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# Questionnaires on Family Satisfaction in the Adult ICU: A Systematic Review Including Psychometric Properties\*

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**Objectives:** To perform a systematic review of the literature to determine which questionnaires are currently available to measure family satisfaction with care on the ICU and to provide an overview of their quality by evaluating their psychometric properties.

**Data Sources:** We searched PubMed, Embase, The Cochrane Library, Web of Science, PsycINFO, and CINAHL from inception to October 30, 2013.

**Study Selection:** Experimental and observational research articles reporting on questionnaires on family satisfaction and/or needs in the ICU were included. Two reviewers determined eligibility.

**Data Extraction:** Design, application mode, language, and the number of studies of the tools were registered. With this information, the tools were globally categorized according to validity and reliability: level I (well-established quality), II (approaching well-established quality), III (promising quality), or IV (unconfirmed quality). The quality of the highest level (I) tools was assessed by further examination of the psychometric properties and sample size of the studies.

**Data Synthesis:** The search detected 3,655 references, from which 135 articles were included. We found 27 different tools that assessed overall or circumscribed aspects of family satisfaction with ICU care. Only four questionnaires were categorized as level

#### \*See also p. 1783.

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I: the Critical Care Family Needs Inventory, the Society of Critical Care Medicine Family Needs Assessment, the Critical Care Family Satisfaction Survey, and the Family Satisfaction in the Intensive Care Unit. Studies on these questionnaires were of good sample size ( $n \ge 100$ ) and showed adequate data on face/content validity and internal consistency. Studies on the Critical Care Family Needs Inventory, the Family Satisfaction in the Intensive Care Unit also contained sufficient data on inter-rater/test-retest reliability, responsiveness, and feasibility. In general, data on measures of central tendency and sensitivity to change were scarce.

**Conclusions:** Of all the questionnaires found, the Critical Care Family Needs Inventory and the Family Satisfaction in the Intensive Care Unit were the most reliable and valid in relation to their psychometric properties. However, a universal "best questionnaire" is indefinable because it depends on the specific goal, context, and population used in the inquiry. (*Crit Care Med* 2015; 43:1731–1744)

**Key Words:** family satisfaction; intensive care; psychometric properties; quality of care; questionnaire

n recent years, quality of care has become a central issue in healthcare systems worldwide. Particularly, the qual-Lity as perceived by patients and their family is a current focus of interest. It is generally accepted that improvement in the quality of care involves a wide range of strategies including the use of evidence-based health care, guidelines and protocols, quality improvement cycles, and changes in safety and risk management (1). Essential in each of these strategies is the monitoring and evaluation of delivered care. In the ICU, satisfaction with the care provided is considered just one of the many quality of care indicators and an important tool for improving care (2–4). Because most ICU patients cannot make decisions themselves, family members are actively involved in the care process as surrogate decision-makers and are, therefore, judges of care quality. However, family satisfaction with care is complex and is not clearly defined.

In the current body of literature, different aspects of family satisfaction are considered important for family members but

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no gold standard currently exists to assess this concept. One line of reasoning is that satisfaction is the fulfillment of family needs or requirements which, if fulfilled, relieve or diminish the distress of the family members or improve their sense of wellbeing (5). However, Heyland et al (6) remark that although satisfaction reflects the amount of fulfillment of needs and expectations, meeting needs does not guarantee satisfaction. In general, expectations of care, information provided, communication, hospital infrastructure, and patient- and familyrelated factors all play a role in family satisfaction with ICU care (1). Family satisfaction is also related to the family being provided with clear information because this enables them to actively participate in the decision-making process (6–8).

At present, there are several tools available, mostly questionnaires, that measure family satisfaction with ICU care. Because family satisfaction can be influenced by multiple factors, and the acquired data must be accurate, good validation is obligatory for the adequate use of the questionnaires. Psychometric properties, such as reliability and validity, are essential elements of questionnaires because these describe the quality of the measurement. Questionnaires lacking good psychometric values may not measure the construct they intend to assess, or the values that arise from the questionnaire may not represent the "true" value. This may not only hamper research but also misguide the clinician working with the tool. Thus, the quality of a questionnaire is determined by its psychometric properties.

Therefore, the aim of this review is to determine which questionnaires assessing family satisfaction with ICU care are currently available and to provide an overview of their quality by determining their psychometric properties.

# **METHODS**

### Search Strategy and Selection Criteria

We searched PubMed, Embase, The Cochrane Library, Web of Science, PsycINFO, and CINAHL from inception to October 30, 2013. The databases were searched for medical literature with the following terms: "questionnaires," "family satisfaction," "family needs," and "intensive care." The complete electronic search strategy can be found in **Appendix I** (Supplemental Digital Content 1, http://links.lww.com/CCM/B257).

Reference lists of review articles and eligible primary studies were checked to identify cited articles not captured by electronic searches.

### **Study Selection**

Included were studies that specifically used a questionnaire to measure family satisfaction and/or family needs in the adult (>18 years) ICU, published in peer-reviewed journals. The language of the articles was restricted to English.

Excluded were studies that did not use a questionnaire to measure family satisfaction. Also excluded were reviews, editorials, and letters to the editor. Furthermore, studies on instruments for *medical staff* satisfaction and *patient* satisfaction were excluded as were studies on parent satisfaction in pediatric or neonatal ICU. The latter was done because the specific parentpatient relationship in children less than 18 years old differs from the family-patient relationship in adults (9). Family was defined as next of kin or other persons with a close relationship to an ICU patient.

Two reviewers (J.B. and A.B.) scrutinized the titles and abstracts of all references on possible inclusion. Second, final inclusion/exclusion decisions were made after independent examination of the full articles. All studies that on fulltext examination failed to meet the inclusion criteria were excluded. Disagreement between reviewers was resolved by consensus, and if necessary, judgment of a third author was decisive. Reference manager 12.0 (Thomson ISI ResearchSoft, Philadelphia, PA) was used to manage all search results.

## **Extracted Data**

The following data were systematically extracted from the studies: author/research group, year of publication, time-frame and means of collecting information, name and version of the tool used, language of the tool, number of questions, and domains (subscales) in the tool. And furthermore, information on sample size and psychometric properties was extracted (see below).

#### **Quality Assessment**

A two-step model was used to assess the quality of the tools and the psychometric properties.

Assessment of General Quality and Global Psychometric Properties. To establish the general quality and global psychometric properties (ie, validity and reliability) of the tool, first all available data for each tool were grouped. Subsequently, the classification model adapted from Cohen et al (10) was applied. This model is an analogue to the well-accepted criteria used to establish effectiveness of treatment in systematic reviews (11). At the highest quality level (level 1), what is taken into account is whether (A) a tool is presented by different research groups in different peer-reviewed articles, (B) sufficient detail of the tool is available to allow evaluation and replication (eg, complete item list and means must be published), and (C) substantial data are available regarding validity and reliability (**Table 1**).

A tool had to fulfill all the criteria of a specific level to be assigned the quality of that level. When the combined research of a tool met all three criteria defined above (A, B, and C) for level I, it was considered "well-established quality" (++). When one of these criteria was not met, but a tool did meet the standards for level II quality described in Table 1, it was classified as "approaching well-established quality" (+). When one or more of these level II standards were not met, the tool was evaluated with respect to the criteria of level III, "promising quality" (+/–). Finally, when the tool did not meet one or more of the criteria of level III, it was considered level IV, of "unconfirmed quality" (–).

