



ORIGINAL

Satisfaction in the Intensive Care Unit (ICU). Patient opinion as a cornerstone[☆]



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KEYWORDS

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Abstract

Objective: To study the agreement between the level of satisfaction of patients and their families referred to the care and attention received during admission to the ICU.

Design: A prospective, 5-month observational and descriptive study was carried out.

Setting: ICU of Marqués de Valdecilla University Hospital, Santander (Spain).

Subjects: Adult patients with an ICU stay longer than 24 h, who were discharged to the ward during the period of the study, and their relatives.

Intervention: Instrument: FS-ICU 34 for assessing family satisfaction, and an adaptation of the FS-ICU 34 for patients. The Cohen kappa index was calculated to assess agreement between answers.

Results: An analysis was made of the questionnaires from one same family unit, obtaining 148 pairs of surveys (296 questionnaires). The kappa index ranged between 0.278 and 0.558, which is indicative of mild to moderate agreement.

Conclusions: The families of patients admitted to the ICU cannot be regarded as good proxies, at least for competent patients. In such cases, we must refer to these patients in order to obtain first hand information on their feelings, perceptions and experiences during admission to the ICU. Only when patients are unable to actively participate in the care process should their relatives be consulted.

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PALABRAS CLAVE

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Concordancia

Satisfacción en la Unidad de Cuidados Intensivos (UCI): la opinión del paciente como piedra angular**Resumen**

Objetivo: Estudiar la concordancia entre los grados de satisfacción de los pacientes y sus familiares (ambos pertenecientes a un mismo núcleo familiar) en cuanto a los cuidados y atenciones proporcionados durante su estancia en la UCI.

Diseño: Estudio transversal, observacional, descriptivo y prospectivo durante 5 meses.

Ámbito: UCI del Hospital Universitario Marqués de Valdecilla de Santander.

Sujetos: Pacientes mayores de 18 años con estancia mayor de 24h que fueron dados de alta de la UCI durante el período de estudio y familiares de dichos pacientes.

Intervención: Instrumento: cuestionario FS-ICU 34 para evaluar la satisfacción de los familiares de pacientes ingresados en la UCI y adaptación de dicho cuestionario para el paciente. Se determina el grado de concordancia mediante el índice de kappa ponderado para muestras pareadas.

Resultados: Se analizaron todos los cuestionarios procedentes de un mismo núcleo familiar, obteniéndose un total de 148 pares de cuestionarios (296 encuestas). Se obtuvieron índices kappa que oscilaron entre 0,278 y 0,558, lo que indica grados de concordancia entre débiles y moderados.

Conclusiones: Los familiares de los pacientes ingresados en la UCI no pueden ser considerados unos representantes adecuados, al menos para el subgrupo de pacientes competentes. En estos casos debemos acudir a esos pacientes para conocer de primera mano sus sentimientos, percepciones y vivencias durante su estancia en la UCI. Solo cuando los pacientes no están en condiciones de participar activamente en el proceso asistencial debemos acudir a sus familias.

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Introduction

Intensive Care Units (ICUs) have become places where high scientific-technical quality medical care is provided. However, as a result of the characteristics inherent to these Units, such care must also be accompanied by special attention and treatment of the patients and their families.¹

In the year 2001, the Institute of Medicine published an article entitled: "Crossing the quality chasm", which defended the concept of "Medicine focused on the patient", in contraposition to "Medicine focused on the supplier or on the disease", which up until then had characterized the physician-patient relationship. The article established a series of recommendations referred to treatment and the decision-making process, based on and adapted to the preferences and opinions of the patients.²

Posteriorly, a number of studies have shown Medicine focused on the patient to be associated to improved clinical outcomes.^{3,4} In this regard, it is in the ICU where this concept acquires particular relevance, since participation of the patients and their families exerts a profound influence upon the decision-making process and on the ultimate prognosis.⁵ In the context of the critical patient, we therefore can speak of "Medicine focused on the tandem patient/family".

