

## FAMILY NEEDS OF PATIENTS ADMITTED IN THE INTENSIVE CARE UNIT: A META-SYNTHESIS

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### ABSTRACT

The life threats for patients admitted in the Intensive Care Unit (ICU) is higher compared to other care units. The magnitude of the life threats in the ICU not only causes anxiety for patients but also for other families. The family has crucial roles in supporting the patient's recovery, so the holistic needs of the patient's family also require to be considered. This meta-synthesis aimed to synthesize findings from qualitative studies that explored and described the needs of families while accompanying patients in the ICU. A systematic literature search from online databases was used to conduct a qualitative meta-synthesis, which was then evaluated using Critical Appraisal Skill Programme (CASP) checklist for Qualitative Study. Literature that fit the requirements was further analyzed. Three main themes that were fundamental for families were revealed including the need for information, the need for family involvement in patient care, and the need for visiting time for the family. Understanding the family as a unit brings benefits to the patient. It is essential to adapt professional practice strategies that involve families in the daily care of critical patients. Further research is required on how to carry out interventions that translate this knowledge into nursing care practices and actions.

Keywords: *Critical illness; family caregiver; needs; ICU; qualitative*



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### INTRODUCTION

Family members of Patients admitted in the intensive care unit (ICU) encounter psychological crisis, stress, and depression due to a relative's admission s to this unit, which is frequently an unanticipated event and aimed for individuals in a critical condition and possibility of high mortality (op 't Hoog et al., 2020). A longitudinal study found that about 43% of the relatives of patients who had been in an ICU had high levels of depressive symptoms in a year after discharge (Cameron et al., 2019).

The clinical condition of the ICU patients and inability to communicate directly with health workers and family members create anxiety and stress, not only about the patients' acute clinical condition but also regarding to about care transitions status and the long-term prognosis after discharge (Alsharari, 2020). Furthermore, stress due to a relative's illness can affect how family members cope with the

condition and thus may hinder the extraordinary support that the patient needs (Suhartini et al., 2023).

The inability of critical patients to interact with health providers or participate in treatment decisions means that the responsibilities typically falls on patient's families as substitutes in decision-making. The presence of family members in the ICU was known to influence the patient experience positively. A study conducted in Canada explained that the family support have a positive impact on improved patient's condition (Dale et al., 2020). The American College of Critical Care Medicine published recommendations for healthcare providers to support families and meet their needs (Davidson et al., 2007).

By considering the importance of family involvement in caring process for critical patients, many researchers have conducted previous studies related to the family needs of

critical patients holistically, so through literature studies, this study have tried to formulate previous findings regarding the family needs of ICU patients. An apparent reference is a demand for health workers, especially nurses, so that nurses are able to identify and to understand every basic need of the families of critical patients in improving the service quality provided to critical patients through good collaboration with the family, merely making the family a complement to providing information on the patient's health history and as informed consent without discussion to consider the best decision for the patient.

**METHOD**

Meta-synthesis is a systematic approach used to search, filter, extract, and encode qualitative data (Lachal et al., 2017). This approach involves combining findings across a variety of qualitative studies to ascertain common patterns and themes within a given topic and to increase understanding of evidence-based interventions (Mungall-Baldwin, 2022). Qualitative synthesis is recognized as a valuable tool for analyzing participant meanings, experiences, and perspectives, both in depth (thanks to a qualitative approach) and broad range (thanks to a combination of articles from various backgrounds and participants) (Lachal et al., 2017). The study applied a meta-synthesis approach with six steps: 1) defining the research questions and selection criteria, 2) driving study selection, 3) conducting study quality assessments, 4) extracting and presenting formal data, 5) directing data analysis and 6) writing a synthesis (Lachal et al., 2017).

**Determining the research questions and selection criteria**

The articles used in the preparation of a qualitative meta-synthesis study related to the needs of families in the ICU. The research question that guides this meta-synthesis analysis is "What are the needs of the family while accompanying patients in ICU care?".

