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Measuring family-centred care practices in adult ICUs: the EMPATHIC-F questionnaire

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ABSTRACT

Background: Engaging relatives in the care of critically ill patients is associated with better outcomes. It is crucial to empower relatives to provide feedback. Valid satisfaction instruments are essential to identify best practices and areas for improvement.

Aim: To adapt the Spanish version of the EMpowerment of PArents in The Intensive Care-30 (EMPATHIC-30) questionnaire in adult Intensive Care Units (ICUs) and psychometrically test the EMpowerment of PAtients in The Intensive Care-Family (EMPATHIC-F) questionnaire to measure family satisfaction.

Design: Cross-sectional, prospective study conducted in two adult ICUs. Participants were relatives of patients who were discharged alive from the ICUs with an ICU length-of-stay >24hours. The EMPATHIC-F questionnaire is divided into five domains that are related to the family-centred care principles. Responses are provided on a 6-point ordinal Likert scale, a score of >5 is considered acceptable.

Results: Patients' relatives confirmed the adaptation of the instrument. A total of 262 relatives responded to the EMPATHIC-F questionnaire (97% response rate). The empirical structure of the instrument was established by confirmatory factor analysis confirming 30 statements within five theoretically conceptualized domains: information, care and treatment, family participation, organization, and professional attitude. On item level, two statements scored a mean below 5.0. Cronbach α at domain level which was between 0.64–0.75. Congruent validity was adequate between the five domains and four general satisfaction items (rs 0.26–0.54). The non-differential validity was confirmed with no significant effect size between three patients' demographic characteristics and the domains.

Conclusions: The EMPATHIC-F questionnaire is a reliable and valid quality performance indicator to measure the perceptions of family members in adult ICU settings.

Relevance to clinical practice: The EMPATHIC-F questionnaire can be used to benchmark and provides a framework for standardized quality improvement toward the development of a family-centred care philosophy within adult ICUs.

INTRODUCTION

Over the past decades, research in critical care and advancements in medical technology have resulted in better ICU outcomes. However, critical illness remains an important and stressful life event for patients and their families. Due to patients' illness severity, stressful decision-making often falls to family members.¹ Relatives of critically ill patients increasingly demand to be involved in patients' daily care and to stay at the bedside as much as possible. Moreover, the engagement of family members in the care of seriously ill patients is associated with better outcomes.^{2,3} This reflects the importance of a family-centred care (FCC) approach to deliver high-quality care to the patient and family while recognizing the needs and experiences of the family members. Furthermore, guidelines for FCC encourage healthcare professionals to engage with family members to participate in the decision-making process about treatment and care of their relative.⁴ Therefore, it is considered that structured interventions and approaches to support family members of critically ill patients are needed.

Patient and family satisfaction outcomes are increasingly recognized as a quality performance indicator in intensive care settings. ⁵⁻⁸ It is important to empower patients and family members to provide feedback to ICU teams. Consequently, satisfaction outcomes might provide valuable information to improve ICU practices such as safety culture, quality-of-care, communication between family and ICU teams, and family-centred care. Accordingly, validated satisfaction measurement tools are essential to evaluate healthcare professionals' performance from the patients' and relatives' points of view. Besides, these tools can be used to detect best practices and areas of care to improve. ⁹ Unfortunately, very few instruments exist to measure the experiences and satisfaction of relatives in adult critical care settings. ¹⁰ Moreover, none of the previously validated instruments in adult ICUs cover all the core principles of FCC. Satisfaction with care is at the heart of a framework comprised of the respect for the needs of family members, adequate information, participation in decision-making, emotional and physical support, and coordination of care.

In contrast, there is a broadly studied satisfaction instrument in paediatric intensive care (PICU) settings. Latour *et al.* created an instrument to assess quality performance and satisfaction

with care amongst parents in PICU. It covers five family-centred care domains: information, organization, care and treatment, professional attitude, and parent participation. The reduced 30-item EMpowerment of PArents in The Intensive Care (EMPATHIC-30) questionnaire was developed and tested in eight Dutch PICUs based on the experiences of both parents and healthcare professionals. Subsequently, the EMPATHIC-30 questionnaire has been validated and used in countries such as Australia, Denmark, Singapore, Brazil and Spain to measure parent satisfaction. He-18

Taking the FCC principles and domains of the EMPATHIC-30 into account, we hypothesized that the EMPATHIC-30 questionnaire could be adapted and used in adult critical care settings as a standardized measure of family members' experience and satisfaction of ICU care. Therefore, the objective of this study was to adapt and test the validated Spanish version of the EMPATHIC-30 questionnaire in adult critical care settings. In addition, this study aimed to explore relatives' experiences and satisfaction with FCC domains in the ICU.