Often as a consequence of the disease or because of the seriousness of the clinical condition, patients admitted to the ICU may not be able to actively participate in the care process. Consequently, in this scenario we usually resort to their families. Traditionally, the patient relatives have been

viewed as hypothetical "mediators" or "representatives" of the patients as regards care and decision making within the ICU – particularly when the patients themselves are unable to state an opinion or decide about their illness. In this respect, few studies have attempted to gain first hand knowledge of the opinion of the patients in the setting of the ICU.^{6,7}

In recent years, a number of instruments have been developed with the aim of measuring the level of satisfaction of the relatives of patients admitted to the ICU.⁸⁻¹³

However, assessment of the level of satisfaction of the patient admitted to the ICU has not been as well developed as in the case of the relatives.¹⁴⁻¹⁷ The main reasons for this seem obvious: the seriousness of the patient condition, which often makes communication impossible; the variety of intensive treatments involved; altered levels of consciousness; and the fact that the mentioned complexity of the situation often causes patients to be unable to make decisions concerning their personal condition. This is the principal reason why the assessment of user satisfaction in the ICU has focused mainly on the patient relatives.

From this perspective, it is necessary for health professionals to know, understand and assume the point of view of the patients in order to increase their satisfaction and the quality of the care provided. Within the intervention lines established by the Strategic Plan of the Spanish Society of Intensive and Critical Care Medicine and Coronary Units (*Sociedad Española de Medicina Intensiva, Crítica y Unidades Coronarias, SEMICYUC*), it was considered of interest to develop tools capable of contributing to

continuous quality improvement. This gave rise to the document "Quality indicators in the critical patient", where satisfaction measured by means of a questionnaire addressing perceived quality at discharge from the Department of Intensive Care Medicine (DICM) was defined as a relevant indicator.¹⁸

Our group carried out a study evaluating satisfaction in the ICU among both the relatives of surviving patients and the relatives of patients that died, and constituted a pioneering effort in measuring the level of satisfaction among the ICU-discharged patients themselves.¹⁹

The present study intends to take a step further by determining whether the relatives can be regarded as good proxies of the patients regarding experiences and decision making, as has traditionally been assumed.

Patients and methods

The present cross-sectional, prospective, descriptive observational study was carried out during a 5-month period in 2011 in Marqués de Valdecilla University Hospital (Santander, Spain)—a third level hospital serving as reference center in this region of Spain.

The study included competent patients over 18 years of age discharged from the ICU after a stay in the Unit of over 24 h, and who agreed to participate in the project, and their direct relatives.

A relative was taken to be a person with close family, social or emotional ties to the patient. This consequently included not only blood relatives but also people close to the patient. Only one relative per patient was considered, with inclusion after agreeing to participate in the study.

The DICM has a total of 30 ICU beds distributed into two Medical-Surgical Units and one Maternal-Children's Unit. The staff in turn is composed of physicians, nurses, nursing assistants and attendants, as well as external staff ascribed to the ICU (e.g., administrative staff).

The patients admitted to the ICU can be medical, surgical (general surgery, neurosurgery, thoracic surgery, specialties), polytrauma cases, or liver, pancreas-kidney and lung transplant patients. Pediatric patients and cardiological or post-heart surgery patients are not included.

Measurement instrument

Of all the instruments described in the literature for measuring family satisfaction, we decided to use the Family Satisfaction in the Intensive Care Unit (FS-ICU 34) questionnaire in its Spanish language version, with some concrete modifications such as the inclusion of questions referred to the work of the nursing assistants and attendants grouped under "other ICU staff", in order to adjust the instrument to the concrete needs of our setting.

In an attempt to incorporate the key elements of a good ICU humanization plan, we moreover included questions regarding the management of symptoms and perceptions, rating of the work and attention received by the different professionals, the ICU environment (noise, illumination, intimacy and comfort), assessment of visits and the work done by the Extended Intensive Care Service.²⁰

During patient admission, we identified the corresponding relative and assessed patient competence or not for inclusion in the study. At least 24 h after discharge from the Unit, and once in the hospital ward, an intensivist delivered the questionnaires to the patient and family, and retrieved them a few days later.

In order to measure the satisfaction of the patients, we adapted the items of the dimension referred to care of the FS-ICU 34 family questionnaire. Questions relating to demographic data were included. The rest of the study questionnaire followed a structure parallel to the family questionnaire, including the sections referred to care received, nursing staff, medical staff, other ICU staff, the wish for religious or psychological support, the ICU environment (noise, illumination, intimacy and comfort), the assessment of visits, and a global evaluation of the care and work carried out by the Extended Intensive Care Service. Lastly, an open-format question addressing comments or suggestions was included.