In category C, "++" was scored when validity and reliability were named precisely and when values presented showed good validity (ie, the values were proven to assess the intended construct, or Cronbach  $\alpha$  was > 0.70 for all factors) and good

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# TABLE 1. Categories for Classification of Instruments Based on Cohen and Modified by Authors

Level of Quality	Criteria for Categories	Quality Indication
I	A. The measure must have been presented in at least two peer-reviewed articles by different investigators or investigatory teams (++)	Well-established quality
	B. Sufficient detail about the measure to allow critical evaluation and replication, e.g., complete description of the items and scoring of the tool (++)	
	C. Detailed information indicating good validity and reliability in at least one peer- reviewed article (++)	
II	A. The measure must have been presented in at least two peer-reviewed articles, which might be by the same investigator or investigatory team (+)	Approaching well- established quality
	B. Sufficient detail about the measure to allow critical evaluation and replication, e.g., the domains and subscales of the tool have been described (+)	
	C. Validity and reliability information either presented in vague terms or only moderate values presented (+)	
	A. The measure must have been presented in at least one peer-reviewed article (+/–)	Promising quality
	B. Sufficient detail about the measure to allow evaluation, e.g., the questionnaire and its purpose have been described, or the questionnaire was presented in another article. (+/-)	
	C. Validity and reliability information presented in vague terms (e.g., no statistics) or low values presented (+/-)	
IV	Negative sore in A, B, and/or C (-)	Unconfirmed quality

"++" in category C was scored when both validity (either face-, content-, or construct -) and reliability (either internal consistency, inter-rater reliability, or test-retest reliability) were named precisely and when values presented showed good validity (ie, the values were proven to assess the intended construct, or Cronbach  $\alpha$  was > 0.70 for all factors), and good reliability (Spearman Brown or Split half > 0.8 of scale and subscales both, or  $\kappa < 0.061$  or Pearson's r > 0.8). "+" in category C was scored when both validity (either face-, content-, or construct-) and reliability (either internal consistency, inter-rater reliability, or test-retest reliability) were named but not precisely defined or when values presented showed moderate validity (authors suggested that the tool assesses the intended construct, or Cronbach  $\alpha > 0.70$  but not for all factors), and reliability (Spearman Brown > 0.8 for either the scale or the subscales, but not both). "+/-" in category C was scored when either validity (either face-, content-, or construct-) or reliability (either internal consistency, inter-rater reliability, or test-retest reliability) were named but not precisely defined, and reliability (Spearman Brown > 0.8 for either the scale or the subscales, but not both). "+/-" in category C was scored when either validity (either face-, content-, or construct-) or reliability (either internal consistency, inter-rater reliability, or test-retest reliability) were named but not precisely defined, or when no values were presented, or when low values were presented (Cronbach  $\alpha < 0.70$  for all factors), or reliability (Spearman Brown < 0.8).

"--" in category C was scored when validity or reliability were not mentioned or when no data on validity or reliability was reported.

reliability (Spearman Brown or Split half > 0.8 of scale and subscales both, or  $\kappa < 0.061$  or Pearson's r > 0.8). In category C, a "+" was scored when both validity (either face validity, content validity, or construct validity) and reliability (either internal consistency, inter-rater reliability, or test-retest reliability) were named but not precisely defined, or when values presented showed moderate validity (Table 1). In category C, a "+/-" was scored when either validity or reliability were named, but not precisely defined, or when no values were presented or when low values were presented. Finally, in category C, a "-" was scored when validity and reliability were not mentioned or when no data on validity or reliability were reported.

Assessment of Psychometric Properties. All studies describing tools that were considered to be of "well-established quality" were entered in the second step of the analysis. The sample size of the studies and the following psychometric properties of the tools were systematically assessed: face-, content-, and construct-validity, reliability, measures of central tendency, sensitivity, responsiveness, and feasibility (12). This was achieved by grouping the data for each version of the tools (eg, language, reduced, or extended version) and coding each psychometric property as 1) good, 2) mediocre, 3) poor, or 4) having insufficient data to judge the quality of the psychometric properties. Psychometric properties were defined as follows

Sample Size. An adequate sample size is needed to detect reliable psychometric data, we used an arbitrary n > 100 per (sub)group cutoff as published by Friberg et al (13).

Validity. Validity refers to the extent to which a tool actually measures family satisfaction. Three types of validity were distinguished: face validity, content validity, and construct validity. Face validity refers to the extent to which a tool is subjectively viewed as covering the concept it purports to assess. Interviews with experts and focus groups are often used to determine this. Furthermore, to fulfill this criterion, the purpose of the tool must be explicitly stated because omission might lead to a discrepancy between an intended and actually assessed target (13). Content validity differs from face validity in that it does not refer to what is subjectively measured but to whether the items of a tool indeed include the appropriate information and content (12). Open-ended questions in a tool can increase its content validity by exploring not mentioned information. As the literature on content validity in family satisfaction is still

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scarce and both face validity and content validity involve the relationship of questions and their intended content, they were grouped together.

Construct validity is determined by the validity of abstract variables that cannot be directly observed (latent variables). These constructs are assessed by their relationships with other variables (12, 14). Factor analysis or comparisons with other scales that are supposed to assess the same construct are used to investigate the internal structure and validity of domains. Without good construct validity, it is hard to determine what the tool exactly measures. In the area of family satisfaction, this could involve questions regarding the atmosphere of the waiting room, which does not necessarily reflect satisfaction with ICU care. Tools were considered adequate in this domain when they either exhibited clear, defined factors that in turn showed good internal consistency (Cronbach  $\alpha > 0.70$ ) or when their concurrent validity was high. The latter means that a questionnaire shows a high correspondence with another questionnaire when assessing the same construct (Pearson's r > 0.70 or high Cronbach  $\alpha$ ) (13). Construct validity also covers the aspect of correct questionnaire translation into a different language (1). Adequate translation of a questionnaire is an important and time-consuming procedure that aims for "equivalence" with the original (12). Because research of family satisfaction is performed in many different countries, results of the data obtained need to be comparable.

Reliability. Reliability refers to the overall consistency of a tool's data across time, settings, and people. This is important because without sufficient reliability the scores obtained may not reflect the "true" scores. For example, the questions may refer to interpersonal conduct of the nurses at a given moment. This may be different from nurse to nurse and subsequently from shift to shift. Therefore, this question score may change daily and is dependent on family members' personal preferences. The following aspects of reliability were investigated: internal consistency, inter-rater reliability, and test-retest reliability. Internal consistency is the extent to which all items of a tool measure the same content. Cronbach  $\alpha$ , which is a measure of the average correlation of scores from a measure with the scores of all of its items, is the most commonly used unit of internal consistency (12). In general, acceptable Cronbach coefficients for research and clinical purposes are 0.70 and 0.90, respectively (12, 15). Other internal consistency units include Spearman-Brown and split-half reliability. In this study, we predetermined a degree of greater than 0.80 for both units to represent adequate internal consistency.

Inter-rater (interobserver) and test-retest reliability are both concerned with the robustness of the outcomes of a tool when applied by another person (inter-rater) or at another moment (test-retest). A good agreement of a measure between different raters/observers or by the same raters at different moments is typically represented by  $\kappa$  statistics (> 0.60) (12) or by a high correlation between the two outcomes (Pearson's *r* > 0.80).