The inclusion criteria were: (a) primary qualitative research exploring the needs of patient families during ICU care, (b) regarding the families of critically ill adult patients admitted in the ICU, (c) written in English, and (e) open access.

**Promoting study selection**

Initial search terms were based on academic literature following PRISMA's guidelines for conducting reviews (Lachal et al., 2017). Five electronic databases were used in this study (Scopus, ScienceDirect, PubMed, and ProQuest) and then relevant topics were included in meta-synthesis analysis. In searching the literature, the Boolean operators "OR/AND" were applied. Keywords used in the search included Needs AND Families OR Relatives AND Hospitalized AND ICU. All peer-reviewed literature searches were carried out using all available sections, including title, abstract, and keywords. The articles that have been obtained are analyzed, as well as differences and duplications. Figure 1 explained the process of searching for and selecting articles as literature using Preferred Reporting Items for Meta-synthesis (Matthew et al., 2021).

**Quality assessment**

This CASP (Critical Appraisal Skill Program) checklist for Qualitative Research assesses ten areas: clarity of research objectives, qualitative characteristics, research design, recruitment strategy, data collection, researcher reflexivity, ethical considerations of issues, the equivalence of data analysis, clarity of stated findings and research value (CASP, 2015). Ratings ranged from 1 to 10 (1=low quality and 10=high quality) on each article reviewed (Lachal et al., 2017).

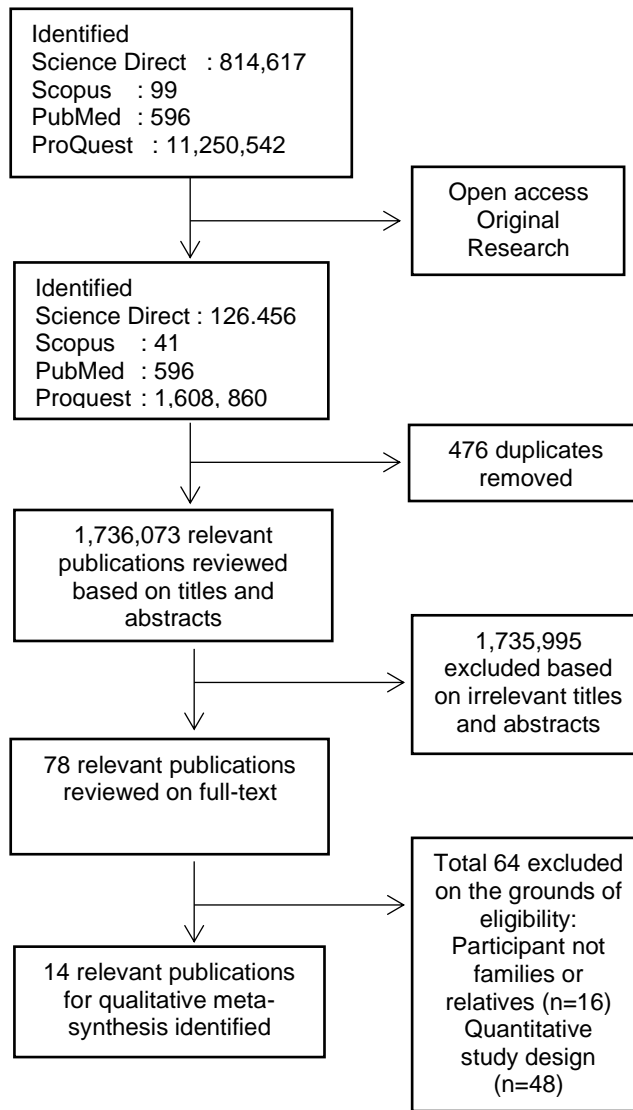


Figure 1. PRISMA Flow Chart

**Data extraction and data synthesis**

Articles that meet the criteria are extracted in the form of a matrix to facilitate data processing and determine the research theme, and the matrix can be seen in Table 1 as the results of the study.