Exclusion criteria

The exclusion criteria varied slightly according to the target population involved (i.e., patients or relatives).

Patients interviewed: We excluded patients under 18 years of age; those discharge with a Glasgow coma score of under 15; patients with an ICU stay of less than 24 h; patients in which consensus-based limitation of therapeutic effort was decided; patients who died in the first 24 h of stay in the hospital ward following discharge from the ICU; individuals discharged home within the first 24 h of admission to the hospital ward; patients moved from the ICU to another hospital center; and individuals who for some reason were unable to read or understand Spanish.

Relatives interviewed: We excluded individuals under 18 years of age; the relatives of patients who died in the first 24 h of stay in the hospital ward following discharge from the ICU; the relatives of patients discharged home within the first 24 h of admission to the hospital ward; the relatives of patients moved from the ICU to another hospital center; and individuals who for some reason were unable to read or understand Spanish.

Questionnaires returned without answering were also regarded as excluded cases (patients or relatives, as applicable).

Ethical particulars

The study project was evaluated and approved by the local Clinical Research Ethics Committee.

Statistical analysis

Continuous variables were expressed as the mean \pm standard deviation (SD).

Conversion of the format of the questionnaire answers (Likert scale) to a 1–100 numerical scale (where 0 = worst result and 100 = best result) proved necessary in order to apply the required statistical calculations. The authors, in both the original version of the instrument (FS-ICU 34) and in

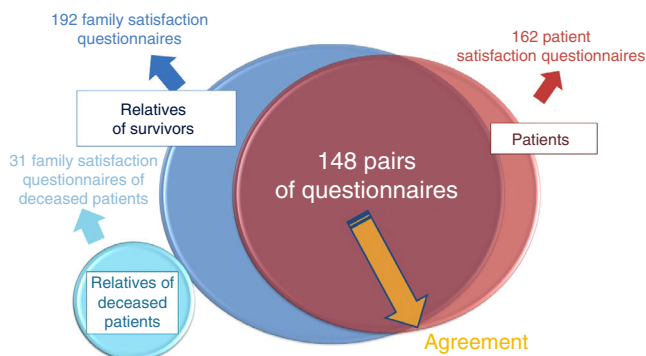


Figure 1 Graphic representation of the distribution of the study questionnaires. The intersection zone of the Venn diagram shows the pairs of questionnaires pertaining to the same family unit: 148 patient questionnaires and 148 questionnaires corresponding to the respective relative.

its shorter version (FS-ICU 24), recommend such conversion to allow more concrete processing of the results.

The Wilcoxon test for paired samples was used to compare the answers of the patients and relatives pertaining to the same family unit, since the data exhibited a non-normal distribution. In turn, the weighted kappa index (κ) for paired samples was used to measure the degree of agreement between the answers of both groups, since more than two categories on an ordinal scale were involved.

The kappa index ranges between 0 and 1, distributed as follows: $\kappa \leq 0.20$: poor agreement; $0.21 \geq \kappa \leq 0.40$: weak agreement; $0.41 \geq \kappa \leq 0.60$: moderate agreement; $0.61 \geq \kappa \leq 0.80$: good agreement; $0.81 \geq \kappa \leq 1.00$: excellent agreement.

Results

A total of 538 patients were admitted to the ICU during the study period. Following application of the different exclusion criteria, a total of 148 pairs of questionnaires (patient and relative) were collected—each corresponding to one same family unit (Fig. 1).

Patient characteristics

A total of 148 patients were finally interviewed—this representing 27.5% of the total patients admitted to the ICU during the study period ($n=538$; 103 deaths, 13 subjects under 18 years of age, 31 non-competent patients, 48 subjects in the ICU <24h, 14 with limitation of therapeutic effort in the ward, 8 deaths in the ward, 28 discharges to the hospital ward within less than 24h, 41 transfers to another hospital, 10 cases presenting cultural differences, 20 non-answered questionnaires, 60 system losses, 14 patient questionnaires not accompanied by the corresponding family questionnaire).

The age mean was 53.14 ± 13.89 years. Ninety-five responders were males (64.1%), and 104 lived outside the city (70.2%). The mean APACHE II score was 14.16 ± 6.98 .