*Measures of central tendency* such as the mean and sD of the scale and subscales need to be known as they form the basis

for comparison (13) and interpretation of scores. Information about the presence or absence of floor and ceiling effects is needed too in this regard. When these effects are present, nonparametric test should be applied. In these cases, the interpretability of high or low scores is limited substantially.

Sensitivity is a related concept. It is the ability of a tool to detect a "true problem case" (resulting in the percentage of dissatisfied family members who are correctly identified as feeling dissatisfied). Specificity, on the other hand, measures the proportion of negatives that are correctly classified as such (satisfied family members correctly identified as such). Floor and ceiling effects greatly compromise sensitivity and specificity because the scores of true problem cases and true negatives then tend to lie close to each other or are even indistinguishable. True sensitivity cannot be determined in the field of family satisfaction because a gold standard is unobtainable.

*Responsiveness* is the ability of a scale to detect (meaningful) changes over time (16, 17). This is a particularly important asset when a tool is used to measure the effect of an intervention, for example, a hospitality workshop for healthcare workers. To demonstrate this ability, the tool must first have good test-retest reliability because otherwise the changes could be attributed to mere chance. Also in this psychometric domain, ceiling and floor effects have detrimental influences.

*Feasibility* relates to the ease and timeframe needed to administer and process an instrument (14, 18). In other words, whether it is acceptable and practical in clinical use and scientific practice. In this study, we focused on the mode of administration (eg, interview and questionnaire) and the amount of time needed to apply the tool.

# RESULTS

# Selected Studies

The search detected 3,655 references, of which 2,354 references were excluded because they were duplicates. Thus, 1,301 records were screened based on title and abstract. Of these 1,301 records, 1,153 articles did not meet the inclusion criteria (ie, the abstract originated from a poster, it was not a peer reviewed article, the article did not study adult patients or did not report on family satisfaction). Subsequently, 148 full-text articles were assessed for eligibility and 13 more articles were excluded (19–31). Reasons for article exclusion were as follows: studies in which family satisfaction was combined with patient satisfaction (19, 28, 31), studies that measured hospital staff satisfaction (22-27, 29, 30), studies in which satisfaction or needs were not measured (20), and a study on the implementation of a quality indicator bundle (21). In total, we selected 135 studies for this review (4-8, 32-170). A flow diagram of the study is depicted in Figure 1.

### Definition

No uniformly used definition of family satisfaction was found. Two main domains were identified; these were "needs met" and "satisfaction with care." Within these domains, several subdomains were studied.

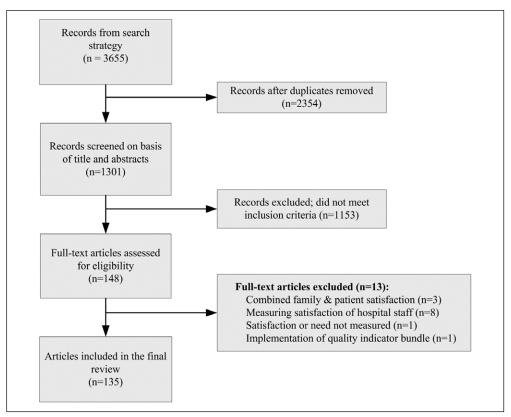


Figure 1. Study selection flow diagram.

#### **Description of the Tools**

In these 135 studies, 27 different questionnaires were described. Twenty-one were self-reported questionnaires, six were applied by structured interview (**Table 2**). Nineteen tools were classified as level IV, "unconfirmed quality," three as level III, "promising quality," and one as level II, "approaching well-established quality" (10). Four questionnaires were classified as level I, "well-established quality": the Critical Care Family Needs Inventory (CCFNI), the Society of Critical Care Medicine Family Needs Assessment (SCCMFNA), the Critical Care Family Satisfaction Survey (CCFSS), and the Family Satisfaction in the Intensive Care Unit (FS-ICU). A detailed overview of the quality of each study can be found in **Supplemental Table 1** (Supplemental Digital Content 2, http://links.lww. com/CCM/B258).

### Analysis of High-Quality (Level I) Questionnaires

The four level I questionnaires found were described in 109 studies (*k*). The psychometric data most reported were as follows: sample size, face/content validity, and internal consistency. In approximately two thirds of these studies, means and sD were reported. Only few studies reported findings on construct validity (k = 17) (4, 8, 35, 43, 56, 60, 71, 83, 86, 97–99, 102, 111, 115, 120, 141), interrater or test-retest reliability (k = 9) (44, 59, 73, 99, 106, 133, 141, 143, 168), measures of central tendency (k = 1) (125), responsiveness (k = 11) (36, 100, 102, 119, 120, 125, 153, 155, 157, 169, 171), and sensitivity (k = 1) (168) (for a detailed overview, see **Supplemental Table 2**, Supplemental Digital Content 3, http://links.lww. com/CCM/B259) (**Table 3**).

#### CCFNI

The CCFNI, developed by Molter (69) and adapted by Leske (5), was the first questionnaire on family satisfaction with ICU care. It consisted of 45 items and measured what the needs of the family were in relation to five domains: 1) information, 2) comfort, 3) proximity, 4) assurance, and 5) support. Questions on these domains had to be answered on a fourpoint Likert scale. Warren (52) in 1993 added the Needs Met Inventory (NMI), to assess the extent to which the needs were met. The NMI consists of an additional 45 items on a four-point Likert scale.

In total, 60 studies of the CCFNI were identified; describing 18 different versions, in eight different languages (English, French, Swedish, Greek, Dutch, Chinese, Arabic,

and Portuguese). Furthermore, 10 varieties of the CCFNI with a total number of questions varying between 14 and 90 items were reported (for a detailed overview, see Supplemental Table 2, Supplemental Digital content 3, http://links.lww.com/CCM/ B259). About half of the studies were of adequate sample size (k = 29; n > 100) (32–35, 38, 40, 43, 46, 49, 50, 54, 57, 58, 60, 62, 64–66, 70, 74, 78, 80–82, 92, 109, 114, 119, 125). With regard to the psychometric data, face/content validity was found to be "good" for most versions with 45 or 46 items, and lower for versions with 30 items or less. Internal consistency was reported for 11 CCFNI versions of which eight demonstrated good internal consistency, whereas it was poor for the three remaining ones. Mean and SD were reported for most versions. Last but not least, responsiveness was studied in three versions of which one study (36) reported positive outcomes (Chinese 45-item version). Responsiveness was not substantiated by other studies or in other versions of the CCFNI. The time needed to complete the questionnaire varied from 20 to 60 minutes (for a detailed overview, see Supplemental Table 2, Supplemental Digital Content 3, http://links.lww.com/CCM/B259)

### SCCMFNA

The SCCMFNA, first described in 1998 by Johnson et al (141), consisted of 14 items and measures the needs of family members with respect to 1) attitude, 2) communication, 3) comforting skill, and 4) isolation. The response scale is a four-point Likert scale.