MATERIALS AND METHODS

This cross-sectional study was designed to adapt and validate the Spanish EMPATHIC-30 questionnaire in the adult ICU, thus constructing and renaming it the EMpowerment of PAtients in THe Intensive Care – Family (EMPATHIC-F) questionnaire. Data were collected between November 2019 and May 2020. The study was conducted in accordance with the 2013 amended Declaration of Helsinki. The local Research Ethics Committee approved the study (ref. CAEG 2019/461). A written informed consent was obtained from all participants. Participation was on a voluntary basis, and all questionnaires were anonymous.

Settings

The EMPATHIC-F questionnaire was tested in two ICUs located in a tertiary University affiliated general hospital situated in northwest Spain. Both ICUs are multi-disciplinary units which provide both medical and surgical adult intensive care, with a total of 23 beds and over 1000 admissions per year. Visiting policies vary between Units. ICU-1 has a more restricted 1-hour twice a day visiting policy coinciding with mealtimes. To the contrary, ICU-2 has an open visiting policy

where relatives may stay with their loved ones most of the time except at night and four hours in the morning. During the last 3 months of the study, visiting policies changed in both Units towards a more restricted policy (1-hour a day) due to COVID-19 pandemic restrictions.

Participants and Data Collection

Based on the number of ICU admissions (1000 per year), considering a 95% of safety and to achieve a precision of 5.00%, a sample of at least 259 participants was deemed necessary for adequate psychometric analysis. ¹⁹ Eligible study participants were patients' primary support persons (PSPs - relatives or primary caregivers) of those patients admitted and discharged from both ICUs between November 2019 and May 2020. PSP was considered the person in the patient's environment (family member or not) who voluntarily assumes the role of responsibility for the patient's care and is willing to make surrogate decisions for the patient's best interest. Questionnaires were handed over to the PSPs by the researchers at ICU discharge. PSPs were able to return the questionnaire in a separate box on the ICU or post it later from home. Inclusion criteria were ICU length of stay greater than 24 hours and good comprehension of the Spanish language by PSPs. The level of Spanish language was assessed during admission when communicating with the PSPs. Three exclusion criteria were defined: (1) discharge from ICU within 24 hours; (2) ICU readmission, a questionnaire was only given after first admission; and (3) patient's death during ICU admission.

Questionnaire adaptation

The original EMPATHIC-30 questionnaire was developed in the Netherlands in eight PICUs.¹³ The Dutch questionnaire was translated into Spanish, culturally adapted, and validated by Pilar Orive *et al.*¹⁸ Following the international principles of good practice,²⁰ the adaptation process was carried out to ensure accuracy and reliability. This method consisted of a stepwise process. The first step consisted in the preparation of the questionnaire by the researchers working along with the original instrument promoter (Prof. J.M. Latour) and the instrument Spanish translator (Prof. F.J. Pilar Orive). Two researchers independently adapted the EMPATHIC-30 questionnaire to the adult ICU setting. The next step was to assure that these versions were suitable for the Spanish adult ICU setting, after which the research team (two critical care nurses and two intensivists)

unified them. Subsequently, harmonization of the unified version comprised reaching full agreement within the research team. This was followed by testing the instrument for cognitive equivalence with a convenience sample of 10 patients' PSPs. Minor wording changes were made based on the comments of the relatives. The final questionnaire was edited and represented as the EMPATHIC-F which was subject to the validity and reliability assessment. The last step is the final report presented in this article.

EMPATHIC-F questionnaire

The self-reported EMPATHIC-F questionnaire comprises three sections. The first collects general information about the ICU patients and their PSP, the second collects information on the PSP experiences during the patients' admission in the ICU, and the third section comprises four openended questions in which the PSP is invited to share the ICU experiences ('during the admission period', 'during the actual ICU stay', 'regarding discharge from the ICU', and any other 'general experiences').

Section 2 of the questionnaire consists of 30 statements conceived to evaluate the family experiences and satisfaction with care provided by intensive care nurses and physicians. The EMPATHIC-F questionnaire is divided into five domains that are related to the FCC principles: information (5 items), care and treatment (8 items), family participation (6 items), organization (5 items), and professional attitude (6 items). Responses are provided on a 6-point ordinal Likert scale (1 = totally disagree; 6 = totally agree), with an additional 'not applicable' option for each statement.

Statistical analysis

Firstly, a descriptive analysis was performed. Categorical variables were expressed as frequencies and percentages. Continuous variables were expressed with mean and standard deviation, or median and interquartile range, depending on their adjustment to a normal distribution (Kolmogorov-Smirnov test with Lilliefors correction). Comparisons between groups were analysed using either the Mann-Whitney test or the Kruskal-Wallis test in cases of variables with more than two factors. Confirmatory factor analysis (CFA) was tailored to unraveling the empirical structure of the interrelationship of the 30 statements. The final model was based on

both theoretical and statistical plausibility. The measures applied in this study were χ^2 test of model fit, and the ratio of χ^2 /df < 3 represents a good model fit. Reliability was assessed using Cronbach's α to confirm internal consistency of the statements within the domains of the instrument. A Cronbach's α of greater than 0.70 represents reasonable to satisfactory reliability estimates. Spearman rank correlation test to estimate the relationship between domains and four general satisfaction questions was used to confirm congruent validity. The four satisfaction questions were related to the following: recommending the ICU to others, coming back again if needed, overall satisfaction of physicians, and overall satisfaction of nurses. These general satisfaction questions have been used by industry and healthcare organizations such as the Friends and Family test by the National Health Services in the United Kingdom. Analysis was performed using R statistic software (version 3.5.2), and for all analyses a p-value < 0.05 was considered to be statistically significant.