Family characteristics

The age mean of the interviewed relatives was 46.23 ± 11.62 years. A total of 103 were females (69.59%). The most frequent kinship corresponded to wives ($n=40$, 27.02%), followed by daughters ($n=31$, 20.94%). Over one-half of the relatives ($n=85$, 57.43%) had no previous experience of the ICU. Most lived with the patient in the same home, and over 70% saw the patient more than once a week. A total of 120 of the interviewed families lived in the province (75.67%).

The levels of satisfaction in both groups were rated as “very good”: global satisfaction with the care received being 84.96 ± 11.91 points for the patients and 82.90 ± 12.63 for the relatives.

Comparison of results

Most of those interviewed considered the care received to be “very good” (the level of satisfaction according to the relatives being 79.6 ± 12.6 points, versus 82.4 ± 11.9 among the patients).

On comparing the results between patients and relatives (within one same family unit/paired samples), the levels of satisfaction were very high in both groups, and significant differences ($p < 0.05$) were only observed in relation to 5 items: two referred to the nursing staff (communication and respect shown: 86.1 ± 18.4 vs 84.2 ± 19.3 , respectively, and 91.1 ± 13.3 vs 88.5 ± 14.2), one referred to the medical staff (understanding of the medical explanations: 84.4 ± 18.9 vs 87.5 ± 18.5) and two referred to other staff (attendants: 77.3 ± 21.9 vs 85.2 ± 15.5 ; nursing assistants: 80.2 ± 21.7 vs 86.8 ± 15.8) (Table 1).

The first two items referred to the nursing staff received higher scores on the part of the patients than from their relatives. In contrast, understanding of the medical explanations and the attention and professionalism of the nursing assistants and attendants received comparatively poorer scores from the patients.

On comparing these same results between patients and relatives per different subgroups (sex of the patient, sex of the relative, ICU room involved, APACHE II score, residency in the city versus in the province), we identified a number of variables, such as the work of the nursing assistants and attendants, that maintained the same differences in all the mentioned subgroups, with poorer scores given by the patients in all cases. The explanations given by the medical staff were generally also poorer rated by the patients in all the subgroups.

Level of agreement of the answers

The kappa index was used to determine the level of agreement between the patients and their relatives. Agreement proved to be moderate, with κ values between 0.278 and 0.558 (Table 2).

The aspects related to the care received by the patient showed moderate agreement, with values between 0.479 and 0.558.

The aspects evaluating the professional care received by the nursing staff and physicians likewise showed weak to

Table 1 Comparison of means for paired samples (of the same family unit) between the answers of the patients and their relatives.

	PQ	Satisfaction patient	Satisfaction relative	Mean difference	CI lower	CI upper	p-value	
Care received								
<i>Concern and care for the patient</i>	148	93.5	94.3	-0.51	-2.31	1.30	0.58	
<i>Management of pain</i>	132	89.5	91.6	-1.14	-3.51	1.23	0.34	
<i>Management of dyspnea</i>	113	87.7	89.4	-0.66	-3.34	2.01	0.62	
<i>Management of anxiety</i>	116	85.2	88.2	-1.94	-4.98	1.10	0.21	
<i>Management of cold</i>	123	84.0	85.4	-0.41	-3.15	2.33	0.77	
<i>Management of heat</i>	120	84.7	85.4	0.83	-1.65	3.31	0.51	
Professional care								
<i>Nursing</i>								
Skills and competences	146	94.3	93.8	0.34	-1.32	2.01	0.68	
Communication with nursing	142	86.1	84.2	3.70	0.58	6.82	0.02	
Respect shown	139	91.1	88.5	3.42	1.26	5.57	0.00	
Comfort provided	136	88.4	87.9	1.65	-0.78	4.09	0.18	
Reduction of anxiety	130	86.3	86.4	1.15	-1.59	3.90	0.41	
General satisfaction with nursing	139	84.4	82.9	0.90	-2.54	4.34	0.61	
<i>Medical staff</i>								
Skills and competences	Attention	146	93.8	94.1	-0.68	-2.72	1.35	0.51
	Confidence	146	90.4	91.4	-0.68	-3.08	1.71	0.57
Communication with physician	Frequency	142	84.2	86.6	-1.06	-4.06	1.94	0.49
	Understanding	145	84.4	87.5	-5.00	-7.97	-2.03	0.00
General satisfaction with physician		145	81.3	82.3	-0.86	-3.74	2.02	0.55
<i>Nursing assistants</i>								
Professionalism and treatment		141	80.2	86.8	-6.38	-9.43	-3.34	0.00
<i>Attendants</i>								
Professionalism and treatment		138	77.3	85.2	-7.43	-10.78	-4.08	0.00
Global satisfaction		140		2.86	-0.62	6.33	0.11	
Extended Intensive Care Service								
<i>Opinion about the initiative</i>		127	93.9	94.0	-0.39	-3.27	2.48	0.79
<i>Work done</i>		122	92.2	92.0	0.41	-2.41	3.23	0.77
<i>General satisfaction with Extended Intensive Care Service</i>		116	85.0	82.3	3.02	-0.92	6.95	0.13