Six studies (7, 133, 138, 141, 146, 166) on the SCCMFNA have been published, including three different language versions:

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# TABLE 2. General Quality and Global Psychometric Properties of Tools to Assess Family Satisfaction with Intensive Care

		Level of Evidence							
Instrument	Year	A. Literature	B. Sufficient Details	C. Validity/ Reliability	Overall Quality (I, II, III, and IV)	Mode of Assessment			
Critical Care Family Needs Inventory (5, 32–82, 90, 92, 109, 114, 116, 119, 124, 125)	1979–2013	++	++	++	Ι	Questionnaire			
Society of Critical Care Medicine Family Needs Assessment (7, 133, 137, 140, 143, 157)	1998–2012	++	++	++	Ι	Questionnaire			
Critical Care Family Satisfaction Survey (8, 83, 85, 86, 95, 97, 98, 111, 115, 120)	2001-2013	++	++	++	Ι	Questionnaire			
Family Satisfaction in the Intensive Care Unit (4, 6, 51, 84, 87, 91, 93, 94, 96, 99, 100, 102,104–106, 110, 113, 121, 127, 130, 131, 141, 146–150, 153, 158–161)	2001–2013	++	++	++	Ι	Questionnaire			
Quality of Death and Dying-communication (103, 22)	2004-2007	+	+	+	II	Questionnaire			
Myhren et al (129, 136)	2004-2011	++	+/-	++	111	Questionnaire			
Family members perception of nurses roles (117)	2005	+/-	+	+		Questionnaire			
Quality of Communication (101)	2006	+/-	+	+/-	Ш	Questionnaire			
Liddle et al (158)	1988	-	-	-	IV	Questionnaire			
Dockter et al (108)	1988	+/-	-	-	IV	Questionnaire			
Dixon et al (112)	1997	+/-	+	-	IV	Questionnaire			
Malacrida et al (140)	1998	+/-	+	-	IV	Questionnaire			
Keenan et al (139)	2000	+/-	-	-	IV	Questionnaire			
Roland et al (151)	2001	+/-	-	-	IV	Questionnaire			
Deitrick et al (118)	2005	+/-	+	-	IV	Questionnaire			
Kjerulf et al (134)	2005	+/-	-	-	IV	Questionnaire			
Humble et al (144)	2009	+/-	+	-	IV	Questionnaire			
Whitcomb et al (156)	2010	+/-	+	-	IV	Questionnaire			
Cheung et al (89)	2010	-	-	-	IV	Questionnaire			
Family needs questionnaire (123)	2010	+/-	-	-	IV	Questionnaire			
Sundararajan et al (126)	2012	+/-	+	-	IV	Questionnaire			
Cuthbertson et al (88–107)	2000-2010	++	+	-	IV	Interview <sup>a</sup>			
Kirchhoff et al (137)	2002	-	-	-	IV	Interview <sup>a</sup>			
Kutash et al (149)	2007	-	+	-	IV	Interview <sup>a</sup>			
Sacco et al (164)	2009	+/-	-	++	IV	Interview <sup>a</sup>			
Nelson et al (132)	2010	+/-	++	-	IV	Interview <sup>a</sup>			
Siddiqui et al (128)	2011	+/-	+	-	IV	Interview <sup>a</sup>			

Mode of assessment: "Assessed by structured interview other questionnaires were self-reported.

English, French, and Arabic. Five of these studies met the predefined sample size criterion (7, 133, 138, 141, 146). In general, face/content validity was found to be "good." However, poor results were reported for construct validity and internal consistency. No information was found on other psychometric data such as measures of central tendency. Mean and sD of the items, as well

# TABLE 3. Sample Size and Psychometric Properties of Well-Established Assessment Tools

		Validity			Reliability			
Instrument	Version	Sample Size	Content/ Face	Construct Validity, of Scales/ Subscales	Internal Consistency	Inter-Rater/ Test-Retest		Responsiveness
Critical Care Family Needs	48-Item French (65, 66)	+	+	0	+	0	0	0
Inventory	46-Item French and English (58)	+	+	0	+	0	0	0
	46-ltem English (56, 67, 77, 78)	+	+	+	+	0	+/-	0
	45-Item English (5, 32, 45, 47, 51, 53, 55, 57, 59–61, 68, 69, 75, 81, 90, 114, 116, 124)	+	+	+	+	+	+/-	0
	90-Item English (+NMI) (39, 52)	-	+	0	0	0	+/-	0
	45-Item Dutch (40, 43, 74)	+	+	+/-	-	0	+/-	0
	45-Item Chinese (35, 36, 41, 42, 44, 76)	+	+	+	+/-	+	+/-	+
	45-Item Arabic (33, 38, 119)	+	+	0	+	0	+/-	+/-
	45-Item French (80, 109)	+	0	0	0	0	0	0
	45-Item Swedish (82)	+	0	0	-	0	+/-	0
	45-Item Greek (125)	+	+	0	0	0	+	+/-
	43-Item English (46)	+	+	0	0	0	+/-	0
	43-Item Portuguese (34, 70, 73, 92)	+	+	0	-	-	+/-	0
	34-Item Spanish (48)	-	0	0	0	0	0	0
	30-Item English (49, 50, 62, 63, 72, 79)	+	+/-	-	+	0	+/-	0
	60-Item English (+NMI) (71)	-	+	-	+	0	0	0
	15-Item English (54, 64)	+	+/-	0	+	0	+/-	0
	14-Item English (37)	-	0	0	+	0	+/-	0
Society of Critical	14-Item English (140)	+	0	-	0	+	0	0
Care Medicine Family Needs Assessment	14-Item French (7, 137, 143)	+	+	-	0	+	0	0
	14-Item Arabic (157, 133)	+	+	0	-	-	0	0
Critical Care Family Satisfaction	20-Item English (8, 83, 86, 97, 98, 111, 115, 120)	+	+	+	+	0	+/-	+/-
Survey	20-Item Arabic (95)	-	+	0	+	0	0	0
	20-Item Swedish (85)	-	+	0	0	0	0	0

(Continued)

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# TABLE 3. (Continued). Sample Size and Psychometric Properties of Well-Established Assessment Tools

		Validity				Reliability		
Instrument	Version	Sample Size	Content/ Face	Construct Validity, of Scales/ Subscales	Internal Consistency	Inter-Rater/ Test-Retest	Measures of Central Tendency	Responsiveness
Family Satisfaction in the Intensive Care Unit	37-Item English (102, 110)	+	+	-	-	0	+/-	-
	34-Item English (6, 93, 94, 104–106, 113, 130, 146)	+	+	0	+	+	+/-	0
	34-Item English +2 (121)	-	+	0	+	0	0	0
	34-Item German (91, 96, 99, 131)	+	+	+/-	+	-	+/-	0
	34-Item Dutch (51)	+	+	0	+	0	0	+
	26-Item Modified English (160, 161)	+	+	-	-	0	+/-	+/-
	24-Item English (4, 84, 87, 100, 127, 141, 147–149)	+	+	+/-	+	_	+/-	+
	24-Item Hebrew (153)	-	+	0	+	0	+/-	0
	24-Item German (159)	+	+	0	+	+	0	0
	24-Item Greek (150)	+	+	0	0	0	+/-	0
	24-Item Filipino (158)	-	+	0	+	0	+/-	0

Sample size and psychometric properties of well-established assessment tools. To improve legibility, sensitivity was not included in the table because scarcely and results indicating sensitivity was reported.

Sample size: "+" = n > 100, "-" = n < 100.

Content/face validity: "+" = assesses intended construct, "+/-" = does not match the original tool, but assesses intended construct, and "-" = does not match the original tool and does not assess intended construct.

Construct validity: "+" = after factor analysis Cronbach  $\alpha > 0.70$  for all factors, "+/-" = after factor analysis, most factors Cronbach  $\alpha > 0.70$ , but not all, "-" = factor analysis shows poor quality with most factors Cronbach  $\alpha < 0.70$ .

