been shown to enhance values that prioritize association between patients, family members and professionals. There is a need to implement self-management to improve engagement and success with more flexible and open approaches and methods.



- E.5** Seeking to humanize intensive care / Spain, 2017 <sup>(13)</sup>. To present the aspects of the HU-CI Project, humanization for the patient, family and healthcare team. Technological advances in ICUs have grown enormously, but it seems that the most essential aspect, the patient and his environment, has been left aside. Having an organized work dynamic, with strategic guidelines, and a committed and humanized attitude allows us to be more aware of the vulnerability and needs of critically ill people and their families. This is achieved through the HU-CI Project, which covers different areas of work, such as visiting hours, communication, patient wellbeing, family participation, among others. It points out that the flexibility of visiting hours and communication are beneficial aspects for patients, families and healthcare personnel, and are the easiest to implement. This point is supported by effective communication, which is the main need expressed by the families due to the high emotional burden associated with stress, anxiety and depression; this effective communication allows for an environment of trust and respect, as families feel involved in the care and decision making process, giving them the possibility of contributing to the recovery of their critically ill family member. It is imperative to search for more evidence to eradicate entrenched policies to distance families, and on the contrary, we must bring them closer to the units and make them participate in the care to enhance the patient's recovery.
- E.6** Evaluating the past to improve the future – A qualitative study of ICU patients' experiences/ Norway, 2017 <sup>(14)</sup>. To investigate how adult patients in intensive care units experienced recovery and rehabilitation during their stay, and at their discharge. Patients admitted to the intensive care unit describe their hospitalization as "unreal and strange" trips as they went from reality to delirium. They describe physical and psychological alterations during their stay. All patients coped with the ICU in different ways, some highlighted elements that allowed them to remember, such as the diary and photographs evidencing their stay in the ICU, while others preferred to forget the stay and move on. The provision of information in brochures was highly valued by the patients and their families, as it helped them to cope and understand that their experience in this unit was considered normal. The study considered that ICU survivors and their families should be included in the care through delivery of informational materials and rehabilitation programs. During their recovery, it was noted that patients valued their family members as their main source of information, especially after their hospitalization, since, with their accompaniment during hospitalization and their stories, they provided reassurance and support.
- E.7** Engaging families in rehabilitation of people who are critically ill: An To explore why the family should be involved in participating There is scarce information regarding the involvement of families in the rehabilitation/recovery of intensive care users.



underutilized resource/ Australia, 2018 <sup>(7)</sup> .	in the recovery of patients hospitalized in intensive care units.	The importance of generating data to help better understand how families might support recovery is mentioned. It is emphasized that in order to empower families in the rehabilitation framework, it is necessary to be open and willing to learn from patients and their families, as they have the potential to lead to improved outcomes, so a shift in the approach of health personnel to a family-centered paradigm must be made. Topics such as rehabilitation, emotional health, support, companionship, and the ability of the personnel to do such things are mentioned. Future research is recommended to explore this area further, as barriers need to be considered.
<b>E.8</b> Family in rehabilitation, empowering careers for improved malnutrition outcomes: Protocol for the FREER pilot study/ Australia, 2019 <sup>(15)</sup> .	To determine if the family is important in rehabilitation and if its empowerment presents an improvement in the nutrition of patients hospitalized in intensive care units.	The family is an underutilized resource for the recovery of the critically ill patient. Family in Recovery and Empowered (FREER) proposes to establish a relationship between the main caregiver and the healthcare team in charge to meet nutritional demands and training, providing them with long-term care tools, thus empowering and giving commitment to the caregiver. Developing attractive research is encouraged, as it could lead to changes in critical care units.
<b>E.9</b> Nurture-Empower-Support: A Human-Centered Approach to Understand and Support ICU Families/ USA, 2019 <sup>(4)</sup> .	To investigate how interventions in intensive care units can facilitate support for families of hospitalized patients.	Six types of needs experienced by family members during the hospitalization process of a critically ill person emerge as results of this study, such as the need for continuous emotional support during hospitalization, increased awareness of family members by the healthcare team, the pursuit of building relationships with the professionals, the need to support the team, the need to be included and be part of the care, and the need to take care of themselves. Therefore we speak of Nurture-Empower-Support (NES) which describes how to: Nurture, giving priority to providing knowledge to the patient care team and the family, Authorize, offering and granting supplementary help based on the patient's health status, and Support for the families, so that they can contribute to the health care team and the ill person.

Source: Table prepared by the authors.

## Discussion

This literature review has the objective of identifying the impact that the family has on the rehabilitation and recovery of adults hospitalized in intensive care units. Physical, psychological and emotional aspects



and experiences of both the family of the critically ill person and the healthcare team are involved in the recovery; in the interactions, advantages, disadvantages and limitations are evidenced, as well as the interaction with the patient's rehabilitation during hospitalization and discharge from the intensive care unit.