## RESULT

Table 1. Data Extraction extracts, presents the formal data, and results of the study

Author Year Country	Aim	Method	Findings	Recommendation	Quality assessment CASP (Appraisal Result: "Y" Yes, "N" No, "U" Unclear. "N/A" Not Applicable)
Söderström 2009 Sweden	Describe and interpret family adaptation during ICU stay and up to 18 months after discharge	Qualitative design, hermeneutic analysis	<ul style="list-style-type: none"> <li>The struggle for resilience;</li> <li>The struggle for consolation;</li> <li>The struggle to rebuild a life.</li> </ul>	Research is needed on families facing critical illness and on factors such as beliefs and anticipation that help families adapt well	9/10 Y— Appropriate qualitative methodology Y— Clear Aims Y—Appropriate data collection Y—Appropriate Analysis of data Y—Appropriate of the interpretation results N— A statement locating the researcher culturally or theoretically Y—Influence of the researcher on the research Y—The participant adequately represented Y—Ethical considerations addressed Y—Conclusions drawn from the analysis, interpretation data
Dale 2020 Canada	Explore potentially modified support needs	Longitudinal qualitative study	<ul style="list-style-type: none"> <li>Information support;</li> <li>Emotional;</li> <li>Training.</li> </ul>	Researchers recommend family-centered care which includes communication and support interventions to facilitate family capacities and moderate long-term negative health outcomes.	9/10 Y— Appropriate qualitative methodology Y— Clear Aims Y—Appropriate data collection Y—Appropriate Analysis of data Y—Appropriate of the interpretation results Y— A statement locating the researcher culturally or theoretically Y—Influence of the researcher on the research Y—The Participant adequately represented U—Ethical considerations addressed Y—Conclusions draw from the analysis, interpretation data
Santana 2007 Spain	compare the level of satisfaction of families who are treated in (ICU) with the perception of health workers about the environment of care and information received.	Qualitative descriptive interview study	<ul style="list-style-type: none"> <li>Improve the waiting room;</li> <li>Personalize care;</li> <li>Assess individual flexibility in visiting hours.</li> </ul>	Researchers recommend using all of these satisfaction data should be used in initiatives to improve the quality of critical care.	7/10 Y— Appropriate qualitative methodology Y— Clear Aims Y—Appropriate data collection Y—Appropriate Analysis data Y—Appropriate of the interpretation results Y— A statement locating the researcher culturally or theoretically Y—Influence of the researcher on the research U—Participant adequately represented N—Ethical considerations addressed Y—Conclusions drawn from the analysis, interpretation data
Ventura et al 2020 Spanish	Know the feelings and needs of the relatives of patients	Qualitative study	<ul style="list-style-type: none"> <li>Psychological assistance;</li> <li>Information;</li> <li>Cooperate in caring for family</li> </ul>	Although research exists into the needs of family members of patients admitted to the ICU, better	10/10 Y— Appropriate qualitative methodology Y— Clear Aims Y—Appropriate data collection Y—Appropriate Analysis of data