Internal consistency: "+" = Cronbach  $\alpha$ , Spearman Brown or Split Half > 0.80 of the scale and subscales both, "+/-" = Cronbach  $\alpha$  is > 0.80 for either the scale or the subscales, but not both, "-" = Cronbach  $\alpha < 0.80$  for the scale and the subscales.

Reliability (inter-rater/test-retest): "+" =  $\kappa$  > 0.61 or Pearson's r > 0.80, "-" =  $\kappa$  < 0.61; Pearson's r < 0.80, or proven change of scores when filled in by junior versus senior staff.

Measures of central tendency: "+" = mean and SD for all subscores, no ceiling or floor effect, "+/-" = Only mean and SD described or no floor and ceiling effects described, "-" = no mean and SD described.

Responsiveness: "+" = scale shows to be able to detect differences over timer or between before and after measurements, "+/-" = differences in before and after intervention scores were found on some items, but no differences were demonstrated on the whole scale or on a domain, "-" = scale is not able to show differences over time, or between before and after measurements.

"0" = no data available.

as completion time of the questionnaire, were not reported (for a detailed overview, see the Supplemental Table 2, Supplemental Digital Content 3, http://links.lww.com/CCM/B259).

### CCFSS

The CCFSS is a questionnaire specifically designed to measure family satisfaction with intensive care. It was developed in 2001 by Wasser et al (8) and consists of 20 items within five domains: 1) assurance, 2) information, 3) proximity, 4) support, and 5) comfort, answered on a five-point Likert scale.

The CCFSS has been published in 10 studies (8, 83, 85, 86, 95, 97, 98, 111, 115, 120) and in three different languages:

English, Arabic, and Swedish. Only studies on the English version were of good sample size (k = 6; n > 100) (8, 83, 97, 98, 111, 115). This version shows "good" validity (face/content and construct). Five studies (8, 86, 95, 98, 120) reported adequate internal consistency, whereas four other studies (83, 97, 111, 115) found it to be poor. The mean and sp have been reported once for the English version only (86), and this version shows mediocre responsiveness. Finally, data on other psychometric data are lacking. Completion time of the questionnaire was not reported (for a detailed overview, see the Supplemental Table 2, Supplemental Digital Content 3, http://links.lww.com/CCM/B259).

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#### FS-ICU

The FS-ICU was developed in 2001 by Heyland and Tranmer (106) and assesses two conceptual domains: 1) satisfaction with care and 2) satisfaction with decision making. The items in the questionnaire were derived from the existing literature on patient satisfaction, quality of care near the end of life, the needs of families of critically ill patients and family satisfaction with decision making (106).

Eleven different versions of the FS-ICU have been published in 32 studies (4, 6, 84, 87, 91, 93, 94, 96, 99, 100, 102, 104–106, 110, 113, 121, 127, 130, 131, 143, 152–157, 161, 167–169, 171). These versions contain a different number of questions: initially the questionnaire consisted of 34 multiple choice and three open-ended questions. Dowling et al (102) in 2005 modified the FS-ICU 34 into a version with 37 questions as part of a critical care family assistance improvement programme. Later in 2007 (4), a more concise version with 24 multiple choice questions was developed. All versions have a five-point Likert response scale. Furthermore, the questionnaire was published in the following languages: English, German, Dutch, Hebrew, Greek, and Filipino (for a detailed overview, see the Supplemental Table 2, Supplemental Digital Content 3, http:// links.lww.com/CCM/B259).

The majority of the studies had good sample size (k = 27; *n* > 100) (4, 6, 84, 87, 91, 93, 96, 99, 100, 102, 104, 105, 110, 113, 127, 130, 131, 143, 152–157, 168, 169, 171), and most versions of the FS-ICU questionnaire showed good psychometric quality. Face/content validity was found to be "good." Only scarce data were found on construct validity (k = 3) (4, 99, 102), showing mediocre quality for the 34-item German version (99) and the 24-item English version (4). Internal consistency was found to be good for most versions, except for the 37-item modified English version where poor construct validity and internal consistency was reported (k = 1) (102). Twelve studies reported on mean and sD (4, 102, 106, 110, 127, 131, 153, 156, 161, 167, 169, 171). In six studies, information on responsiveness was found (100, 153, 155, 157, 169, 171). This was reported mainly for individual items that showed differences in measurements taken before and after the event. The time needed to complete the questionnaire varied from 20 to 30 minutes (for a detailed overview, see the Supplemental Table 2, Supplemental Digital Content 3, http://links.lww.com/CCM/B259).

On the basis of summaries of psychometric properties (Table 3), with focus on sample size, validity and measures of central tendency, we concluded that of the four questionnaires, the CCFNI and the FS-ICU displayed the most extensively researched and best psychometric properties.

## DISCUSSION

The aim of this review was to determine which questionnaires assessing family satisfaction with ICU care are currently available and to provide an overview of their quality by determining their psychometric properties. Therefore, we critically examined the quality of all known versions of family satisfaction assessment tools in a two-step model. First, we determined the general quality and psychometric properties of the questionnaires. Second, we evaluated the questionnaires with the highest quality with respect to their psychometric properties.

Only four questionnaires could be classified as being of "well-established quality": the CCFNI, the SCCMFNA, the CCFSS, and the FS-ICU. However, these high-quality instruments consisted of 35 different versions, each with large disparities in psychometric qualities. Of the four, the CCFNI and the FS-ICU displayed the most extensively researched and best psychometric properties; hence, we would recommend these for further use and study. The CCFNI and the FS-ICU differ in many ways. The CCFNI is primarily designed to measure family needs, whereas the FS-ICU focuses on family satisfaction. Although the definition of "family satisfaction with ICU care" is not clearly defined and overlaps with "family needs," they are not the same. Meeting needs does not necessarily reflect satisfaction (6) Despite this potential drawback of focus on needs, studies on the CCFNI, especially in combination with the NMI, have been of great value for increased understanding of the needs contributing to overall satisfaction with ICU care. These studies also contributed to an increase in (content) validity of other questionnaires, such as the FS-ICU (106).

The FS-ICU assesses satisfaction with *decision making*, besides satisfaction with *care*. These two domains are central to overall family satisfaction with ICU care (106). First, satisfaction with care provides data on how families experience general aspects of care. Second, family satisfaction with decision making is a major component because the family is a substitute decision maker for their critically ill family member in a complex healthcare environment. The FS-ICU is available in many languages, but some language versions have not yet been published in peer-reviewed journals (172). Although a lot of data exist on the 10 different versions of the FS-ICU, it should be noted that not all these versions display an overall high quality.

In general, limitations of the tools include insufficient data regarding (1) construct and content validity (2) inter-rater reliability (3), test-retest reliability (4), measures of central tendency (5), responsiveness, and especially sensitivity(6). Because construct validity is the extent to which a tool actually measures what it claims to measure, and content validity refers to whether the questionnaire includes the appropriate information, they both are of great importance, especially in a subjective outcome such as satisfaction. However, many different language versions of the originally high-quality questionnaires are available in which construct and content validity data are lacking. Therefore, these versions cannot be necessarily called "equivalent." Differences may arise due to inherent semantic differences and cultural differences. For example, the degree of family participation in the decision-making process differs across the world (7).

