Medicina Intensiva 49 (2025) 237–244

medicina intensiva

http://www.medintensiva.org/en/

UPDATE IN INTENSIVE CARE MEDICINE: CRITICAL PATIENT SAFETY

How to involve the patient and family in improving safety in intensive medicine services (SMI)?

Olga Rubio Sanchiz[a,*], Joan Escarrabill[a], Joan Fernando Peidró[a], Anne Sophie Gresle[b]

[a] *Patient Experience Observatory, Hospital Clínic de Barcelona, Barcelona, Spain*
[b] *Patient Experience Observatory, ISGlobal, Hospital Clínic de Barcelona, Barcelona, Spain*

Received 15 February 2024; accepted 24 May 2024
Available online 14 September 2024

KEYWORDS
Safety;
Patient participation;
Patient experience;
Intensive medicine services;
PRIMS (patient reported incident measures)

Abstract Patient safety is a priority for health systems and is especially relevant for critically ill patients. Despite its relevance in recent years, many patients suffer adverse events with harm and negative repercussions for professionals and institutions.

Numerous safe practices have been promoted and strategies have been developed that have been incorporated into institutional policies and thereby improving the safety culture. But there are still underdeveloped strategies, such as incorporating the participation of patients and family members in their safety.

Until recently, the patient and family have been considered as a passive part in the reception of health services, not as an active part, much less as a possible opportunity to improve safety against errors that occur during care.

The critically ill patient and/or family members must be informed and, ideally, trained to facilitate active participation in their safety. It is not about transferring responsibility, but about facilitating and promoting their participation by reinforcing their safety. And professionals must be committed to their safety and facilitate the conditions to encourage their participation.

We provide tools and reflections to help professionals implement the participation of patients and family members in safety as they pass through intensive medicine services.

DOI of original article: https://doi.org/10.1016/j.medin.2024.05.020
* Corresponding author.
E-mail address: orubio@clinic.cat (O. Rubio Sanchiz).

https://doi.org/10.1016/j.medine.2024.06.012

PALABRAS CLAVE
Seguridad;
Participación paciente;
Experiencia paciente;
Servicios medicina intensiva;
PRIMS (medidas de incidentes reportadas por pacientes)

¿Cómo implicar al paciente y familia en la mejora de la seguridad en los servicios de medicina intensiva?

Resumen La seguridad del paciente constituye una prioridad de los sistemas sanitarios y es especialmente relevante en los pacientes críticos. A pesar de su importancia en los últimos años son muchos los pacientes que sufren eventos adversos y con repercusiones negativas para pacientes, los profesionales y las instituciones.

Se han promovido prácticas seguras, y desarrollado estrategias, que se han ido incorporando en las políticas institucionales, mejorando la cultura de seguridad. Pero todavía existen estrategias poco desarrolladas, tales como, incorporar la participación de pacientes y familiares en su seguridad.

Hasta hace poco se ha considerado al paciente y familiares como parte pasiva en la recepción de los servicios sanitarios, no como parte activa, ni mucho menos, como una posible oportunidad de mejora en la seguridad frente a los errores que suceden durante la asistencia.

El paciente crítico y/o familiares deben estar informados e, idealmente, formados para facilitar una participación activa en su seguridad. No se trata de traspasar la responsabilidad, sino de facilitar y promover su participación reforzando su seguridad.Y los profesionales deben estar comprometidos con su seguridad y facilitar las condiciones para fomentar su participación.

Aportamos herramientas y reflexiones para ayudar a profesionales a implementar la participación de pacientes y familiares en la seguridad a su paso por los servicios de medicina intensiva.

Introduction

Intensive care units (ICUs) are areas of increasing complexity and use of multiple health care resources, where patient safety is a priority and is particularly relevant. Despite its importance and advancements made in recent years, several patients experience adverse events with negative repercussions for professionals and institutions.[1]

Adverse Events (AEs) are a common finding in the intensive care unit (ICU) setting. In the S̈afety and risk in the critically ill patients(SYREC) study conducted in Spain, the probability of a patient experiencing at least one PSRI (patient safety-related incident) was 62%. The rate of occurrence of AEs was 2.04/100 patient-hours of ICU stay. A total of 74% of the AEs were related to drugs, equipment, care, vascular access, tubes, airway, and mechanical ventilation. Sixty-six percent of harmless incidents and 34% were AEs; 29.5% caused temporary harm and 4.28% caused permanent harm that compromised the patient's life or contributed to death. Ninety percent of all incidents without harm and 60% of all AEs were considered undoubtedly preventable or possibly preventable.[2]