Author Year Country	Aim	Method	Findings	Recommendation	Quality assessment CASP (Appraisal Result: "Y" Yes, "N" No, "U" Unclear. "N/A" Not Applicable)
	treated in the ICU of a third-level hospital in Catalonia and II) studying the participation strategies put forward by relatives.		members.	knowledge of this is still needed to guide strategy and care for families.	Y—Appropriate of the interpretation results Y— A statement locating the researcher culturally or theoretically Y—Influence of the researcher on the research Y—the Participant adequately represented Y—Ethical considerations addressed Y—Conclusions drawn from the analysis, interpretation data
Czerwonka et al 2015 Canada	Explore the needs of survivors and caregivers during critical illness episodes until they return to independent living	Qualitative study	Information needs of survivors' transition from dependence to independence.	Further research can be enhanced by including a diverse and representative sample population.	8/10 Y— Appropriate qualitative methodology Y— Clear Aims Y—Appropriate data collection Y—Appropriate Analysis of data Y—Appropriate of the interpretation results N— A statement locating the researcher culturally or theoretically U—Influence of the researcher on the research Y—the Participant adequately represented U—Ethical considerations addressed Y—Conclusions drawn from the analysis, interpretation data
Op 't Hoog et al 2020 Dutch	Understand what relatives are experiencing and what is needed to provide input in improving family-centered care and reducing PICS symptoms.	Qualitative study	<ul style="list-style-type: none"> <li>Relief;</li> <li>Uncertainty;</li> <li>Need to be recognized as a caregiver;</li> <li>Sharing hope;</li> <li>The need for continuity in care.</li> </ul>	Recommendations for further research should provide more insight into factors such as culture and family situation.	9/10 Y— Appropriate qualitative methodology Y— Clear Aims Y—Appropriate data collection Y—Appropriate Analysis of data Y—Appropriate of the interpretation results N— A statement locating the researcher culturally or theoretically Y—Influence of the researcher on the research Y—The Participant adequately represented Y—Ethical considerations addressed Y—Conclusions drawn from the analysis, interpretation data
Ågård et al 2007 Denmark	Contribute to understanding the needs of the family as well as to developing communication, and better	A qualitative study with a Grounded Theory approach	<ul style="list-style-type: none"> <li>Withstand uncertainty;</li> <li>Put yourself aside;</li> <li>Form personal cues.</li> </ul>	More research is needed with an emphasis on communication and cooperation seen from the perspective of relatives and caregivers. It is also recommended that ICU nurses develop	9/10 Y— Appropriate qualitative methodology Y— Clear Aims Y—Appropriate data collection Y—Appropriate Analysis of data Y—Appropriate of the interpretation results Y— A statement locating the researcher culturally or theoretically Y—Influence of the researcher on the research

Author Year Country	Aim	Method	Findings	Recommendation	Quality assessment CASP (Appraisal Result: “Y” Yes, “N” No, “U” Unclear. “N/A” Not Applicable)
	cooperation between nurses and families			educational programs that recognize the complexities of family situations.	Y—The Participant adequately represented U—Ethical considerations addressed Y—Conclusions drawn from the analysis, interpretation data
Keenan & Joseph 2010 Canada	Identify needs expressed by family members as patients with severe brain injury progress through their recovery	Qualitative study	<ul style="list-style-type: none"> <li>• Manage life;</li> <li>• Involvement in care;</li> <li>• Need for information.</li> </ul>	a larger sample can provide a more complete picture of family needs.	10/10 Y— Appropriate qualitative methodology Y— Clear Aims Y—Appropriate data collection Y—Appropriate Analysis of data Y—Appropriate of the interpretation results Y— A statement locating the researcher culturally or theoretically Y—Influence of the researcher on the research Y—the participant adequately represented Y—Ethical considerations addressed Y—Conclusions drawn from the analysis, interpretation data
Iverson et al 2014 USA	Identify the needs expressed by family members in making decisions	A focus group qualitative study	<ul style="list-style-type: none"> <li>• Flying;</li> <li>• Information search;</li> <li>• Tracking;</li> <li>• Gather resources.</li> </ul>	Stress is exacerbated when family needs are not identified or adequately met and recommend that family needs assessment be incorporated into patient care plans.	10/10 Y— Appropriate qualitative methodology Y— Clear Aims Y—Appropriate data collection Y—Appropriate Analysis of data Y—Appropriate of the interpretation results Y— A statement locating the researcher culturally or theoretically Y—Influence of the researcher on the research Y—The participant adequately represented Y—Ethical considerations addressed Y—Conclusions drawn from the analysis, interpretation data
Naef et al 2020 Swiss	Investigate the experiences of families and healthcare workers with nurse-led family support interventions in intensive care	Qualitative evaluation study	<ul style="list-style-type: none"> <li>• Family is the most critical part of ICU care;</li> <li>• Facilitate staff-family interaction and communication ;</li> <li>• Promote quality of family care;</li> <li>• Family support interventions.</li> </ul>	More studies are needed that address the impact of nurse-led family support interventions on ICU care processes and outcomes.	8/10 Y— Appropriate qualitative methodology Y— Clear Aims Y—Appropriate data collection Y—Appropriate Analysis of data Y—Appropriate of the interpretation results N— A statement locating the researcher culturally or theoretically Y—Influence of the researcher on the research N—The participant adequately represented Y—Ethical considerations addressed Y—Conclusions drawn from the analysis, interpretation data
Bohart et al	Explore	exploratory	<ul style="list-style-type: none"> <li>• Ongoing</li> </ul>	Researchers did	10/10