RESULTS

A total of 472 patients were admitted to the ICU over the 6-month study period and 270 PSPs were invited to complete the EMPATHIC-F questionnaire. Overall, 262 (97.0%) PSPs responded (Electronic Supplement Material 1). Characteristics of the patients and PSPs are presented in Table 1. Patients' children (39.7%) and spouses (24.4%) were the most frequent PSPs who answered the questionnaires.

Mean and SD of the individual statements are presented in Electronic Supplement Material 2 and are ranked per domain on the highest mean score. A score greater than 5.0 was considered acceptable. Most of the 30 items performed well, two answers (6.7%) showed a mean value less than or equal to 5.0: one in the care and treatment domain ("Every day we knew who was responsible for our relative, regarding the nurses"), and one in the family participation domain ("We were able to be close to our relative even during invasive procedures"). The internal consistency of the five domains, expressed as Cronbach's α , ranged between 0.64 (Organization) and 0.75 (Professional attitude) (Table 2). Deletion of individual items did not affect the domain level Cronbach's α (Electronic Supplement Material 2). All domains of the EMPATHIC-F

questionnaire showed good positive correlations with the four general satisfaction statements which confirms adequate congruent validity (Table 3). Mean values of the gold standards "ICU recommendation to others" and "come back again if needed" were 5.83 ± 0.52 and 5.82 ± 0.60 , respectively. The overall satisfaction measures for physicians and nurses (answer scale was 1 extremely poor to 10 excellent) were 9.75 ± 0.42 and 9.68 ± 0.48 , respectively. As shown in Table 4, there was no significant difference between the mean scores of the domains and patients' characteristics. The effect size measured with Cohen's d was always less than 0.30.

The median domain responses ranged from 5.7 in the family participation to 6.0 in the professional attitude domain (Table 2 and Electronic Supplement Material 3). Interestingly, very few participants choose the "not applicable" response type. It was selected most frequently for two items: "The ICU could easily be reached by telephone" (n = 115; 43.9%) and "Even during invasive procedures, we could always stay close to our relative" (n = 55; 21.0%).

During the process of structural equation modelling, the CFA confirmed that the performance of the model fit of the 30 statements in the five domains was adequate (p < 0.001). Standardized model parameter estimates show good explained variance of latent and dependent variables of the fitted model (Electronic Supplement Material 4), and there are no signals of any problem of the constructed domains.

DISCUSSION

Family-centred care has been defined as an approach to health care that is respectful of and responsive to individual families' needs and values.⁴ It requires that the patient's family participates and collaborates with healthcare professionals as partners in care. Individualized care by paying attention to what patients and family members need must be part of the humanization of intensive care.²³ Thus, the implementation of FCC should further improve ICU care. Current efforts to explore family satisfaction serve as a quality performance indicator in critical care setting.^{5,8} In this sense, the availability of a valid family-reported outcome measure would enable benchmarking and might contribute to identifying interventions to improve quality of care in the ICU.

Unfortunately, in recent years, only a few ICU family satisfaction instruments have been developed and tested. Despite the Family Satisfaction in the Intensive Care Unit questionnaire (FS-ICU) being the most widely validated measure of family experience in adult ICU,^{24,25} it did not specifically originate from a FCC perspective but from frameworks of patient satisfaction, decision-making, and quality of end-of-life care.¹⁰ Moreover, the FS-ICU only measures family satisfaction in two domains: satisfaction with care and satisfaction with medical decision-making.^{26,27} In contrast, the EMPATHIC-30 questionnaire, which was broadly studied in PICU settings,¹⁴⁻¹⁸ covers five FCC domains: information, organization, care and treatment, professional attitude, and parent participation.¹³ The 30 statements of this questionnaire have been shown to provide a comprehensive conceptualization of parent satisfaction. This instrument fits in the concept of continuous quality of care measurements, empowerment of parents and international benchmarking strategies. In view of the above, we undertook our study to try to adapt the EMPATHIC-30 into the EMPATHIC-F questionnaire for adult critical care settings, and to subsequently validate it.

