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Families' experiences of intensive care unit quality of care: Development and validation of a European questionnaire (euroQ2)☆

Hanne Irene Jensen, PhD, MHSc [a,b,*], Rik T. Gerritsen, MD [c], Matty Koopmans, MSc [c], Jan G. Zijlstra, MD, PhD [d], Jared Randall Curtis, MD, MPH [e], Helle Ørding, MD, DMSc, MPM [a]

[a] Department of Anaesthesiology and Intensive Care, Vejle and Middelfart Hospitals, 7100 Vejle, Denmark
[b] Institute of Regional Health Research, University of Southern Denmark, 5000 Odense, Denmark
[c] Center of Intensive Care, Medisch Centrum Leeuwarden, 8901 BR Leeuwarden, The Netherlands
[d] University Medical Center Groningen, University of Groningen, 9713 GZ Groningen, The Netherlands
[e] Cambia Palliative Care Center of Excellence, Harborview Medical Center, University of Washington, Seattle, WA, USA

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ABSTRACT

Purpose: The purpose of the study is to adapt and provide preliminary validation for questionnaires evaluating families' experiences of quality of care for critically ill patients in the intensive care unit (ICU).
Materials and methods: This study took place in 2 European ICUs. Based on literature and qualitative interviews, we adapted 2 previously validated North American questionnaires: "Family Satisfaction with the ICU" and "Quality of Dying and Death." Family members were asked to assess relevance and understandability of each question. Validation also included test-retest reliability and construct validity.
Results: A total of 110 family members participated. Response rate was 87%. For all questions, a median of 97% (94%-99%) was assessed as relevant, and a median of 98% (97%-100%), as understandable. Median ceiling effect was 41% (30%-47%). There was a median of 0% missing data (0%-1%). Test-retest reliability showed a median weighted κ of 0.69 (0.53-0.83). Validation showed significant correlation between total scores and key questions.
Conclusions: The questions were assessed as relevant and understandable, providing high face and content validity. Ceiling effects were comparable to similar instruments; missing data, low; and test-retest reliability, acceptable. These measures are promising for use in research, but further validation is needed before they can be recommended for routine clinical use.

1. Introduction

Most patients admitted to intensive care unit (ICU) are critically ill, and 10% to 15% of the patients die in the unit [1,2]. For health care professionals, the high-technology environment becomes commonplace, but for families, this is a new and uncertain world [3]. Families often see their role as guardian and protector of the patient, but they also have needs of their own. They need support to cope with the uncertainty and need complete information to be able to understand what is going on and how to navigate in the ICU [4]. The strains experienced by families during an ICU stay may subsequently lead to posttraumatic stress syndrome and depression [5-8]. Care that also takes the needs of families into account is, therefore, very important, but to be able to offer family-centered care, it is necessary to understand families' experiences [9].

A Canadian questionnaire (Family Satisfaction in the Intensive Care Unit [FS-ICU]), which examines families' general satisfaction with intensive care [9,10], and an American questionnaire, which examines families' rating of the quality of dying and death (QODD) [11,12], have been developed and validated. The QODD questionnaire has been used in a Dutch study [13], but a high percentage of nonrelevant or missing responses suggested that the questionnaire is not automatically transferable to European ICU environments.

The overall goal of this study was to adapt and validate questionnaires to evaluate families' experiences of quality of care for critically ill and dying patients in the ICU based on the FS-ICU and the QODD and adapted to Northern European environments. The questionnaires, including both a European FS-ICU and a European QODD, were named "euroQ2" (European Quality Questionnaire). Our specific aims were to (*a*) pilot test the instrument with family members, intensivists, ICU nurses, and questionnaire experts and then (*b*) examine the responses from family members of patients in the ICU to assess the distribution of response, the proportion of missing values, the content validity, and the construct validity of the euroQ2.

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* Corresponding author at: Department of Anaesthesiology and Intensive Care, Vejle and Middelfart Hospitals, Kabbeltoft 25, 7100 Vejle, Denmark. Tel.: +45 7940 6228; fax: +45 7940 6875.
E-mail addresses: hanne.irene.jensen@rsyd.dk (H.I. Jensen), RTGerritsen@ZNB.NL (R.T. Gerritsen), Matty.Koopmans@ZNB.NL (M. Koopmans), j.g.zijlstra@umcg.nl (J.G. Zijlstra), jrc@u.washington.edu (J.R. Curtis), oerding@dadlnet.dk (H. Ørding).

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2. Materials and methods

The euroQ2 incorporates issues identified as the most important by family members as well as an opportunity to add qualitative comments about issues not addressed in the questionnaire. The euroQ2 consists of 2 components: satisfaction with care measured with the adapted FS-ICU for family members of all patients in the ICU and quality of dying and death measured with the adapted QODD for family members of patients who died in the ICU. The adapted questionnaires will be referred to as euroFS-ICU and euroQODD, respectively.

2.1. Setting

The study took place in 2 ICUs. The Danish ICU was a general ICU from a 300-bed regional hospital with 8 ICU beds and receives mainly patients from medical and surgical specialities. The Dutch ICU was a medical-surgical ICU from an 800-bed university-affiliated hospital with 22 ICU beds and admits surgical, trauma, medical, and cardiothoracic patients.

