



ORIGINAL

Main information requests of family members of patients in Intensive Care Units[☆]

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KEYWORDS

Communication;
Critical care;
Decision making;
Family;
Health knowledge, attitudes, practice;
Needs assessment;
Professional-family relations;
Patient care planning

Abstract

Objective: To compile an inventory of information requests prioritized by the family members, to find out which professionals they consider able to respond these requests, and to explore the differences in perception between family members and professionals.

Design: Qualitative analysis of content validation and descriptive cross-sectional study.

Scope: 41 Spanish ICU.

Participants: Relatives, physicians and nurses of critical patients.

Intervention: From an initial list of questions extracted from literature review, physicians, nurses, and relatives of critical patients incorporated issues that they considered not included. After analyzing content validity, a new list was obtained, which was again submitted to the participants' assessment to evaluate the level of importance that they assigned to each question and which professional they considered appropriate to answer it.

Results: Most important questions for the relatives: concern about the clinical situation, measures to be taken, prognosis and information. There was a coincidence between relatives and professionals in the priority issues for families. There were significant differences in the importance given to each question: between doctors and relatives (72/82 questions), and between nurses and relatives (66/82 questions) ($p < .05$). For the relatives, 63% of the questions could be answered by doctors or nurses, 27% preferably by doctors and 10% by nurses.

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[◇] The names of the collaborating professionals in this study are related in [Annex 1](#).

PALABRAS CLAVE

Comunicación;
Cuidados críticos;
Toma de decisiones;
Familia;
Conocimientos,
actitudes y práctica
en salud;
Evaluación de
necesidades;
Relaciones
profesional-familia;
Planificación de
atención al paciente

Conclusions: The most relevant issues for families were prognosis and severity, but also the need for information. Healthcare professionals tend to underestimate the importance of many of the questions that concern families. Relatives feel that most of their concerns can be resolved either by doctors or nurses.

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Principales demandas informativas de los familiares de pacientes ingresados en Unidades de Cuidados Intensivos

Resumen

Objetivo: Elaborar un catálogo de demandas informativas priorizadas por los familiares, conocer qué profesionales consideran estos que pueden responder a estas demandas y explorar las diferencias de criterio entre familiares y profesionales.

Diseño: Análisis cualitativo de validación de contenido; estudio descriptivo transversal.

Ámbito: Cuarenta y una UCI españolas.

Participantes: Familiares, médicos y enfermeras/os de pacientes críticos.

Intervención: De un listado inicial de preguntas extraído de revisión de la literatura, médicos, enfermeras/os y familiares de pacientes críticos incorporaron cuestiones que consideraron no incluidas. Tras análisis de validación de contenido, se obtuvo un nuevo listado que fue valorado nuevamente por los participantes para determinar el nivel de importancia que asignaban a cada pregunta y qué profesional consideraban adecuado para responderla.

Resultados: Cuestiones más importantes para los familiares: preocupación por la situación clínica, medidas a tomar, pronóstico e información. Existió coincidencia entre familiares y profesionales en las cuestiones prioritarias para las familias. Existieron diferencias significativas en la importancia dada a cada pregunta: entre médicos y familiares (72/82 preguntas) y entre enfermeras/os y familiares (66/82 cuestiones) ($p < 0,05$). Para los familiares, el 63% de las preguntas podrían ser contestadas por médicos o enfermeras/os indistintamente, el 27% preferentemente por los médicos y 10% por las enfermeras/os.

Conclusiones: Las cuestiones más relevantes para las familias fueron pronóstico y gravedad, pero también la necesidad de información. Los profesionales sanitarios tendemos a subestimar la importancia de muchas de las cuestiones que preocupan a las familias. Los familiares consideran que la mayoría de sus inquietudes pueden ser resueltas indistintamente por médicos o enfermeras/os.

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Introduction

The fact that most patients assisted at Intensive Care Units (ICU) are unable to communicate themselves makes their families the main speakers in the information process.¹ There are multiple studies²⁻⁵ that say that the priorities of the families of critically ill patients are information and nearness with the patient and the medical team, being this need for information especially relevant for the families of patients who have passed away or are about to.⁶ Clear, easy to understand information is the key to go from that initial stage of confusion to a better control of the situation,⁷ understand the situation of the patient and promote implication during the decision-making process since information provides us with elements that make it easier to choose between this or that option.⁸

The information process to the families at the ICU can be better. This is what the scientific literature, both in

Spain^{9,10} and worldwide^{8,11} tells us. Some studies tell us that the difficulties identified during the first decade of the 21st century are still not solved such as the lack of team work, the role of the nursing team that does not know what kind of information they can disclose, or the need for consensus on the contents of the information provided.^{12,13}

These difficulties are very relevant and have a direct impact on the quality of the information process. At the Spanish ICUs, the doctor is the "official" spokesperson.^{14,15} Information is usually provided once a day¹⁵ and at a given time. In a high percentage of cases this information is whether not understood⁸ or misunderstood.¹⁶ Usually, this information is all about technical aspects and issues that the medical team considers relevant, and these aspects may coincide, or not, with the family's preferences or needs. So it comes as no surprise that the families have doubts afterwards and try to solve them with other resources such

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