Our results indicated that, with slight adaptations, the utility of the EMPATHIC-30 may be extended to adult critical care settings. The EMPATHIC-F questionnaire reliability and validity testing indicated an adequate performance in a Spanish adult critical care setting. We used Cronbach α to assess the reliability of the questionnaire. We found that the overall Cronbach α at domain level was homogenous, ranging between 0.64 (Organization) and 0.75 (Professional attitude). The organization and the family participation domains showed a questionable internal consistency with a value less than 0.7. We observed that the mean values of all the statements in both domains were above 5, and there was not a specific statement that could increase the Cronbach's α value. These results could be explained by the low number of participants. When testing the overall reliability of an instrument with many domains and a limited number of items, it has been recommended to do it with more than 300 responses. Taking this into account, further studies with larger sample sizes are suggested. To measure the congruent validity, we have assessed the correlation between the five EMPATHIC-F domains scores and four overall satisfaction indicators. We found an adequate congruent validity. In addition, we evaluated the

validity of EMPATHIC-F to confirm that it meant the same for subgroups of PSPs such as gender, whether the patient's admission was medical or surgical, and whether the patient needed mechanical ventilation during ICU stay. Each domain of the instrument really measures what it is expected for each of the subgroups since there were no significant differences in responses between each of these groups.

In contrast to Latour's original study,¹³ where the questionnaires were mailed 2-3 weeks after discharge of the child, we handed the questionnaires over to the PSPs face-to-face at ICU discharge. Our strategy resulted in a response rate up to 97%, higher than in the previous paediatric studies.^{13,29} Therefore, the EMPATHIC-F questionnaire seems to be easy to complete and feasible to use. Additionally, we wonder if the experience in ICU could be reported differently if expressed immediately compared to weeks after discharge.

In our study, overall and domain-specific family satisfaction items measured with the EMPATHIC-F questionnaire received excellent scores. However, potential for improvement was identified. Two statements showed a mean value less than or equal to 5.0: one in the care and treatment domain ("Every day we knew who was responsible for our relative, regarding the nurses"), and one in the familiar participation domain ("We were able to be close to our relative even during invasive procedures"). Both statements are important aspects of FCC. Concerning the first statement, the relationship between the responsible staff and the family members might be less effective if there is not one person in charge for the daily talks. The low score in the statement of knowing the responsible nurse of the patient might be explained by the fact that in the ICUs in which the study was conducted nurses are not present in daily information meetings with the families. Besides, patients are assigned to the responsibility of the same intensivist from admission to discharge in both ICUs, while they do not have an assigned nurse. Nurses use to be in charge of more than one patient each shift. For the second statement, no general rule exists about the presence of family members during invasive procedures, so decisions are individually made by the staff at any particular case scenario. During the study period, most physicians and nurses in both ICUs did not allow family members to stay near their relative during invasive procedures. Patients in these situations are usually scared and need to feel supported from their loved ones. Despite the fact that current guidelines recommend more presence of family members at the bedside,⁴ including during invasive procedures, this is not yet happening in our ICUs and hence there is room for improvement.

The "not applicable" response type was more frequent in two particular statements than in the others. The response of "not applicable" to "The ICU could easily be reached by telephone" may be explained because family members did not need to phone the ICU to know the status of their relative. They were daily informed by the responsible physician of their relative. Besides, intensivists could easily reach the families on their private mobile phones. The response of "not applicable" to "Even during invasive procedures, we could always stay close to our relative" may reflect that physicians and nurses do not allow family members in the ICU while invasive procedures are being undertaken. However, this could also mean that PSPs did not expect to be close to their family member during invasive procedures. Therefore, the results of the EMPATHIC-F should be carefully assessed and compared to the wider principles of FCC⁴ to identify interventions to improve these practices.

Our study has some limitations to be considered. First, it was conducted in only two ICUs in one hospital located in northwest Spain. However, the EMATHIC-F was based on the FCC principles and its current validation outcomes might justify its applicability to other ICUs. This offers an opportunity to invite several ICUs from different Spanish regions and perhaps including family satisfaction data in a continuously open national ICU registry for benchmarking. Second, we did not evaluate the test-retest reliability of our results by comparing two different cohorts in two different periods of time. After careful consideration, we decided not to burden the families with two questionnaires in a short period of time. Third, including only family members of patients who were discharged from the ICU alive prevented us from assessing the experiences of family members whose relative died in the ICU. Of course, this is an essential aspect that should be explored, perhaps with specific measurement instruments, in future studies. Fourth, correlations among domains and general questions are significant, but most are less than 0.5. Fifth, CFA was performed by the domains of the EMPHATIC-F and seems adequate, both for the coefficients of the model as for the Cronbach's alpha. However, analysing the model fit with

adjustment measures such as the comparative fit index and the Tucker–Lewis index was not possible due to the low sample size. Finally, secondary analysis of the data collected during the COVID-19 months were not performed as this was not the aim of the study.

CONCLUSIONS

The EMPATHIC-F questionnaire has been proven to be a reliable and valid instrument to measure family satisfaction in adult critical care settings in Spain. This instrument should contribute to the empowerment of relatives to work along with nurses and physicians focusing on high-quality ICU FCC issues. Furthermore, the EMPATHIC-F questionnaires, if adapted and tested in other languages, could allow benchmarking the quality of FCC between ICUs and between countries.