In recent years, patient involvement in health-related aspects has gained prominence, coining terms such as patient-centered care,[3] disease self-management,[4] active patient,[5] expert patient,[6,7] and patient experience, being increasingly present in the agenda of policymakers and health care managers.[8–11] It is increasingly recommended to incorporate the patient and their surroundings to care for their health, manage their disease, and involve them in their safety. ICUs are no exception.[12] However, empirical knowledge is lacking on the effectiveness of interventions aimed at promoting patient participation in their safety.[13]

The severity of critical illness, communication barriers, a high number of activities per patient per day, the practice of diagnostic procedures and invasive treatments, the use of numerous high-risk drugs, the volume of data generated in their care, the use of technology, stress, workload, the quantity and complexity of information used, handoffs, and the need for teamwork, as well as professional burnout, among other factors, make these units high-risk areas for safety incidents.[14–19]

What patient and family participation means and the necessary elements for it to occur

Participation means intervening in something alongside others to improve a situation.[20] For someone to participate in a process, in this case, the patient, certain prerequisites are necessary, which are summarized by the English acronym **CLEAR**: **C**an do, **L**ike do, **E**nable to do, **A**sk to do, and Respond to.

Table 1 outlines these prerequisites in relation to patient participation in their health care; these will facilitate patient participation and make it more useful. For these prerequisites to occur, information and good communication are essential.[21]

We should clarify that participation is not a binary all-or-nothing concept but will have a gradation in its process depending on the patient's intrinsic determinants and the socio-environmental situation (extrinsic determinants related to professionals and the context in which the health care action takes place). Therefore, even if a patient has all favorable characteristics and qualities to participate to improve safety, the impact of unfavorable factors can reduce their ability to participate.[22]

Table 1 Aspects related to patient participation.

Can: have the resources and knowledge to participate.
Want: be aware of the problems that affect them and feel the need to do things to improve them.
Permission: find opportunities to participate.
Invitation: patients are mobilized, whether by patient associations, professionals, or the administration *per se* through its services and managers.
Receiving a response: see evidence that their contribution has made a difference.

Additionally, in the context of intensive care medicine, it is common for the patient to not always be able to exercise their capacity to participate. Hence the importance of broadening the concept of patient (and patient participation) to include family members, caregivers, or companions.

Participation raises awareness, has an empowering effect, and predisposes to learning, motivating the desire to learn. Although there are multiple ways to learn, they can basically be summarized in two: through education (educational knowledge) and through experience (experiential knowledge). If the patient and/or family members feel capable, want to participate, and find the opportunity to do so, they will. If they receive a benefit in response, and the response they get from professionals is positive, they will continue to acquire the capacity and knowledge to keep participating. Their participation will become increasingly effective, and their empowerment will grow.[22]

The World Health Organization (WHO) defines empowerment as the ''process by which people gain greater control over decisions and actions affecting their health and, as such, individuals and communities need to develop skills, access information and resources, and have the opportunity to participate and influence factors that affect their health and well-being''.[23]

Some patients and family members of critically ill patients, especially those with chronic and recurrent diseases, have acquired knowledge and skills that allow them to participate, reinforcing their safety. This may be because they have previously had negative experiences or because they have witnessed risky situations as spectators. They have thus learned to take certain precautions and act as real safety barriers in their care processes.[22]

Barriers to patient and family participation at the ICU setting

The lack of information about the activities and processes performed at the ICU setting is one of the key factors that hinders patient participation in their safety. This information is essential for participation. It raises awareness and motivates patients and families, having a triggering effect that empowers them to participate in their safety.

In this regard, there are initiatives that provide written information manuals to patients and families about the procedures performed in ICUs, which empowers them to participate. Examples of guides and recommendations for active patient participation in the prevention of safety incidents are already numerous.[24] Most of these refer to aspects related to drugs, an especially problematic issue in all areas of the health care system and the leading cause of safety incidents in hospitals.[25]

Patient and family participation in factors influencing their safety at the ICU setting: a paradigm shift

In a complex, specialized, and technologically advanced ICU, coordination difficulties between the parts or elements that compose it are also increasing, making it challenging for professionals to have ëverything under control.Ḧandoffs between shifts, communication between different professional disciplines, and the information shared with the patient can facilitate the occurrence of safety incidents.