An example of importance of inter-rater reliability is Damghi's study (133), using the SCCMFNA. It was found that when the questionnaire was self-completed by highly educated family members, they were significantly less satisfied with the provided care compared with members of less educated families for whom the questionnaire was filled out by the investigator in

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a face to face interview (173). Test-retest reliability is important in determining whether the outcome of a tool is susceptible to small timing differences. The lack of data on central tendency measures refers to the omission of information on ceiling and floor effects. However, when examining the score range of the published tools, the mean and sD strongly implicate that ceiling effects are present. Indeed, most studies report that family members were generally highly satisfied (91, 100, 104).

The most important question is whether these tools are capable of detecting dissatisfaction (sensitivity) or change in satisfaction (responsiveness). Unfortunately, even with all methodological issues combined, it can be concluded that it is not clear whether this is the case. A few causes might account for this. First, patients may tend to respond in a bimodal fashion, eg, globally satisfied or globally not satisfied. With a fouror five-point Likert scale, the depth of responses cannot be assessed (114) and the continuum between the minimum and maximum score is then, in essence, meaningless. As a consequence, this affects the distribution of the acquired data and therefore no parametric statistics can be applied. More importantly, the value of the derived mean scores does not reflect the actual state. Second, as the majority of the questionnaires use four- or five-point Likert scales, it is conceivable that most family members' answers convey "good" or "excellent" (174). This could be explained by the possibility that the family might not have experience with other healthcare facilities to compare, or because they do not want to come across picky, and probably because they are grateful for the help they received in this stressful and frightening time in their lives. Third, no consensus of absolute cutoffs on Likert scale signifying importance have been stated for the questionnaires listed here (125). Therefore, Lynn-McHale and Bellinger (67) suggested that an instrument should be developed that would take into consideration both the level of perceived satisfaction and the importance that the family members associate with it. Another solution for this problem could be to use a more differentiated scoring system, eg, widening the range to six-point Likert scales (49), or even to seven or eight might correct this problem at least to some extent. In addition, it makes sense that the family fills in the questionnaire anonymously and in the absence of staff.

Besides the limitations of the tools described above, this study also holds limitations. First, in an ideal comparative study, a "gold standard" would be used to assess other measurement tools. Alas there are currently none available. Nevertheless, there were two comparative studies in which the Quality of Dying and Death (QODD), family and nurse version, and the FS-ICU were compared (4, 127). Although the QODD is not a tool specifically tailored for the ICU environment, there was a strong correlation between the QODD family and the FS-ICU, especially on the subscale of satisfaction with care (4). Furthermore, the QODD and the FS ICU both showed different performances across different age groups (127). Once again implicating that satisfaction differs across (age) groups.

Another limitation of this study is that we did not report on measures connected to response rates because there was

not enough information provided in the included studies. Response rate is an important aspect of feasibility. We only studied fill in time and mode of application. Furthermore, we have only included articles published in English, which might have led to omission of relevant studies on questionnaires in other languages. Also, studies on patient satisfaction combined with family satisfaction were excluded. Although this increased the clarity of the search, it is possible that some studies with data on this subject were not included. Nevertheless, this is the first study that critically examined the psychometric properties of all the different published versions of family satisfaction questionnaires. Finally, we defined high quality by psychometric properties. Although this is a commonly used and approved method, it may still not be possible to point out one single best questionnaire. The quality of a questionnaire is also highly dependent on the circumstances under which it is used. First, the quality of a questionnaire depends on the aim of the measurement. This can be, for example, the measurement of an aspect of care or of changes in satisfaction. Second, it depends on what population it is used on. For example, differences in language, culture, and patient population have a high effect on the appropriateness of a questionnaire. To comply with these factors, many adjusted versions to primarily high-quality questionnaires have been developed. The risk of these adjusted versions is that they are not per se of the same quality as the original version, especially because the psychometric properties of those versions are often scarce. The second aspect is the method of using psychometric properties itself. Although used worldwide, this method for assessing family satisfaction questionnaires is a reflective analysis method. Theoretically, a formative approach exists as well. Because family satisfaction is not well defined, it is possible that not all aspects of family satisfaction are in fact measured.

In conclusion, at present four well-established questionnaires are available to measure family satisfaction with ICU care. When using these questionnaires in clinical practice or for research activities, it is of importance to be aware of the limitations of each tool. Of these four tools, CCFNI and FS-ICU have the best psychometric properties. The CCFNI measures *needs* and the FS-ICU measures *satisfaction*. Finally, in the evaluation of family satisfaction with intensive care, the use of valid instruments is essential to gain proper and high-quality information. This information is necessary as an outcome quality indicator and to better target improvement initiatives in the ICU.

### REFERENCES

- Rothen HU, Stricker KH, Heyland DK: Family satisfaction with critical care: Measurements and messages. *Curr Opin Crit Care* 2010; 16:623–631
- Flaatten H: The present use of quality indicators in the intensive care unit. Acta Anaesthesiol Scand 2012; 56:1078–1083
- Schleyer AM, Curtis JR: Family satisfaction in the ICU: Why should ICU clinicians care? *Intensive Care Med* 2013; 39:1143–1145
- Wall RJ, Engelberg RA, Downey L, et al: Refinement, scoring, and validation of the Family Satisfaction in the Intensive Care Unit (FS-ICU) survey. Crit Care Med 2007; 35:271–279
- 5. Leske JS: Needs of relatives of critically ill patients: A follow-up. *Heart Lung* 1986; 15:189–193