References

- 1. Prendergast TJ. Resolving conflicts surrounding end-of-life care. New Horiz. 1997;5(1):62–71.
- 2. Adelman RD, Tmanova LL, Delgado D, Dion S, Lachs MS. Caregiver burden: A clinical review. JAMA. 2014;311(10):1052–1060. https://doi.org/10.1001/jama.2014.304
- Lynn J. Strategies to ease the burden of family caregivers. JAMA. 2014;311(10):1021– 1022. https://doi.org/10.1001/jama.2014.1769
- Davidson JE, Aslakson RA, Long AC, Puntillo KA, Kross EK, Hart J, et al. Guidelines for Family-Centered Care in the Neonatal, Pediatric, and Adult ICU. Crit Care Med. 2017;45(1):103-128. https://doi.org/10.1097/CCM.0000000000002169
- Pronovost PJ, Berenholtz SM, Ngo K, McDowell M, Holzmueller C, Haraden C, et al. Developing and pilot testing quality indicators in the intensive care unit. J Crit Care. 2003;18(3):145-155. https://doi.org/10.1016/j.jcrc.2003.08.003
- de Vos M, Graafmans W, Keesman E, Westert G, van der Voort PHJ. Quality measurement at intensive care units: which indicators should we use? J Crit Care. 2007;22(4):267–274. https://doi.org/10.1016/j.jcrc.2007.01.002
- 7. Black N, Jenkinson C. Measuring patients' experiences and outcomes. BMJ. 2009;339:b2495. https://doi.org/10.1136/bmj.b2495
- 8. Flaatten H. The present use of quality indicators in the intensive care unit. Acta Anaesthesiol Scand. 2012;56(9):1078-1083. https://doi.org/10.1111/j.1399-6576.2012.02656.x
- 9. Latour JM, van Goudoever JB, Hazelzet JA. Parent satisfaction in the pediatric ICU. Pediatr Clin North Am. 2008;55(3):779-790. https://doi.org/10.1016/j.pcl.2008.02.013
- 10. Heyland DK, Tranmer JE, Kingston General Hospital ICU Research Working Group. Measuring family satisfaction with care in the intensive care unit: The development of a questionnaire and preliminary results. J Crit Care. 2001;16(4):142–149. https://doi.org/10.1053/jcrc.2001.30163

- 11. Latour JM, van Goudoever JB, Duivenvoorden HJ, Albers MJIJ, van Dam NAM, Dullaart E, et al. Construction and psychometric testing of the EMPATHIC questionnaire measuring parent satisfaction in the pediatric intensive care unit. Intensive Care Med. 2011;37(2):310–318. https://doi.org/10.1007/s00134-010-2042-y
- Latour JM, Duivenvoorden HJ, Hazelzet JA, van Goudoever JB. Development and validation of a neonatal intensive care parent satisfaction instrument. Pediatr Crit Care Med. 2012;13(5):554–559. https://doi.org/10.1097/PCC.0b013e318238b80a
- 13. Latour JM, Duivenvoorden HJ, Tibboel D, Hazelzet JA, EMPATHIC Study Group. The shortened EMpowerment of PArents in THe Intensive Care 30 questionnaire adequately measured parent satisfaction in pediatric intensive care units. J Clin Epidemiol. 2013;66(9):1045–1050. https://doi.org/10.1016/j.jclinepi.2013.02.010
- 14. Gill FJ, Wilson S, Aydon L, Leslie GD, Latour JM. Empowering Parents of Australian Infants and Children in Hospital: Translation, Cultural Adaptation, and Validation of the EMpowerment of PArents in The Intensive Care-30-AUS Questionnaire. Pediatr Crit Care Med. 2017;18(11):e506-e513. https://doi.org/10.1097/PCC.0000000000001309
- Mikkelsen G, Rasmussen B, Larsson K. Abstract P-355: Translation of the Danish version of the EMPATHIC-30 questionnaire. Pediatr Crit Care Med. 2018;19(6S):155-156.
- 16. Sng QW, Kirk AHP, Buang SNH, Lee JH. The Impact of Ethnic and Cultural Differences on Parental Satisfaction in the PICU. Pediatr Crit Care Med. 2017;18(4):e167–e175. https://doi.org/10.1097/PCC.0000000000001095
- 17. Lessa AD, Cabral FC, Tonial CT, Costa CAD, Andrades GRH, Crestani F, et al. Brazilian Translation, Cross-Cultural Adaptation, Validity, and Reliability of the EMpowerment of PArents in THe Intensive Care 30 Questionnaire to Measure Parental Satisfaction in PICUs. Pediatr Crit Care Med. 2020; Volume Online First. https://doi.org/10.1097/PCC.000000000000002594
- 18. Pilar Orive FJ, Basabe Lozano J, López Zuñiga A, Fernández YML, Argaluza JE, Latour JM. Spanish translation and validation of the EMPATHIC-30 questionnaire to measure