In this regard, the Reason's Swiss cheese model of accident causation[18] applied to the health care context of ICU patient care states that medical errors result from a chain of safety problems, suggesting that the more tools professionals and health care organizations have to prevent errors, the less likely they are to occur. However, this theory does not consider the contribution of patients and families as protective barriers regarding safety.

In this scenario, the patient and/or the families could act as safety enhancers to minimize risks. They are not passive recipients of medical care but should also play an active role in their own safety and well-being. When patients and their families are informed and actively participate in their care, a collaborative atmosphere is created between professionals and them, which helps improve the quality of care, reduce medical errors, and promote better patient outcomes.[21]

Therefore, family members of patients can identify risky situations before professionals, detecting failures or errors that the professionals themselves had not been able to detect. In fact, patients and their families are the only ëlementöf the system present in different settings and levels, occupying a privileged position to m̈onitorẅhat is happening and even älertẅhen something is not right if detected. Additionally, patients and their families have the greatest interest in ensuring everything goes well.[21]

This approach helps overcome the cultural resistance inherent in the traditional paternalistic relationship model, through which the scientific-technical knowledge of professionals prevails over the knowledge or experience of the

Table 2 Indicators for improving health care.

Name	Concept	Example	Scope
PROMs: Patient Reported Outcomes Measures	Health outcomes perceived by the patient	Health-related quality of life as perceived by the patient.	Quality and patient experience Safety and efficacy
PREMs: Patient Experience Reported Measures	Experience perceived by the patient	Timeliness of care, accessibility, information received, impact of the disease on the patient's life.	Patient experience
PRIMs: Patient Incidents Reported Measures	Safety incidents perceived by the patient during health care	Perception of safety, perceived risk of falls, perceived risk of allergies, medication errors perceived by the patient.	Clinical safety and patient experience

patient, restricting their participation. It is about incorporating the knowledge and experiences of the patient to achieve safer care.

Different ways of patient and family participation regarding safety at the ICU setting

The spectrum of participation can be broad, ranging from shared decision-making to the presence of patients in clinical sessions, or participation in patient committees with the capacity to influence decisions, to consultative bodies.[26] The main characteristics of these initiatives and some examples of how patients and families can be involved in safety at the ICU setting are presented in Tables 2 and 3.

Participation can be active in its various forms (complaints, user associations, community participation bodies, active participation in the care process) or at the initiative of the system (perceived quality surveys, qualitative research, etc.).

Available evidence indicates that the most useful interventions for involving patients in their safety are those that help them identify specific safety issues, mainly awareness campaigns and educational actions implemented in health care settings, encouraging patients to take specific measures related to their safety during their health care process,[27,28] such as unambiguous identification, safe use of drugs, or hand hygiene, among others.

Also useful are actions that facilitate and encourage the patient to ask professionals to clarify their doubts regarding diagnosis, treatment, and disease progression, and those that allow patients to provide retrospective information on safety issues through surveys, interviews, incident reporting, and improvement suggestions.[29]

Below are the main activities and strategies to promote patient and family participation in safety.

Mobilizing patients as a group

Mobilizing patients as primary agents for raising awareness of safety issues among the population and health care professionals, and as drivers of active participation by other patients, is one of the 6 priority action areas of the WHO's Global Patient Safety Alliance.[30]

Its main objective is to identify leaders and patient organizations that, based on their own experience of the issue at stake can promote the participation of other patients and health care institutions to prevent the incident from happening again.

In this same vein, we can also include safety incident reporting systems that involve patients as potential active reporters. Although they are in the minority, they exist, such as the National Learning and Reporting System of the U.K. National Patient Safety Agency and the medication error reporting system of the Institute for Safe Medical Practices.[31,32]

Active participation of patients and families in the health care process

As previously mentioned, there has been a growing interest on incorporating patients in the decision-making process regarding their health care. Examples of guides and recommendations for active patient participation in the prevention of safety incidents are already numerous, with the U.S. Agency for Health Research and Quality (AHRQ) being particularly notable for its breadth and leadership (they can be consulted at: http://www.ahrq.gov/consumer/espanoix.htm).