As the first aspect, the importance of strengthening research on the subject is emphasized, in order to better understand the families <sup>(4, 7, 15)</sup>; this way, they can modify their behavior and contribute to the improvement of the critically ill user. It is important to know how intensive care unit nurses can promote a family-centered environment by including the family in rehabilitation activities where appropriate. The studies reviewed indicate that empowering families in the rehabilitation setting requires an openness and willingness to learn from and with patients and their families, and to understand that all of these actions have the potential to lead to improved outcomes <sup>(9, 14)</sup>. Further research is recommended to explore this area in more depth <sup>(7, 10)</sup>. The authors postulate that it would be interesting and very necessary to develop other studies with different approaches, i.e. quantitative, qualitative and mixed, that would allow responding to the knowledge gaps regarding the impact caused by the family in the recovery of patients with critical health conditions, in order to answer questions such as: Are there macro-hemodynamic benefits in patients with family support during hospitalization? How long does it take to implement family support in the ICU? How many resources are needed to establish solid strategies regarding the incorporation of the family in the recovery of the critically ill? Should the healthcare team develop new visiting protocols for critical care units in Chile? Will the development of further studies help to break down the barriers visualized in this study and experienced in healthcare?

As a second relevant aspect, studies show that there are some key factors or aspects to strengthen the recovery of the critically ill patients. Authors describe key elements for the recovery of persons with critical health alterations, which include the following: a) medical knowledge and expectations, including the justification for rehabilitation, the perceived benefits and the actual impact of the benefits; b) evidence



and application of rehabilitation, including when to intervene; c) patient factors such as prognosis, sedation, delirium, cooperation, motivation, goals and the presence of family; d) safety considerations, such as the physiological stability of the patient and the presence of devices; e) environmental influences, such as available personnel, resources, equipment, time and competing priorities; f) culture and teamwork, multidisciplinary team participation, professional roles, and communication; the culture of the unit was considered as the most relevant point <sup>(11)</sup>. Other studies recognize the family as a central and vital part of the critically ill person. However, the problem arises in clinical practice (in the everyday life of the ICU), since intensive care units are highly complex areas, which are characterized by being stressful and generating an emotionally labile atmosphere, for professionals as well as for patients and their families <sup>(1-3, 12-13)</sup>.

Finally, the literature reviewed indicates that a great deal of self-management by healthcare teams and families is required, so that entry and access is not arbitrary (12); some new methodologies have been applied in developed countries, but have not yet been implemented in developing countries or countries with lower economic income, or have not been reported to evaluate their effectiveness. On the other hand, it is recognized that empowering families in the framework of recovery and rehabilitation requires a cohesive health team that is available and prepared to learn from patients and their families, as the latter also have the potential to lead to improved outcomes <sup>(11, 16)</sup>, considering the possible constraints that may arise and the time needed to implement the measures. In order to enhance these work strategies, changes must be made with respect to the design, infrastructure and internal organization of intensive care units to improve the well-being and privacy of patients and their families, bearing in mind the personal and emotional demands of each of the patients and their families <sup>(1)</sup>.



## Conclusions

The review conducted allows us to conclude that the units for critically ill patients continue to be a restricted and highly complex place, making it difficult for families to be admitted to these units. Although studies reveal the importance of incorporating the family in the recovery of the critically ill patient, since they are recognized as an important element in this health-illness process, there are still other aspects and areas to be researched, such as the consequences on clinical and hemodynamic factors, to mention a few, in order to demonstrate conclusively that the family resource should not be underestimated for the improvement of people with critical health conditions.

From the results obtained in this review, the positive impact of the family on the recovery of the person in critical condition is indirectly highlighted; however, there is still a void of expected clinical evidence for the application in intensive care units, due to the high demand for applicable and demonstrable evidence that these units require due to their high complexity.

The selected studies reflect on the need for educational interventions for the healthcare team as a strategy to understand the importance of recovery and rehabilitation from the moment the patient is admitted to the intensive care unit, in order to transmit the knowledge acquired by the team to the family, with the aim of providing greater confidence and security to enhance care. We cannot fail to mention that there are different mechanisms for implementing the improvement measures, regardless of what they are; all are evidence that there is a significant impact on outcomes, on family members' experiences and on patients independently. Finally, it is necessary to develop additional research from the discipline of critical care nursing, in order to explore the importance of incorporating families in the recovery of the person in critical condition, which not only have an influence on the emotional level, but also on the clinical level.



## Conflict of interest

The authors stated there are no conflicts of interest.

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