- parental satisfaction in intensive care units. An Pediatr (Barc). 2018;89(1):50-57. https://doi.org/10.1016/j.anpedi.2017.08.004
- 19. Teixidó A. *Ene 3.0: Programa para el cálculo del tamaño muestral*. Barcelona, Spain: Universitat Autónoma de Barcelona and GlaxoSmithKline; 2008.
- 20. Wild D, Grove A, Martin M, Eremenco S, McElroy S, Verjee-Lorenz A, et al. Principles of good practice for the translation and cultural adaptation process for patient-reported outcomes (PRO) measures: Report of the ISPOR task force for translation and cultural adaptation. Value Health. 2005;8(2):94–104. https://doi.org/10.1111/j.1524-4733.2005.04054.x
- 21. National Health Services (NHS). The Friends and Family Test. http://www.nhs.uk/NHSEngland/AboutNHSservices/Documents/FFTGuide_Final_180 7_FINAL.pdf. Accessed October 14, 2020.
- R Development Core Team: A language and environment for statistical computing. https://www.R-project.org/. Accessed October 14, 2020.
- 23. Vaeza NN, Martin Delgado MC, Heras La Calle G. Humanizing Intensive Care: Toward a Human-Centered Care ICU Model. Crit Care Med. 2020;48(3):385-390. https://doi.org/10.1097/CCM.0000000000000191
- 24. Wall RJ, Engelberg RA, Downey L, Heyland DK, Curtis JR. Refinement, scoring, and validation of the Family Satisfaction in the Intensive Care Unit (FS-ICU) survey. Crit Care Med. 2007;35(1):271e9. https://doi.org/10.1097/01.CCM.0000251122.15053.50
- 25. van den Broek JM, Brunsveld-Reinders AH, Zedlitz AMEE, Girbes ARJ, de Jonge E, Arbous MS. Questionnaires on family satisfaction in the adult ICU: a systematic review including psychometric properties. Crit Care Med. 2015;43(8):1731–1744. https://doi.org/10.1097/CCM.0000000000000000000
- 26. 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(7):1413–1418. https://doi.org/10.1097/00003246-200207000-00002

- 27. Latour JM, Zhu L, Gill FJ. Measuring Parent Satisfaction in the PICU Across the World: Does One Size Fits All? Pediatr Crit Care Med. 2017;18(4):393-395. https://doi.org/10.1097/PCC.0000000000001130
- Rouquette A, Falissard B. Sample size requirements for the internal validation of psychiatric scales. Int J Methods Psychiatr Res. 2011;20(4):235–249. https://doi.org/10.1002/mpr.352
- Sitzia J, Wood N. Response rate in patient satisfaction research: an analysis of 210 published studies. Int J Qual Health Care. 1998;10(4):311-317. https://doi.org/10.1093/intqhc/10.4.311

Impacts

What is known about this topic

- Admission of a patient to ICU is a stressful experience for relatives.
- A family-centred care approach to engage relatives in the care of critically ill patients is associated with better outcomes.
- Valid satisfaction measurement instruments are essential to identify both best practices and areas for improvement.

What this paper adds

- The EMpowerment of PAtients in The Intensive Care-Family (EMPATHIC-F) questionnaire is a reliable and valid quality performance indicator to measure the perceptions of relatives in adult ICU settings.
- This instrument should empower relatives to work along with nurses and physicians focusing on family-centred care principles.
- The EMPATHIC-F questionnaire can provide a framework for a standardized quality improvement approach toward the development of a family-centred care philosophy within adult ICUs worldwide.

TABLE 1 Characteristics of the patients and their primary support persons

_	Patients	Patients' primary support persons
	n = 262	n = 262
Age (years)	64 (52 - 76)	51 (40 – 59)
Length of stay (days)	4 (2 – 4)	-
Female, %	99 (37.8)	165 (63.0)
APACHE-II	15 (10 – 21)	-
SOFA	4 (2 – 7)	-
Type of admission, %	· · ·	
Surgical	43 (16.4)	-
Medical	219 (83.6)	-
Mechanical ventilation required, %		
Invasive mechanical ventilation	103 (39.3)	-
Non-invasive mechanical ventilation	70 (26.8)	-
No	89 (33.9)	-
Who completed the questionnaire? %	,	
Parent	-	29 (11.1)
Husband / Wife	-	64 (24.4)
Son / Daughter	-	104 (39.7)
Political family	-	10 (3.8)
Others	-	55 (21.0)
Family culture, %		
Spanish	-	251 (95.8)
Foreigner	-	11 (4.2)
Education, %		
Secondary school graduate	-	89 (33.9)
High school graduate	-	33 (12.6)
Vocational Training	-	66 (25.2)
University degree	-	74 (28.3)
Employment situation, %	·	
Unemployed	-	50 (19.1)
Self-employed worker	-	37 (14.1)
Employee	-	123 (46.9)
Retired	-	52 (19.9)

Abbreviations: APACHE = acute physiology and chronic health evaluation, SOFA = sequential organ failure assessment.