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- Heyland DK, Rocker GM, Dodek PM, et al: Family satisfaction with care in the intensive care unit: Results of a multiple center study. *Crit Care Med* 2002; 30:1413–1418
- Azoulay E, Pochard F, Chevret S, et al; FAMIREA Study Group: Half the family members of intensive care unit patients do not want to share in the decision-making process: A study in 78 French intensive care units. *Crit Care Med* 2004; 32:1832–1838
- Wasser T, Pasquale MA, Matchett SC, et al: Establishing reliability and validity of the critical care family satisfaction survey. *Crit Care Med* 2001; 29:192–196
- 9. Latour JM, van Goudoever JB, Hazelzet JA: Parent satisfaction in the pediatric ICU. *Pediatr Clin North Am* 2008; 55:779–90, xii
- Cohen LL, La Greca AM, Blount RL, et al: Introduction to special issue: Evidence-based assessment in pediatric psychology. J Pediatr Psychol 2008; 33:911–915
- Cicerone KD, Dahlberg C, Kalmar K, et al: Evidence-based cognitive rehabilitation: Recommendations for clinical practice. Arch Phys Med Rehabil 2000; 81:1596–1615
- Streiner DL, Norman G.R.: Health Measurement Scales: A Practical Guide to Their Development and Use. Fourth Edition, Oxford, Oxford University Press, 2008
- Friberg JC: Considerations for test selection: How do validity and reliability impact diagnostic decisions? Child Language Teaching and Therapy 2010; 26:77–92
- Fitzpatrick R, Davey C, Buxton MJ, et al: Evaluating patient-based outcome measures for use in clinical trials. *Health Technol Assess* 1998; 2:i-74
- Portney LG, Watkins MP: Foundations of Clinical Research: Applications to Practice. Third Edition, Upper Saddle River, Prentice Hall, 2008
- Guyatt GH, Deyo RA, Charlson M, et al: Responsiveness and validity in health status measurement: A clarification. J Clin Epidemiol 1989; 42:403–408
- Liang MH: Longitudinal construct validity: Establishment of clinical meaning in patient evaluative instruments. *Med Care* 2000; 38:II84–II90
- Stinson JN, Kavanagh T, Yamada J, et al: Systematic review of the psychometric properties, interpretability and feasibility of self-report pain intensity measures for use in clinical trials in children and adolescents. *Pain* 2006; 125:143–157
- Dullenkopf A, Rothen HU; Swiss CoBaTrICE Group: What patients and relatives expect from an intensivist-the Swiss side of a European survey. Swiss Med Wkly 2009; 139:47–51
- Chui WY, Chan SW: Stress and coping of Hong Kong Chinese family members during a critical illness. J Clin Nurs 2007; 16:372–381
- Nelson JE, Mulkerin CM, Adams LL, et al: Improving comfort and communication in the ICU: A practical new tool for palliative care performance measurement and feedback. *Qual Saf Health Care* 2006; 15:264–271
- Takman C, Severinsson E: A description of healthcare providers' perceptions of the needs of significant others in intensive care units in Norway and Sweden. *Intensive Crit Care Nurs* 2006; 22:228–238
- Takman C, Severinsson E: Comparing Norwegian nurses' and physicians' perceptions of the needs of significant others in intensive care units. *J Clin Nurs* 2005; 14:621–631
- Hughes F, Bryan K, Robbins I: Relatives' experiences of critical care. Nurs Crit Care 2005; 10:23–30
- Takman CA, Severinsson EI: The needs of significant others within intensive care-the perspectives of Swedish nurses and physicians. *Intensive Crit Care Nurs* 2004; 20:22–31
- Garrouste-Org, Philippart F, Timsit JF, et al: Perceptions of a 24-hour visiting policy in the intensive care unit. *Critical Care Medicine* 2008; 36:30–35
- 27. Peel N: The role of the critical care nurse in the delivery of bad news. Br J Nurs 2003; 12:966–971
- Danis M, Patrick DL, Southerland LI, et al: Patients' and families' preferences for medical intensive care. JAMA 1988; 260:797–802
- Ward CR, Constancia PE, Kern L: Nursing interventions for families of cardiac surgery patients. J Cardiovasc Nurs 1990; 5:34–42
- Curry S: Identifying family needs and stresses in the intensive care unit. Br J Nurs 1995; 4:15–19

- Eagleton BB, Goldman L: The quality connection: Satisfaction of patients and their families. *Crit Care Nurse* 1997; 17:76–80, 100
- Hinkle JL, Fitzpatrick E, Oskrochi GR: Identifying the perception of needs of family members visiting and nurses working in the intensive care unit. J Neurosci Nurs 2009; 41:85–91
- 33. Omari FH: Perceived and unmet needs of adult Jordanian family members of patients in ICUs. J Nurs Scholarsh 2009; 41:28–34
- Fumis RR, Nishimoto IN, Deheinzelin D: Measuring satisfaction in family members of critically ill cancer patients in Brazil. *Intensive Care Med* 2006; 32:124–128
- Chien WT, Ip WY, Lee IY: Psychometric properties of a Chinese version of the critical care family needs inventory. *Res Nurs Health* 2005; 28:474–487
- Chien WT, Chiu YL, Lam LW, et al: Effects of a needs-based education programme for family carers with a relative in an intensive care unit: A quasi-experimental study. *Int J Nurs Stud* 2006; 43:39–50
- 37. Auerbach SM, Kiesler DJ, Wartella J, et al: Optimism, satisfaction with needs met, interpersonal perceptions of the healthcare team, and emotional distress in patients' family members during critical care hospitalization. Am J Crit Care 2005; 14:202–210
- Al-Hassan MA, Hweidi IM: The perceived needs of Jordanian families of hospitalized, critically ill patients. Int J Nurs Pract 2004; 10:64–71
- Kosco M, Warren NA: Critical care nurses' perceptions of family needs as met. Crit Care Nurs Q 2000; 23:60–72
- Bijttebier P, Vanoost S, Delva D, et al: Needs of relatives of critical care patients: Perceptions of relatives, physicians and nurses. *Intensive Care Med* 2001; 27:160–165
- Leung KK, Chien WT, Mackenzie AE: Needs of Chinese families of critically ill patients. West J Nurs Res 2000; 22:826–840
- Lee IY, Chien WT, MacKenzie AE: Needs of families with a relative in a critical care unit in Hong Kong. J Clin Nurs 2000; 9:46–54
- Bijttebier P, Delva D, Vanoost S, et al: Reliability and validity of the Critical Care Family Needs Inventory in a Dutch-speaking Belgian sample. *Heart Lung* 2000; 29:278–286
- 44. Tin MK, French P, Leung KK: The needs of the family of critically ill neurosurgical patients: A comparison of nurses' and family members' perceptions. J Neurosci Nurs 1999; 31:348–356
- Hunsucker SC, Frank DI, Flannery J: Meeting the needs of rural families during critical illness: The APN's role. *Dimens Crit Care Nurs* 1999; 18:24–32
- Burr G: Contextualizing critical care family needs through triangulation: An Australian study. *Intensive Crit Care Nurs* 1998; 14:161–169
- Mendonca D, Warren NA: Perceived and unmet needs of critical care family members. Crit Care Nurs Q 1998; 21:58–67
- Zazpe C, Margall MA, Otano C, et al: Meeting needs of family members of critically ill patients in a Spanish intensive care unit. *Intensive Crit Care Nurs* 1997; 13:12–16
- Quinn S, Redmond K, Begley C: The needs of relatives visiting adult critical care units as perceived by relatives and nurses. Part 2. *Intensive Crit Care Nurs* 1996; 12:239–245
- Quinn S, Redmond K, Begley C: The needs of relative visiting adult critical care units as perceived by relatives and nurses. Part I. *Intensive Crit Care Nurs* 1996; 12:168–172
- Lopez-Fagin L: Critical Care Family Needs Inventory: A cognitive research utilization approach. *Crit Care Nurse* 1995; 15:21, 23–21, 26
- 52. Warren NA: Perceived needs of the family members in the critical care waiting room. *Crit Care Nurs Q* 1993; 16:56–63
- Engli M, Kirsivali-Farmer K: Needs of family members of critically ill patients with and without acute brain injury. *J Neurosci Nurs* 1993; 25:78–85
- Henneman EA, McKenzie JB, Dewa CS: An evaluation of interventions for meeting the information needs of families of critically ill patients. *Am J Crit Care* 1992; 1:85–93
- Kahn EC: A comparison of family needs based on the presence or absence of DNR orders. *Dimens Crit Care Nurs* 1992; 11:286–292
- Rukholm EE, Bailey PH, Coutu-Wakulczyk G: Anxiety and family needs of the relatives of cardiac medical-surgical ICU patients. *Can J Cardiovasc Nurs* 1992; 2:15–22