Column one examines the pairs of questionnaires (PQ) analyzed; columns two and three refer to the levels of satisfaction of the patients and their relatives; column four shows the differences between means (with negative values when the patient mean is smaller than the mean corresponding to the relative); columns five and six show the 95% confidence intervals (CI) (lower and upper limits); and the last column represents the p-value (level of significance $p < 0.05$). Those values reaching statistical significance appear in italics and boldface.

moderate agreement—the lowest values corresponding to the communication process.

The lowest level of agreement between patients and relatives was referred to the work of the nursing assistants and attendants.

We also explored the possible existence of differences in agreement according to certain characteristics of the

interviewed individuals: sex of the patient, ICU room involved, APACHE II score, sex of the relative, or place of residency. There were no significant differences referred to these characteristics, with the sole exception of the APACHE II score. In effect, the kappa index was almost always greater when the patient APACHE II score was below the median score (i.e., when the patients were less seriously ill).

Table 2 Kappa values between the patients and their relatives.

	Kappa
Care received	
<i>Concern and care of the patient</i>	0.513
<i>Management of pain</i>	0.479
<i>Management of dyspnea</i>	0.525
<i>Management of anxiety</i>	0.542
<i>Management of cold</i>	0.558
<i>Management of heat</i>	0.528
Professional care	
Nursing	
Skills and competences	0.528
Communication with nursing	0.359
Respect shown	0.435
Comfort provided	0.487
Reduction of anxiety	0.410
General satisfaction with nursing	0.412
Medical staff	
Skills and competences	Attention 0.391
	Confidence 0.419
Communication with physician	Frequency 0.468
	Understanding 0.402
General satisfaction with physician	0.539
Nursing assistants	
Professionalism and treatment	0.374
Attendants	
Professionalism and treatment	0.278
Religious support	0.528
Psychological support	0.510
Global satisfaction	0.456
Extended Intensive Care Service	
<i>Opinion about the initiative</i>	0.296
<i>Work done</i>	0.384
<i>General satisfaction with Extended Intensive Care Service</i>	0.472

None of the kappa values exceeded the threshold of 0.6 indicative of good agreement.

Discussion

Satisfaction in the ICU has become a very important issue over the last decade, considering that the patients and their families constitute the cornerstone of attention and treatment in the context of critical care. Our group has been working for several years in this field, seeking to know the opinions of these patients and their relatives with a view to improving the quality of our DIMC.^{19,21}

The fundamental aim of this study was to know the direct opinion of the patients that have been admitted to the ICU, and which because of their clinical characteristics were able to answer a questionnaire designed to evaluate their stay in the Unit, compare their answers with those of their relatives, and determine whether the latter can be regarded as adequate proxies of the patients, as has traditionally been assumed.