Author Year Country	Aim	Method	Findings	Recommendation	Quality assessment CASP (Appraisal Result: “Y” Yes, “N” No, “U” Unclear. “N/A” Not Applicable)
2022 Denmark	perspectives and wishes for patient and family-centered care among adult patients and family members with experience of admission to adult intensive care units	descriptive using inductive thematic analysis	<ul style="list-style-type: none"> <li>dialogue;</li> <li>Humanize quality care;</li> <li>Equip the family to navigate.</li> </ul>	not apply validated instruments test of participants for delirium before formal interviews. This could be a relevant consideration in future studies	<p>Y— Appropriate qualitative methodology</p> <p>Y— Clear Aims</p> <p>Y—Appropriate data collection</p> <p>Y—Appropriate Analysis of data</p> <p>Y—Appropriate of the interpretation results</p> <p>Y— A statement locating the researcher culturally or theoretically</p> <p>Y—Influence of the researcher on the research</p> <p>Y—The Participant adequately represented</p> <p>Y—Ethical considerations addressed</p> <p>Y—Conclusions drawn from the analysis, interpretation data</p>
Wong et al 2020 Australia	Describe the perspective of family participation in patient care in the ICU	Qualitative study	<ul style="list-style-type: none"> <li>Families are part of the health team;</li> <li>Motivators;</li> <li>The role of the family during recovery.</li> </ul>	Further studies are needed to validate the association between long-term critically ill patients and family participation rates	<p>8/10</p> <p>Y— Appropriate qualitative methodology</p> <p>Y— Clear Aims</p> <p>Y—Appropriate data collection</p> <p>Y—Appropriate Analysis of data</p> <p>Y—Appropriate of the interpretation results</p> <p>N— A statement locating the researcher culturally or theoretically</p> <p>Y—Influence of the researcher on the research</p> <p>N—The participant adequately represented</p> <p>Y—Ethical considerations addressed</p> <p>Y—Conclusions drawn from the analysis, interpretation data</p>
Blom et al 2013 Sweden	Explore the phenomenon of participation and support experienced by close relatives of patients in the ICU.	Qualitative Studies, phenomenological approach	<ul style="list-style-type: none"> <li>Participate in care and be close to the patient;</li> <li>Confidence in care;</li> <li>Support engagement in care.</li> </ul>	Further research is needed on how to conduct interventions that translate this knowledge into practice and action	<p>10/10</p> <p>Y— Appropriate qualitative methodology</p> <p>Y— Clear Aims</p> <p>Y—Appropriate data collection</p> <p>Y—Appropriate Analysis of data</p> <p>Y—Appropriate of the interpretation results</p> <p>Y— A statement locating the researcher culturally or theoretically</p> <p>Y—Influence of the researcher on the research</p> <p>Y—The participant adequately represented</p> <p>Y—Ethical considerations addressed</p> <p>Y—Conclusions drawn from the analysis, interpretation data</p>
Ågård et al 2019 Denmark	Provide a richer context for a family's quantitative assessment of the	Qualitative study	<ul style="list-style-type: none"> <li>Information;</li> <li>Clinical skills;</li> <li>ICU environment;</li> <li>Discharge of ICU.</li> </ul>	combining qualitative and quantitative data sources to allow a more complete picture of patient and family experiences in the	<p>9/10</p> <p>Y— Appropriate qualitative methodology</p> <p>Y— Clear Aims</p> <p>Y—Appropriate data collection</p> <p>Y—Appropriate Analysis of data</p> <p>Y—Appropriate of the interpretation results</p>