Initiatives such as the publication of brochures or small manuals that inform patients of the safety problems they may be exposed to when receiving health care, emphasize those that can be easily perceived, and indicate what they can do to avoid them should also be considered.

Table 3 Examples of patient and/or family involvement in safety at the ICU setting.

1. Participation in decision-making: patients and their families should have clear information about their condition, available treatment options, and potential risks or complications. This enables them to actively participate in decisions related to their medical care.
2. Effective communication: Open and transparent communication among the medical staff, the patient, and their family is essential to ensure mutual understanding. This can include discussing treatment plans, changes in the patient's condition, or any concerns they may have.
3. Monitoring the health care plan: The patient and family should be aware of the care plan established by the medical team and actively involve themselves in its implementation. This involves following medical instructions, taking medications as prescribed, attending scheduled appointments or recommended therapies, among other aspects.
4. Reporting adverse events: If the patient or their family observes any adverse events or errors in medical care, it is important to report them to the medical staff immediately. This allows for timely corrective actions and helps prevent future occurrences

A commitment and active partnership between health care professionals and patients and families working at all levels of the health care system are needed to improve health and quality, safety, and health care delivery. This commitment includes, among other things, participation in direct care, communication of patient values and goals, and transforming care to promote and protect respect and dignity of individuals.[33]

Regarding the involvement of families in the health care of patients at the ICU setting, various studies demonstrate its benefits, especially by promoting their presence and visits, shared decision-making, and even direct patient care.[34–37]

However, it is common that, although family members actively participate in communication and decision-making processes, they are excluded from ward rounds and witnessing cardiopulmonary resuscitation, among other restrictions,[38]

Informative campaigns

In 2019, the WHO World Assembly proclaimed September 17th as World Patient Safety Day. Since then, various activities have been held around this day every year in all countries worldwide to raise awareness and encourage citizens to get involved in this cause. On its website, the WHO offers recommendations for organizing a patient safety campaign, as well as graphic and audiovisual tools and resources for its development.[39]

Training activities

There is a wide range of tools and web resources, with graphic and audiovisual materials, to raise awareness and promote the participation of patients, their families, and caregivers in safety, particularly in the care of patients at the ICU setting

In this regard, the objective of ICU professionals regarding training should be double: anyone, even before needing care and becoming a patient, should have the basic knowledge to know how and in which aspects to participate to reinforce their safety when needed by establishing a participation plan; and, on the other hand, professionals should recognize its importance, identify barriers and facilitators, and provide it to the ICU setting.[40–42]

Incorporating patient experience indicators

The quality of care is defined by considering 3 domains or dimensions, although these are not the only ones: patient safety, clinical effectiveness, and patient experience. Currently, the idea of quality is linked to the patient's perspective and revolves around the idea of *value*.[43]

Health care must increase value from the perspective of the service recipient. More and more opinions place patient experience as the third pillar of quality care[43] and, additionally, as a key element for improving health care in the context of person-centered care.[44]

Patient experience is defined as the sum of all interactions between the patient and the health care system,[45] within a specific organizational culture that influences the perception of the person being cared for.[46] Since 2017, the OECD (Organization for Economic Cooperation and Development) has recommended collecting indicators of interest to the individuals receiving care within the framework of the Patient-Reported Indicators Surveys (PaRIS).[47]

The evaluation of patients' experience, or Patient Reported Experience Measures (PREMs), focuses, as described by Black,[48] on the humanity of care and its value. PREMs are tools that measure care experience from the patient's perspective, capturing *what* happened in a patient-system interaction and *how* it was, from the patient's perspective.[49]

On the other hand, Patient-Reported Outcome Measures (PROMs) are measurements of outcomes reported by patients to assess their health and well-being.

Both PROMs and PREMs represent standardized measures to quantify the patient's perspective and help us understand how illness, the health care system, and health care delivery impact patients.[50]

Evaluating patient experience has shown favorable results, even in the perception of their safety. A previous study suggests that ICU patients' vulnerability can be reduced by the security they experience when adequately informed about what is happening and when medical and nursing care is personalized based on their individual needs.[51]

PROMs and PREMs measure patient experience based on information provided by the patient about their functional well-being and health status (PROM) and the experiences they report (PREM) after receiving treatment. Recently, the term PRIM (Patient Reported Incident Measures) has been coined to measure safety-related patient experience. Table 2 includes the concepts and examples of these indicators that measure patient experience.