Data are expressed as the number (%) or median (interquartile range).

TABLE 2 Descriptives and reliability estimates for EMPATHIC-F domains

Domain	Number of items	n	Median	IQR	α
Professional attitude	6	262	6.0	5.8 - 6.0	0.75(0.70 - 0.80)
Organization	5	262	5.8	5.4 - 6.0	0.64 (0.57 - 0.71)
Care and Treatment	8	262	5.8	5.3 - 6.0	0.70 (0.65 - 0.75)
Information	5	262	5.8	5.4 - 6.0	0.69 (0.63 - 0.74)
Family participation	6	262	5.7	5.2 - 6.0	0.66 (0.60 - 0.71)
Satisfaction total items	30	262	5.8	5.5 – 5.9	0.90 (0.88 – 0.91)

Abbreviations: IQR, interquartile range; α, Cronbach's alpha as a measure of internal consistency; EMPATHIC-F, EMpowerment of PAtients in THe Intensive Care – Family.

TABLE 3 Correlation among domains and general questions

Domain	Would recommend ICU to others	Would come back again if needed	Overall satisfaction with physicians	Overall satisfaction with nurses
Professional attitude	0.33	0.31	0.27	0.30
Organization	0.51	0.48	0.36	0.34
Care and Treatment	0.54	0.52	0.48	0.50
Information	0.38	0.40	0.40	0.30
Family participation	0.39	0.37	0.38	0.36
Spearman's rank correlation	is significant at p<0.001			

TABLE 4 Overall nondifferential validity, differences between domains and participant characteristics: gender, type of admission and the use of mechanical ventilation during ICU stay

			Male			Female					
Domain	n	Media	an	IQR	n		Median		IQR	Cohen's d	<i>p</i> -value
Professional attitude	97	6.0		5.8 - 6.0	165		6.0	5	5.6 – 6.0	0.28	0.08
Organization	97	6.0		5.5 - 6.0	165		6.0	5	5.2 – 6.0	-0.13	0.65
Care and Treatment	97	5.8		5.5 - 6.0	165		5.7 5.2 - 6.0		6.2 - 6.0	0.05	0.73
Information	97	6.0		5.6 - 6.0	165		5.8	5	6.2 - 6.0	0.16	0.19
Family participation	97	5.5		5.0 - 6.0	165		5.5	5	6.0 - 6.0	0.08	0.67
, , , ,		Medical				Sur	gical				
Domain	n	Media	an	IQR	n		Median		IQR	Cohen's d	<i>p</i> -value
Professional attitude	219	6.0		5.7 – 6.0	43		6.0	5	5.6 – 6.0	-0.08	0.71
Organization	219	6.0		5.4 - 6.0	43		6.0	5	6.4 - 6.0	-0.06	0.98
Care and Treatment	219	5.8		5.3 - 6.0	43		5.6	5	6.2 - 6.0	0.23	0.27
Information	219	5.8		5.3 - 6.0	43		5.8	5	6.3 - 6.0	0.05	0.82
Family participation	219	5.6		5.0 - 6.0	43		5.4	4	.8 – 5.8	0.30	0.17
		Invasive MV	/	Non-inva		vasive MV No MV				_	
Domain	n	Median	IQR	n	Median	IQR	n	Median	IQR	Cohen's d	<i>p</i> -value [‡]
Professional attitude	103	6.0	5.8 – 6.0	70	6.0	5.6 – 6.0	89	6.0	5.8 - 6.0	0.005	0.66
Organization	103	5.8	5.4 - 6.0	70	5.8	5.2 - 6.0	89	6.0	5.5 - 6.0	0.01	0.26
Care and Treatment	103	5.7	5.3 - 6.0	70	5.8	5.3 - 6.0	89	5.7	5.3 - 6.0	0.03	0.76
Information	103	5.8	5.3 - 6.0	70	5.8	5.4 - 6.0	89	5.8	5.4 - 6.0	0.004	0.87
Family participation	103	5.4	4.8 - 6.0	70	5.6	5.1 - 6.0	89	5.6	5.0 - 6.0	0.02	0.36

Data are expressed as median and interquartile range (IQR). p-values calculated by Mann-Whitney U test (‡Kruskal-Wallis test). Statistically significant difference between

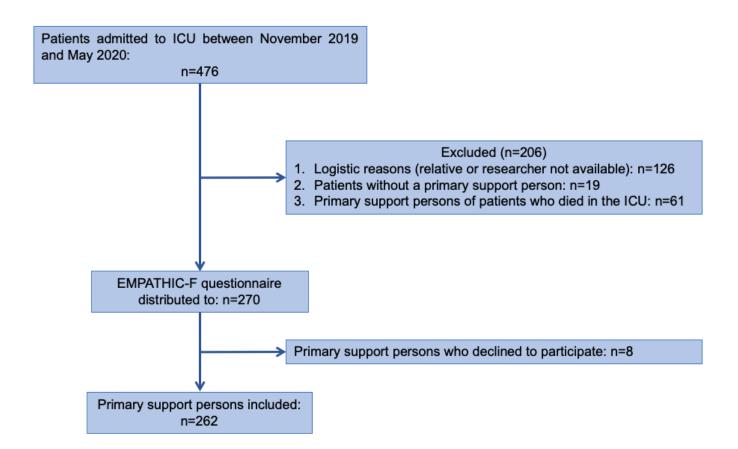
groups: p < 0.05

Supplement to:

Measuring family-centred care practices in adult ICUs: the EMPATHIC-F questionnaire

Journal: Nursing in Critical Care

SUPPLEMENTARY FIGURE 1 Study flowchart



Supplement to:

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TABLE S1 Descriptive analysis for each statement ranked per domain on the highest mean

Domain and Statements	Mean	SD	Cronbach's α if item deleted
Professional attitude			
At admission, we felt welcome	5.7	0.65	0.89
The team worked hygienically	5.8	0.54	0.89
The team respected the privacy of our relative and ours	5.8	0.54	0.89
The team showed respect for our relative and for us	5.8	0.43	0.89
We received sympathy from the doctors	5.8	0.54	0.89
We received sympathy from the nurses	5.8	0.57	0.89
Organization			
The ICU was clean	5.9	0.40	0.89
The ICU could easily be reached by telephone	5.5	1.06	0.90
Noise in the ICU was muffled as well as possible	5.5	0.94	0.89
There was enough space around our relative's bed	5.5	0.93	0.89
The team worked efficiently	5.8	0.49	0.89
Information			
The doctor clearly informed us about the consequences of our relative's treatment	5.7	0.56	0.89
We received clear information about the examinations and tests	5.6	0.72	0.89
We received understandable information about the effects of the drugs	5.4	1.10	0.89
We had daily talks about our relative's care and treatment with the doctors	5.9	0.43	0.90
We had daily talks about our relative's care and treatment with the nurses	5.4	1.23	0.89
Care and Treatment			
The doctors and nurses worked closely together	5.7	0.69	0.89
The team was alert to the prevention and treatment of pain in our relative	5.7	0.70	0.89

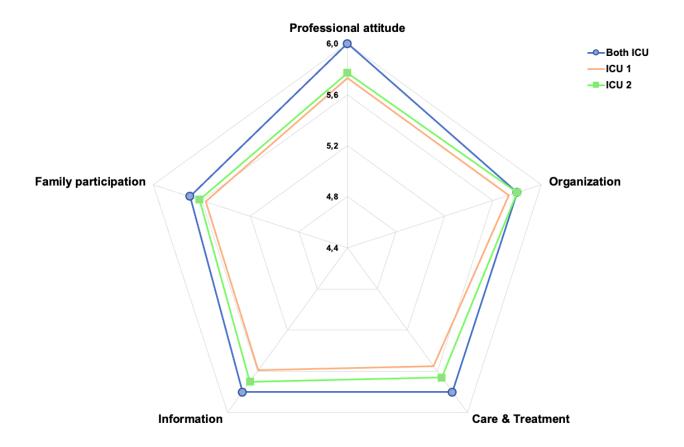
Our relative's comfort was taken into account by the doctors	5.9	0.33	0.89
Our relative's comfort was taken into account by the nurses	5.8	0.44	0.89
Every day we knew who was responsible for our relative, regarding the doctors	5.3	1.31	0.89
Every day we knew who was responsible for our relative, regarding the nurses	4.9	1.56	0.89
We were well prepared for our relative's discharge by the doctors	5.8	0.71	0.89
We were well prepared for our relative's discharge by the nurses	5.4	1.23	0.89
Family participation			
We were actively involved in decision-making on care and treatment of our relative	5.3	1.14	0.89
We were encouraged to stay close to our relative	5.1	1.25	0.89
Even during intensive procedures, we could always stay close to our relative	4.3	1.98	0.90
During our stay, the staff regularly asked for our experiences	5 4	4.00	0.89
	5.4	1.08	0.09
We had confidence in the doctors	5.4	0.42	0.89

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SUPPLEMENTARY FIGURE 2 EMPATHIC-F scores for each domain. Values are overall median per domain (information, care and treatment, family participation, organization, and professional attitude). Median responses for each domain range from 1 to 6. While in both Units (circles) overall median domain scores ranged from 5.7 in the family participation to 6.0 in the professional attitude domain, score in ICU 1 (lines) ranged from 5.6 in the care and treatment domain to 5.7 in the organization and professional attitude domains and in ICU 2 (squares) scores ranged from 5.6 in the family participation to 5.8 in the organization domain.



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SUPPLEMENTARY FIGURE 3 Confirmatory factor analysis (CFA). The empirical structure of the instrument was established by CFA confirming 30 statements within five theoretically conceptualized domains: information (inf), care and treatment (car), family participation (prt), organization (org), and professional attitude (att).