The levels of satisfaction were high in both interviewed groups. On comparing the answers, we observed significant differences in relation to 5 items. In this regard, the explanations given by the physicians received poorer scores from the patients than from their relatives. This probably reflects usual practice in the ICU, where the medical staff typically spends more time informing the family than the actual patient – perhaps forgetting that the ICU patient might be able to state an opinion and of course receive information.²² In this regard, in the European CoBaTrICE (Competency-Based Training in Intensive Care Medicine) questionnaire, the patients demanded “clarity of the explanations”, defined as “explaining the medical terms in such a way that they are easy to understand”.²³

The literature describes several factors that influence the satisfaction of the patients and their relatives in the ICU, with communication in the broadest sense of the word being a key factor. Indeed, information is one of the most highly valued items for the relatives and patients in the DICM.^{24–28}

While the communication and respect received from the nursing staff was associated to high levels of satisfaction in both groups, the scores were higher among the patients than in the case of the relatives. This supports the recommendations of Escudero et al., according to which “the professional must understand, deal with and assertively redirect inadequate emotional reactions while also showing understanding and empathy. The ties between the family and the nursing staff are characterized by greater confidence and the transmission of doubts and concerns. In this regard the information should be divided: nurses should talk about general patient care and the apparatuses used, while the physician should address the diagnosis, treatment and prognosis”.²⁹

The nursing assistants and attendants obtained somewhat lower scores in both interviewed groups. This is difficult to interpret, because such staff members are not comparable to those of other studies, as they are specific of the Spanish healthcare system. The aspects evaluated in relation to these professionals were referred to professionalism and the attention given. It is important to mention that this is one of the items where significant differences were observed between the scores given by the patients and their relatives—the former expressing comparatively lower levels of satisfaction. It is also one of the items showing the poorest agreement between the patients and relatives. The explanation for this could be that these professionals pertain to the ICU and are involved in activities that tend to cause greater patient discomfort (e.g., patient mobilization in the presence of pain, feeding without an appetite, personal hygiene when such measures cause discomfort for the patient, etc.). As a result, these professionals receive poorer scores.

We analyzed the agreement between the answers of the patients and their relatives, and found that the latter are

not good proxies of the patients regarding the situations experienced in the ICU—specifically of those patients who are able to answer the questionnaire. The only study addressing this issue to date has been published by Stricker et al.¹⁵. These authors carried out a prospective, multi-center observational study involving 235 patients and 266 relatives. The questionnaires were distributed after discharge from the ICU, and the instrument used was the FS-ICU 34 questionnaire in its German language version for the relatives, and an adaptation of that questionnaire in short form and focused on those aspects with a direct bearing upon medical care (e.g., treatment of pain, dyspnea or agitation) for the patients. Both groups showed high levels of satisfaction (with mean scores above 80), with discretely higher scores in the patient group (84.2 ± 16.9 vs 82.2 ± 17.2). On examining the agreement between the answers of the patients and their relatives, the authors obtained kappa indices of between 0.24 and 0.4, i.e., lower than in our own study, though these indices were nevertheless regarded as indicating “moderate agreement”. In addition, the authors compared agreement between the patients and different groups of relatives, and in this regard observed greater agreement when the relatives were the partners or spouses of the patients. The authors concluded that relatives may be regarded as good proxies of the patients. However, κ values of under 0.6 cannot be taken to represent good agreement.³⁰ Consequently, the results obtained by Stricker et al., with κ values below this limit for all the items, are not indicative of good agreement. Unfortunately, the opinions of the subgroup of patients that could not be interviewed (i.e., theoretically the most seriously ill individuals) are not known. As a result, the relatives in this case must be regarded as the only possible proxies as far as care and decision making are concerned, since these at least in theory are the people who know the patients best.

Puntillo et al.¹⁶ analyzed the agreement between 245 patients and 243 relatives, 103 nurses and 92 physicians regarding the perception of certain symptoms on the part of the patients, comparing the levels of intensity or discomfort caused by such symptoms in the patients or their relatives. The results yielded correlation coefficients of sufficient magnitude to justify taking the relatives into account when assessing the symptoms of those patients admitted to the ICU who are unable to communicate. Much lower correlation coefficients were obtained in the case of the physicians or nurses. However, the authors concluded that further studies are needed to establish how to measure or rate the perception of certain symptoms among patients that are unable to express themselves during admission to the ICU. In our study, it is important to note that agreement was greater when the patients were less seriously ill. This could be a result of the discussion of feelings and experiences between the patients and their relatives, causing them to show greater agreement in response to questions addressing the care provided. The fact that agreement was poorer in the more seriously ill patients raises an important doubt in relation to the key issue of the study: If agreement between the patients and relatives is poorer when the patients are more seriously ill, is it really acceptable to regard the relatives as adequate proxies or surrogates of the patients?