PRIMs would be indicators associated with patient safety that can be collected through validated self-administered surveys by patients and/or families. In its 2019 report entitled Ṗatient-Reported Safety Indicators: Question Set and Data Collection GuidanceÖECD proposes using a series of indicators to monitor patient safety through a validated survey that asks a series of questions about potential safety issues related to medical care.[52] Its main limitation is that the questions are not specifically formulated for the ICU setting.

In this regard, the Spanish Society of Intensive Care Medicine, Critical and Coronary Units (SEMICYUC) has encouraged various initiatives to reduce health care-related harm. One example is the development and updating of quality indicators for critically ill patients, many of which are related to patient safety.[53]

Measuring these indicators through these validated surveys submitted to patients and/or families can help involve patients and families in their safety, complementing the actions performed by professionals and organizations.

Conclusions

At the ICU setting, clinical safety is an objective to improve quality and minimize AEs caused by health care involuntarily. Therefore, now more than ever, given the renewed emphasis on quality, alongside the emphasis on safety and patient participation in their care, the role of patients and families cannot be ignored.

Although there are initiatives and methodological advances in the field of patient and family participation in the continuous improvement of safety, both in providing information to identify problematic areas and in actively collaborating in problem prevention, their full incorporation into safety still seems to be an ongoing task.

It is highly recommended to engage patients and families in their safety, providing information even before admission and encouraging participation, as they represent genuine opportunities for improvement against potential clinical safety gaps.

Through targeted surveys, evaluation tools like PREMs and PRIMs can help identify safety issues and implement preventive and corrective measures.

Incorporating patient experience into safety at the ICU setting can not only contribute to improving the experience of patients, families, and professionals but also enhance safety and quality of care.

Authors' contributions

All authors of this update have actively contributed to the preparation and review of the manuscript.

Barcelona, February 12th, 2024.

Conflict of interest

The authors declare that they have no conflict of interest.

References

1. Martín Delgado MC. Seguridad del paciente en Medicina Intensiva. Aspectos bioéticos. Revista de Bioética y Derecho. 2020;48:61–79. Epub 11 de mayo de 2020.
2. Merino P, Álvarez J, Cruz Martín M, Alonso Á, Gutiérrez I, SYREC Study Investigators. Adverse events in Spanish intensive care units: the SYREC study. Int J Qual Health Care. 2012;24:105–13, http://dx.doi.org/10.1093/intqhc/mzr083. Epub 2011 Dec 21. PMID: 22190588.
3. Red Regional de Educación Interprofesional de las Américas y Organización Panamericana de la Salud. Atención centrada en el paciente en la práctica interprofesional colaborativa: elementos clave, estrategias y próximos pasos. Washington DC. [Internet]. 2019 [consultado 15 Dic 2023].
4. González A. La autonomía del paciente con enfermedades crónicas: De paciente pasivo a paciente activo. Enferm Clin [Internet]. 2014;24:67–73, http://dx.doi.org/10.1016/j.enfcli.2013.11.005.
5. Jovell AJ, Navarro MD, Fernández L, Blancafort S. Participación del paciente: nuevo rol del paciente en el sistema sanitario. Aten Primaria [Internet]. 2006;38:234–7 [accessed 15 Dic 2023].
6. Navarro MD. Pacientes implicados: participación del paciente en la toma de decisiones. Papeles de Economía Española [Internet]. 2014;142 [accessed 15 Dic 2023].
7. Experiencia de Pacientes News. Gestión hospitalaria. Gestión del BQ y Cronicidad. [Internet]. Experiencia de Pacientes. [consultado 15 Dic 2023].
8. OECD. Citizens as Partners. In: OECD Handbook on Information, Consultation and Public Participation in Policy-Making. [Internet]; 2001 [accessed 15 Dic 2023].
9. Vasco Gobierno. Libro Blanco de Democracia y Participación Ciudadana para Euskadi. Un punto de partida. Departamento de Salud. [Internet]; 2014 [accessed 15 Dic 2023].
10. Ministerio de Sanidad, Servicios Sociales e Igualdad. Estrategia Seguridad del Paciente 2015-2020 [Internet]. Ministerio de Sanidad, Servicios Sociales e Igualdad. Centro de Publicaciones; 2016 [consultado 15 Dic 2023].
11. Osakidetza. Estrategia de Seguridad del Paciente 2020. [Internet]. 2018 [accessed 15 Dic 2023].