2.2. Study design

The study included a pilot test phase and a validation phase. Before pilot testing, we adapted the FS-ICU and QODD based on results from the Dutch prestudy [13]; results from serial, semistructured interviews with 8 family members of Danish ICU patients; and previously published research on the experiences of the family of critically ill patients. This adaptation phase was conducted from January to August 2013 and resulted in an initial draft of the euroQ2 in English. An overview of the adaptions can be found as supplementary material.

2.3. Inclusion criteria

We included family members of patients admitted to the ICU for 48 hours or more. Up to 3 family members per patient could participate. Family members were defined as the persons closest to the patient (as defined by the patient), including partners, siblings, children, parents, and friends. If there were more than 3 family members who wanted to participate, the family members themselves decided who it should be based on who had spent most time in the ICU.

2.4. Exclusion criteria

The following are exclusion criteria: family members younger than 18 years, family members with cognitive impairment, and family members not able to read or write Danish or Dutch.

2.5. Pilot testing phase

The initial draft of euroQ2 was reviewed by 2 family members, 5 nurses, 4 intensivists, and 2 questionnaire experts from both Denmark and The Netherlands. For each item, feedback was obtained about the clarity, relevance, and acceptability (is the question phrased in an acceptable way or is it, for example, condescending or value laden). After adjustments (please see Supplementary material for details) based on the feedback, the final draft was discussed with and approved by 1 of the developers of the FS-ICU and QODD (JRC) and then translated into Danish and Dutch. In both countries, the translation process consisted of 2-way translations (the questionnaire was translated from English to Danish [and likewise to Dutch] by 2 persons fluent in both languages and then back from Danish by 2 others fluent in both languages but without knowledge of the original English version), discussion of the different versions in a research group, and consensus decision on which phrasings were correct in Danish (and likewise in Dutch). The questionnaire was then evaluated qualitatively in both Denmark and The Netherlands by family members (6 from each country). The family members filled in the questionnaire, assessed for each question whether they found it relevant and/or understandable, and were interviewed subsequently about their overall assessment of the questionnaire: if there were important areas missing, if the information was adequate, and how they understood each question. After the pilot testing phase, the euroFS-ICU consisted of 20 questions and 2 options for providing comments (compared to 27 questions and 3 options to provide comments in the FS-ICU) [9]. Ten of the questions were identical, 5 were partially different, and 5 were completely different from the FS-ICU. The euroQODD consisted of 15 questions and 1 option for providing comments (compared to 47 questions in the QODD) [11]. Six questions were almost identical; the others were different from the QODD. The pilot testing phase was conducted from February to November 2013. A copy of the euroQ2 (euroFS-ICU and euroQODD) is available as Supplementary material.

2.6. Validation phase

The aim of this phase was to quantitatively validate the euroQ2 in regard to distribution of responses, the proportion of missing values, the content validity (do the questionnaires reflect the areas that are essential to clarify the purpose of the questionnaires), and the construct validity (the extent to which the questionnaires measure the expected concepts) of the 2 measures. In this phase, 55 family members from the Danish ICU and 55 family members from the Dutch ICU participated. As in the pilot testing phase, the participants were asked to assess relevance and understandability for each question. They also filled in the Hospital Anxiety and Depression Scale (HADS) [14] and the revised Impact of Event Scale (IES-R) [15]. There already existed validated Danish and Dutch versions of the HADS and a Dutch version of the IES-R. A 2-way translation with consensus discussion (as described above) was conducted for a Danish IES-R version. While still at the ICU, the families were asked by the patients' nurse or physician whether they wanted to take part in the study and were provided with written information (please see Supplementary material). If the family members agreed to participate, they were asked to fill in a form with name, address, and telephone number. Three weeks after the patient either died or was discharged from the ICU, the questionnaire (together with an accompanying letter and a prepaid envelope) was mailed to family members. If the questionnaire was not returned after 2 weeks, the participants were contacted by telephone and asked to return the questionnaire. All returned questionnaires were included in the analyses independently of when they were returned. To get an indication of test-retest reliability, questionnaires were sent 2 weeks after a questionnaire was returned until 10 completed questionnaires were collected in each country. For the participating families, the following patient data were obtained from the medical record: sex, age, medical or surgical speciality of the admitting physician, diagnosis, length of stay in the ICU, any withholding or withdrawal decisions, Acute Physiology and Chronic Health Evaluation II (APACHE II) [16], Simplified Acute Physiology Score (SAPS) [17], and Sepsis-Related Organ Failure Assessment (SOFA) scores [18]. The validation phase was conducted from December 2013 to July 2014.

2.7. Scoring

For correlation analyses, Likert scale responses in the euroFS-ICU were transformed to a 0-100 scale according to the FS-ICU scoring [9,10], and 1 single question "When major decisions were made, did you have adequate time to have your concerns addressed and questions answered?" was transformed as 100 for yes and 0 for no. A total score for the euroFS-ICU was calculated as means of individual item scores provided that the respondents had answered more than 70% of the items included [9]. The euroQODD consists of more diverse response categories, and therefore, correlation analyses were based on a single item response of overall assessment of care (scale from 0 to 10) transformed to a 0-100 scale and a key question: "End-of-life care according to wishes." For this question, response options were "yes," "partially," "no," and "don't know," and the responses were scored as 100 for yes, 50 for partially, and 0 for no.