Until further studies are able to contribute additional information in this regard, the relatives of the more seriously ill patients will continue to be taken as adequate proxies for the assessment of symptoms and in decision making. However, the most relevant conclusion is that whenever possible, patients admitted to the ICU should be asked and evaluated, since they undoubtedly can offer more reliable information about their personal perception during admission to the ICU.

In the context of the current tendency to work to consolidate the structure, organization and functioning of the ICU with a view to improving comfort and ensuring humanization of the care provided,²⁹ dedicating more time and effort to listening to our patients seems a clear option that can help the ICU to become more personalized and comfortable, and capable of offering high human and scientific-technical quality.

Conclusions

The present study shows that competent patients admitted to the DICM can actively participate in the care process, thus making it feasible to measure their level of satisfaction—this aspect having received little attention in the literature to date.

The FS-ICU 34 questionnaire with minor modifications has been shown to be a valid instrument for assessing the satisfaction of patients discharged from the ICU, and could be used in Spain in other Units of similar characteristics.

As has been reported in the literature, the levels of satisfaction with the care received in the ICU are very high. In our study this has been confirmed for both the patients and their relatives, with no great differences between the two groups in terms of global values.

However, the level of agreement between the patients and their relatives was not found to be as high as theoretically presumed. For this reason, competent patients admitted to the ICU should be asked and considered, since they undoubtedly can offer more reliable information about their personal perception during admission to the ICU.

In the case of patients that are not in a condition to actively participate in the care process, we must resort to the relatives as proxies, since these theoretically are the people who know the patient best and can offer a more reliable impression of his or her feelings, experiences and perceptions.

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Authorship

The signing authors have collaborated in the project described in the article and have read the final manuscript prepared for publication.

Conflicts of interest

The authors declare that they have no conflicts of interest.