12. Martín MC, León C, Cuñat J, del Nogal F. Intensive care services resources in Spain. Med Intensiva. 2013;37(7):443–51, http://dx.doi.org/10.1016/j.medin.2013.06.002.
13. Schwappach DLB. Review: engaging patients as vigilant partners in safety: a systematic review. Med Care Res Rev [Internet]. 2010;67:119–48 [accessed 15 Dic 2023].
14. Martín MC, Ruiz J. Acontecimientos adversos en Medicina Intensiva. Gestionando el riesgo. Med Intensiva. 2006;30:284–92.
15. Donchin Y, Gopher D, Olin M, Badihi Y, Biesky M, Sprung CH, et al. A look into the nature and causes of human errors in the intensive care unit. Crit Care Med. 1995;23:294–300.
16. Cullen DJ, Sweitzer BJ, Bates DW, Burdick E, Edmondson A, Leape LL. Preventable adverse drug events in hospitalized patients: a comparative study of intensive care and general care units. Crit Care Med. 1997;25:1289–97.
17. Van den Bemt PA, Fijn R, Van der Voort J, Gossen AA, Egberts TC, Brouwers JR. Frequency and determinants of drug administration errors in the intensive care unit. Crit Care Med. 2002;30:846–50.
18. Reason J. Human error: models and management. BMJ. 2000;320:768–70.
19. Saturno APJ. Los métodos de participación del usuario en la evaluación y mejora de la calidad de los servicios sanitarios. Rev Esp Salud Pública. 1995;69:163–75.
20. Moliní E. Moliní; Barcelona: 2012. Libro sobre participación genuina o el arte de pensar, decidir y trabajar juntos. [accessed 15 Dic 2023].
21. Añel RM, González MJ, Rodríguez E. Modelo participativo de comunicación en salud: el caso del Centro Penitenciario Álava. Comunidad [Internet]. 2021;23:5.
22. Añel Rodríguez RM, Aibar Remón C, Martín Rodríguez MD. La participación del paciente en su seguridad [Patient participation in its own safety]. Aten Primaria. 2021;53 Suppl 1:102215. Spanish. doi: 10.1016/j.aprim.2021.102215. PMID: 34961579; PMCID: PMC8721344.
23. Arnstein SR. A ladder of citizen participation. Am Inst Planners [Internet]. 1966;35:216–24 [consultado 8 Jul 2021].
24. World Health Organization. Regional Oficce for Europe. Health 2020 policy framework and strategy. [Internet]. 2012 [accessed 15 Dic 2023].
25. Cuzco C, Castro P, Marín R, Ruiz S, Núñez AI, Romero M, et al. Impact of a nurse-driven patient empowerment intervention on the reduction in patients' anxiety and depression during ICU discharge: a randomized clinical trial. Crit Care Med. 2022;50(12):1757–67, http://dx.doi.org/10.1097/CCM.0000000000005676. Epub 2022 Sep 30. PMID: 36178294.
26. Estella Á, Saralegui I, Rubio Sanchiz O, Hernández-Tejedor A, et al. Update and recommenda-tions in decision making referred to limitation of advanced lifesupport treatment. Med Intensiva (Engl Ed). 2020;44:101–12, http://dx.doi.org/10.1016/j.medin.2019.07.006.
27. Aranaz JM, Aibar C, Vitaller J, Ruiz P. Estudio nacional sobre los efectos adversos ligados a la hospitalización. ENEAS 2005. Madrid: Ministerio de Sanidad y Consumo; 2006 [access 30 May 2008].
28. Schwappach DLB. Review: engaging patients as vigilant partners in safety: a systematic review. Med Care Res Rev [Internet]. 2010;67:119–48 [accessed 8 Jul 2021] Available from: https://journals.sagepub.com/doi/10.1177/1077558709342254. [PubMed] [Google Scholar].
29. Walters CB, Duthie E. Patient engagement as a patient safety strategy: Patients' perspectives. Oncol Nurs Forum [Internet]. 2017;44:712–8 [accessed 15 Dic 2023]. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5720142/
30. National Patient Safety Agency; National Learning and Reporting System; Reporting Incidents [access 8 Ago 2008].
31. USP-ISMP Medication Errors Reporting Program (MERP) [access 8 Ago 2008].