Author Year Country	Aim	Method	Findings	Recommendation	Quality assessment CASP (Appraisal Result: "Y" Yes, "N" No, "U" Unclear. "N/A" Not Applicable)
	quality of ICU care, and delineate further areas of quality that are important to family members			ICU.	N— A statement locating the researcher culturally or theoretically Y—Influence of the researcher on the research Y—Participant adequately represented Y—Ethical considerations addressed Y—Conclusions drawn from the analysis, interpretation data

### Thematic synthesis of the results

Following a qualitative meta-synthesis process from the 14 included articles, three main themes were identified. The synthesis took three stages including coding the themes and sub-themes on the findings of the primary study; organization of 'free codes' into related fields to develop 'descriptive' themes and developing an analytic themes by discussion with the review team (Schmidt et al., 2021). Articles are provided to illustrate each theme, and citations given in italics are from participants in the original study, and citations that are not italicized represent the interpretations of the study authors.

#### Theme 1: Information Needs for Families

The need for 'information' was identified in all research articles collected as an essential need (Ågård et al., 2019; Ågård & Harder, 2007; Blom et al., 2013; Bohart et al., 2022; Czerwonka et al., 2015; Dale et al., 2020; Harrison et al., 2019; Iverson et al., 2014; Keenan & Joseph, 2010; Naef et al., 2020b; op 't Hoog et al., 2020; Santana Cabrera et al., 2007; Söderström et al., 2009; Ventura Expósito & Arreciado Maraño, 2021). Family experiences related to information needs that are included in the very significant category include being able to talk and discuss with doctors every day, knowing the reasons why an intervention is performed on a patient, knowing how the patient is treated medically and knowing clearly what is being done to the patient. Knowing is a means that can provide certainty or clarity for the family. This need to know seems important to them, the family will understand each patient's condition even when facing the possibility of losing their loved one and help the family understand their role so that they are able to be actively involved in the care process in the ICU (op 't Hoog et al., 2020).

*"I need to know. I want to know and be told about everything they are going through" N14 (Ventura Expósito & Arreciado Maraño, 2021).*

*"We need answers, we need to know the terminology, 'what does this mean', and yes, it's very important that we want to be part of the decision making" [Caregiver 16] (Dale et al., 2020).*

*"During visiting hours we mostly have to ask for information, it's an unpleasant situation. We are only informed about our inquiries and nothing more. This is a burden for us." (Dutch respondents)(Ågård et al., 2019).*

#### Theme 2: The need for families to be involved in patient care

Apart from social support, the family expressed a need for nurses and staff to recognize them as caregivers more. Families were disappointed with their involvement level in medical care. Families explained that sometimes, information was only shared with patients. Of course, this created more

confusion for family members than clarity because the patient was delirious, and the family felt neglected in some ways (op 't Hoog et al., 2020).

*"I need to take care of him, help him and make sure he gets well" N14.*

*"I will do everything I can. I'm doing everything I can make him better" O15.*

*"I will do whatever my mother needs, I will do it. I will comb her hair or help her with cleaning, dress her. . . I'll look after it, and I think we'll both enjoy it."*

Families explained the importance of feeling close to their loved ones. Many of them also wanted to be able to provide support and care for family members who are currently undergoing treatment in the ICU. In other words, it helped patients emotionally and psychologically and raise their spirits to fight against illness (Ventura Expósito & Arreciado Maraño, 2021).