References

- Angus DC, Barnato AE, Linde-Zwirble WT, Weissfeld LA, Watson RS, Rickert T, et al. Use of intensive care at the end of life in the United States: an epidemiologic study. *Crit Care Med.* 2004;32:638–43.
- Crossing the quality chasm: a new health system for the 21st century. Institute of Medicine; March 2001.
- Dwamena F, Holmes-Rovner M, Gauden CM, Jorgenson S, Sadigh G, Sikorskii A, et al. Interventions for providers to promote a patient-centred approach in clinical consultations. *Cochrane Database Syst Rev.* 2012;12:CD003267.
- Aslakson R, Cheng J, Vollenweider D, Galusca D, Smith TJ, Pronovost PJ. Evidence-based palliative care in the intensive care unit: a systematic review of interventions. *J Palliat Med.* 2014;17:219–35.
- Norton SA, Hogan LA, Holloway RG, Temkin-Greener H, Buckley MJ, Quill TE. Proactive palliative care in the medical intensive care unit: effects on length of stay for selected high-risk patients. *Crit Care Med.* 2007;35:1530–5.
- Wennberg E. Proxies as surrogates for patients in the intensive care unit? *Acta Anaesthesiol Scand.* 2011;55:137–8.
- Kross EK, Engelberg RA, Downey L, Cuschieri J, Hallman MR, Longstreth WT Jr, et al. Differences in end-of-life care in the ICU across patients cared for by medicine, surgery, neurology, and neurosurgery physicians. *Chest.* 2014;145:313–21.
- Heyland DK, Rocker GM, Dodek PM, Kutsogiannis DJ, Konopad E, Cook DJ, et al. Family satisfaction with care in the intensive care unit: results of a multiple center study. *Crit Care Med.* 2002;30:1413–8.
- Rothen HU, Stricker KH, Heyland DK. Family satisfaction with critical care: measurements and messages. *Curr Opin Crit Care.* 2010;16:623–31.
- Pérez Cárdenas MD, Rodríguez Gómez M, Fernández Herranz AI, Catalán González M, Montejo González JC. [Evaluation of satisfaction among the relatives of patients admitted to an intensive care unit]. *Med Intensiva.* 2004;28:237–49 [in Spanish].
- Azoulay E, Pochard F, Chevret S, Lemaire F, Mokhtari M, Le Gall J, et al. Meeting the needs of intensive care unit patient families: a multicenter study. *Am J Respir Crit Care Med.* 2001;163:135–9.
- Santana Cabrera L, Ramírez Rodríguez A, García Martul M, Sánchez Palacios M, Martín González JC, Hernández Medina E. [Satisfaction survey administered to the relatives of critical patients]. *Med Intensiva.* 2007;31:57–61 [in Spanish].
- van den Broek JM, Brunsveld-Reinders AH, Zedlitz AM, Girbes AR, de Jonge E, Arbous MS. Questionnaires on family satisfaction in the adult ICU: a systematic review including psychometric properties. *Crit Care Med.* 2015;43:1731–44.
- Charles C, Gauld M, Chambers L, O'Brien B, Haynes RB, Labelle R. How was your hospital stay? Patients' reports about their care in Canadian hospitals. *CMAJ.* 1994;150:1813–22.
- Stricker KH, Kimberger O, Brunner L, Rothen HU. Patient satisfaction with care in the intensive care unit: can we rely on proxies? *Acta Anaesthesiol Scand.* 2011;55:149–56.
- Puntillo KA, Neuhaus J, Arai S, Paul SM, Gropper MA, Cohen NH, et al. Challenge of assessing symptoms in seriously ill intensive care unit patients: can proxy reporters help? *Crit Care Med.* 2012;40:2760–7.
- Jongerden IP, Slooter AJ, Peelen LM, Wessels H, Ram CM, Kesecioglu J, et al. Effect of intensive care environment on family and patient satisfaction: a before-after study. *Intensive Care Med.* 2013;39:1626–34.
- Martín MC, Cabré L, Ruiz J, Blanch L, Blanco J, Castillo F, et al. [Indicators of quality in the critical patient]. *Med Intensiva.* 2008;32:23–32 [in Spanish].
- Holanda Peña MS, Ots Ruiz E, Domínguez Artiga MJ, García Miguelez A, Ruiz Ruiz A, Castellanos Ortega A, et al. [Measuring the satisfaction of patients admitted to the intensive care unit and of their families]. *Med Intensiva.* 2015;39:4–12 [in Spanish].
- Holanda Peña MS, Domínguez Artiga MJ, Ots Ruiz E, Lorda de los Ríos MI, Castellanos Ortega A, Ortiz Melón F. SECI (Servicio Extendido de Cuidados Intensivos): mirando fuera de la UCI. *Med Intensiva.* 2011;35:349–53.
- Holanda Peña MS [tesis doctoral] Medición de la satisfacción de los pacientes ingresados en la Unidad de Cuidados Intensivos y sus familiares. Santander: Facultad de Medicina, Universidad de Cantabria; 2015.
- Ricart A. La comunicación en Medicina Intensiva. 1.a ed REMI, Libro electrónico de Medicina Intensiva; 2008.
- CoBaTrICE Collaboration. The views of patients and relatives of what makes a good intensivist: a European survey. *Intensive Care Med.* 2007;33:1913–20.
- Siddiqui S, Sheikh F, Kamal R. What families want – an assessment of family expectations in the ICU. *Int Arch Med.* 2011; 4:21.
- Di Gangi S, Naretto G, Cravero N, Livigni S. A narrative-based study on communication by family members in intensive care unit. *J Crit Care.* 2013;28:483–9.
- Jacobowski NL, Girard TD, Mulder JA, Ely EW. Communication in critical care: family rounds in the intensive care unit. *Am J Crit Care.* 2010;19:421–30.
- Hwang DY, Yagoda D, Perrey HM, Tehan TM, Guanci M, Ananian L, et al. Consistency of communication among intensive care unit staff as perceived by family members of patients surviving to discharge. *J Crit Care.* 2014;29:134–8.
- Shaw DJ, Davidson JE, Smilde RI, Sondoozi T, Agan D. Multidisciplinary team training to enhance family communication in the ICU. *Crit Care Med.* 2014;42:265–71.
- Escudero D, Viña L, Calleja C. [For an open-door, more comfortable and humane intensive care unit. It is time for change]. *Med Intensiva.* 2014;38:371–5 [in Spanish].
- Cohen J. Weighted kappa: nominal scale agreement with provision for scaled disagreement or partial credit. *Psychol Bull.* 1968;70:213–20.