32. Carman KL, Dardess P, Maurer M, Sofaer S, Adams K, Bechtel C, et al. Patient and family engagement: a framework for understanding the elements and developing interventions and policies. Health Aff (Millwood). 2013;32:223–31.
33. McConnell B, Moroney T. Involving relatives in ICU patient care: critical care nursing challenges. J Clin Nurs. 2015;24(7-8):991–8 [PubMed: 25597494].
34. Brown SM, Rozenblum R, Aboumatar H, Fagan MB, Milic M, Sarnoff Lee B, et al. Defining patient and family engagement in the intensive care unit. Am J Respir Crit Care Med. 2015;191(3):358–60 [PubMed: 25635496].
35. Olding M, McMillan SE, Reeves S, Schmitt MH, Puntillo K, Kitto S, et al. Patient and family involvement in adult critical and intensive care settings: a scoping review. Health Expect. 2016;19(6):1183–202 [PubMed: 27878937].
36. Davidson JE, Powers K, Medayat KM, Tieszen M, Kon AA, Shepard E, et al. Clinical practice guidelines for support of the family in the patient-centered intensive care unit: American College of Critical Care Medicine Task Force 2004-2005. Crit Care Med. 2007;35(2):605–22 [PubMed: 17205007].
37. Lederman Z. Family presence during cardiopulmonary resuscitation. J Clin Ethics. 2019;30(4):347–55.
38. Organización Mundial de la Salud. Día Mundial de la Seguridad del Paciente 2019. [Internet]. [17 de septiembre de 2019; accessed 14 Jul 2021].
39. Rodríguez E, Añel RM. Campaña de sensibilización ciudadana en Seguridad del Paciente: Modelo de Plan de Comunicación. Rev Esp Comun en Salud [Internet]. 2019;10:206–17.
40. Rodríguez E, Añel RM. Campaña de sensibilización ciudadana en Seguridad del Paciente: Modelo de Plan de Comunicación. Rev Esp Comun en Salud [Internet]. 2019;10:206–17 [accessed 8 Jul 2021] Available from: https://e-revistas.uc3m.es/index.php/RECS/article/view/4606. [Google Scholar].
41. McKinley S, Nagy S, Stein-Parbury J, Bramwell M, Hudson J. Vulnerability and security in seriously ill patients in intensive care. Intensive Crit Care Nurs. 2002;18:27–36. ISSN 0964-3397.
42. Doyle C, Lennox L, Bell D. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. BMJ Open. 2013;3:1.
43. Integrated Care Patient reported outcome measures and patient reported experience measures - a rapid scoping review. NSW Agency for clinical innovation. Jack Chen University of New South Wales, Australia.
44. Escarrabill J, Jansà M. Experiències de pacients: el tercer pilar de la qualitat. Desembre 2018. Papers de la fundació Unió. Referent 17; 38-45.
45. Wolf JA, Niederhauser V, Marshburn D, LaVela SL. Operationalizing and defining the patient experience. Patient Exp J. 2014;1(1):7–19.
46. USP-ISMP Medication Errors Reporting Program (MERP) [access 8 Ago 2008].
47. Patient-Reported Indicators Surveys (PaRIS) (Patient-reported Indicator Surveys (PaRIS)(28). Available from: https://www.oecd.org/helath/paris.htm.
48. Black N. Patient reported outcome measures could help transform healthcare. BMJ. 2013;346:f167.
49. Bull C, Byrnes J, Hettiarachchi R, Downes M. A systematic review of the validity and reliability of patientreported experience measures. Health Serv Res. 2019;54(5):1023–35.

50. Escarrabill J, Almazán C, Barrionuevo-Rosas L, Moharra M, Fité A, Jiménez J. Elementos clave que influyen en la experiencia del paciente Patients reported experience measurements (PREM) [Internet]. Barcelona: Agencia de Calidad y Evaluación Sanitarias de Cataluña. Departamento de Salud. Generalitat de Cataluña; 2020 [accessed 8 Jul 2024].
51. McKinley S, Nagy S, Stein-Parbury J, Bramwell M, Hudson J. Vulnerability and security in seriously ill patients in intensive care. Intensive Crit Care Nurs. 2002;18:27–36.
52. OECD (2019). Patient reported safety indicators: question set and data collection guidance.
53. SEMICYUC. In: Indicadores de calidad del enfermo crítico; 2017.