#### Theme 3: The need for family visiting time

The percentage of relatives who requested more time to stay with their loved ones showed that visiting time was important.

*"We spent a lot of time waiting outside, the time we wanted to have with Dad. Being allowed to sit quietly by the bed means a lot to us, so more time with Dad would be even better." (Danish respondent) (Ågård et al., 2019).*

Being beside the patient makes it easier for family members to carry out affective and health care functions (Ahlberg et al., 2023). The affective function is the internal function of the family to fulfill psychosocial needs, such as caring for each other, providing love, and accepting and supporting each other (op 't Hoog et al., 2020). Meanwhile, the function of health care is the family's ability to care for family members who experience health problems related to the patient's condition and ensure that the patient receives the best care (Naef et al., 2020a).

## DISCUSSION

Taking into account the present family context as an extension of the patient is becoming more widely accepted in ICU practice and is a concept underlying patient-centered care (Mitchell et al., 2016). Family needs have been identified using a variety of approaches, including understanding more deeply what the family is experiencing and what is needed in an effort to improve family-centered care.

Information is the most essential need for families and one of the most valued needs of the patient's family. Difficulties in facilitating the understanding of information among patient families have been identified during the early stages of critical

patient admission. Families do not retain information or have the ability to interpret information easily (Ventura Expósito & Arreciado Marañón, 2021).

Other researchers suggest to escalate family's understanding, information should be presented in simple terms, using pictures and written materials that families can keep or refer to on their own time as they try and understand the injury conditions of their family member being treated to the likely outcomes (Ågård & Harder, 2007). Attention should be paid to the content and form of information, and high-quality information is described in terms such as "honest", "clear", "understandable", "empathetic", "not too little, not too much", "not rushed and vice versa for low-quality information. Finding the right balance between realism and optimism is a highly valued characteristic of high-quality information (Ågård et al., 2019).

Optimizing the provision of information and knowledge about the patient's condition brings relief to family members and helps them understand the situation (Bohart et al., 2022). Effective communication affects the role of the family in participation. Families feel confident in advocating and making decisions to provide treatment to patients and to guide their participation in physical care (Iverson et al., 2014). Family participation in nursing care activities can be beneficial for patients and families. Wong illustrates how family participation provides comfort and support to patients and facilitates adherence to treatment, while, at the same time, meeting the need for families to feel that they are contributing to their relative's recovery.

The role of the family in minimizing the psychological impact and supporting the patient's emotional well-being can be attributed to the close and intimate relationship between them. This condition also allows the family to maintain patient orientation. They are able to communicate information that reduces uncertainty and anxiety and provide social support that fulfills the patient's sense of isolation and loneliness (Wong et al., 2020). These findings illustrate the reasons why the treatment method is currently not only patient-centered but also important in taking into account the presence of the family in the process of providing care in the ICU. Suppose families are to be involved in care. In that case, they must be accepted and invited to participate, and a professional approach and attitude are essential for both the family and the patient. If not supported and allowed to participate, they may suffer, endure silence, and retreat to wait for change (Blom et al., 2013). This empirical evidence approach can be considered to allow adjustments and new insights in policy making both visits and family involvement in providing care to patients (Ventura Expósito & Arreciado Marañón, 2021). An unrestricted visit policy for patients and their families will provide benefits and influence the provision of nursing care and the function of care in the ICU. Nurses should develop clear policies and procedures for ICU visits that will be supported and reinforced by all nurses in the unit (Santana Cabrera et al., 2007)

## CONCLUSIONS AND RECOMMENDATIONS

A clear concept on family needs while receiving care in the ICU has yet to be standardised. Thus, the results of the study still describe gaps in the field. The family will use all source of information to support the assessment of the patient's medical history. Understanding family needs will gain the communication with nurses and health care providers, and create professional practice to improve tailored nursing care.

## CONFLICT OF INTEREST

None

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