#### Critical Care Medicine

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- Kleinpell RM, Powers MJ: Needs of family members of intensive care unit patients. Appl Nurs Res 1992; 5:2–8
- Rukholm E, Bailey P, Coutu-Wakulczyk G, et al: Needs and anxiety levels in relatives of intensive care unit patients. J Adv Nurs 1991; 16:920–928
- Macey BA, Bouman CC: An evaluation of validity, reliability, and readability of the Critical Care Family Needs Inventory. *Heart Lung* 1991; 20:398–403
- 60. Leske JS: Internal psychometric properties of the Critical Care Family Needs Inventory. *Heart Lung* 1991; 20:236–244
- Koller PA: Family needs and coping strategies during illness crisis. AACN Clin Issues Crit Care Nurs 1991; 2:338–345
- Price DM, Forrester DA, Murphy PA, et al: Critical care family needs in an urban teaching medical center. *Heart Lung* 1991; 20:183–188
- Forrester DA, Murphy PA, Price DM, et al: Critical care family needs: Nurse-family member confederate pairs. *Heart Lung* 1990; 19:655–661
- Halm MA, Titler MG: Appropriateness of critical care visitation: Perceptions of patients, families, nurses, and physicians. *J Nurs Qual Assur* 1990; 5:25–37
- Coutu-Wakulczyk G, Chartier L: French validation of the critical care family needs inventory. *Heart Lung* 1990; 19:192–196
- Chartier L, Coutu-Wakulczyk G: Families in ICU: Their needs and anxiety level. *Intensive Care Nurs* 1989; 5:11–18
- Lynn-McHale DJ, Bellinger A: Need satisfaction levels of family members of critical care patients and accuracy of nurses' perceptions. *Heart Lung* 1988; 17:447–453
- Rodgers CD: Needs of relatives of cardiac surgery patients during the critical care phase. *Focus Crit Care* 1983; 10:50–55
- 69. Molter NC: Needs of relatives of critically ill patients: A descriptive study. *Heart Lung* 1979; 8:332–339
- Fumis RR, Nishimoto IN, Deheinzelin D: Families' interactions with physicians in the intensive care unit: The impact on family's satisfaction. J Crit Care 2008; 23:281–286
- Maxwell KE, Stuenkel D, Saylor C: Needs of family members of critically ill patients: A comparison of nurse and family perceptions. *Heart Lung* 2007; 36:367–376
- Gelling L, Prevost AT: The needs of relatives of critically ill patients admitted to a neurosciences critical care unit: A comparison of the perceptions of relatives, nurses and doctors. *Care of the Critically III* 1999; 15:53–58
- Freitas KS, Kimura M, Ferreira KA: Family members' needs at intensive care units: Comparative analysis between a public and a private hospital. *Rev Lat Am Enfermagem* 2007; 15:84–92
- Delva D, Vanoost S, Bijttebier P, et al: Needs and feelings of anxiety of relatives of patients hospitalized in intensive care units: Implications for social work. Soc Work Health Care 2002; 35:21–40
- Higgins I, Cadd A: The needs of relatives of the hospitalised elderly and nurses' perceptions of those needs. *Geriaction* 1999; 17:18–22
- Chiu YL, Chien WT, Lam LW: Effectiveness of a needs-based education programme for families with a critically ill relative in an intensive care unit. J Clin Nurs 2004; 13:655–656
- 77. Daley L: The perceived immediate needs of families with relatives in the intensive care setting. *Heart Lung* 1984; 13:231–237
- Rukholm EE, Bailey PH, Coutu-Wakulczyk G: Family needs and anxiety in ICU: Cultural differences in northeastern Ontario. *Can J Nurs Res* 1991; 23:67–81
- Murphy PA, Forrester DA, Price DM, et al: Empathy of intensive care nurses and critical care family needs assessment. *Heart Lung* 1992; 21:25–30
- Moreau D, Goldgran-Toledano D, Alberti C, et al: Junior versus senior physicians for informing families of intensive care unit patients. *Am J Respir Crit Care Med* 2004; 169:512–517
- Noor Siah AA, Ho SE, Jafaar MZ, et al: Information needs of family members of critically ill patients in intensive care unit of a tertiary hospital. *Clin Ter* 2012; 163:63–67
- 82. Hoghaug G, Fagermoen MS, Lerdal A: The visitor's regard of their need for support, comfort, information proximity and assurance in the intensive care unit. *Intensive Crit Care Nurs* 2012;28:263–268

- Hickman RL Jr, Daly BJ, Douglas SL, et al: Evaluating the critical care family satisfaction survey for chronic critical illness. West J Nurs Res 2012; 34:377–395
- Henrich NJ, Dodek P, Heyland D, et al: Qualitative analysis of an intensive care unit family satisfaction survey. *Crit Care Med* 2011; 39:1000–1005
- Karlsson C, Tisell A, Engström A, et al: Family members' satisfaction with critical care: A pilot study. Nurs Crit Care 2011; 16:11–18
- Roberti SM, Fitzpatrick JJ: Assessing family satisfaction with care of critically ill patients: A pilot study. *Crit Care Nurse* 2010; 30:18–26; quiz 27
- Jacobowski NL, Girard TD, Mulder JA, et al: Communication in critical care: Family rounds in the intensive care unit. *Am J Crit Care* 2010; 19:421–430
- van der Klink MA, Heijboer L, Hofhuis JG, et al: Survey into bereavement of family members of patients who died in the intensive care unit. *Intensive Crit Care Nurs* 2010; 26:215–225
- Cheung W, Aggarwal G, Fugaccia E, et al: Palliative care teams in the intensive care unit: A randomised, controlled, feasibility study. *Crit Care Resusc* 2010; 12:28–35
- Bailey JJ, Sabbagh M, Loiselle CG, et al: Supporting families in the ICU: A descriptive correlational study of informational support, anxiety, and satisfaction with care. *Intensive Crit Care Nurs* 2010; 26:114–122
- Stricker KH, Kimberger O, Schmidlin K, et al: Family satisfaction in the intensive care unit: What makes the difference? *Intensive Care Med* 2009; 35:2051–2059
- Fumis RR, Deheinzelin D: Family members of critically ill cancer patients: Assessing the symptoms of anxiety and depression. *Intensive Care Med* 2009; 35:899–902
- Gerstel E, Engelberg RA, Koepsell T, et al: Duration of withdrawal of life support in the intensive care unit and association with family satisfaction. *Am J Respir Crit Care Med* 2008; 178:798–804
- Kaufer M, Murphy P, Barker K, et al: Family satisfaction following the death of a loved one in an inner city MICU. *Am J Hosp Palliat Care* 2008; 25:318–325
- Brown A, Hijazi M: Arabic translation and adaptation of Critical Care Family Satisfaction Survey. Int J Qual Health Care 2008; 20:291–296
- Gries CJ, Curtis JR, Wall RJ, et al: Family member satisfaction with end-of-life decision making in the ICU. *Chest* 2008; 133:704–712
- Gajic O, Afessa B, Hanson AC, et al: Effect of 24-hour mandatory versus on-demand critical care specialist presence on quality of care and family and provider satisfaction in the intensive care unit of a teaching hospital. *Crit Care Med* 2008; 36:36–44
- Steel A, Underwood C, Notley C, et al: The impact of offering a relatives' clinic on the satisfaction of the next-of-kin of critical care patients-a prospective time-interrupted trial. *Intensive Crit Care Nurs* 2008; 24:122–129
- Stricker KH, Niemann S, Bugnon S, et al: Family satisfaction in the intensive care unit: Cross-cultural adaptation of a questionnaire. *J Crit Care* 2007; 22:204–211
- Wall RJ, Curtis JR, Cooke CR, et al: Family satisfaction in the ICU: Differences between families of survivors and nonsurvivors. *Chest* 2007; 132:1425–1433
- Stapleton RD, Engelberg RA, Wenrich MD, et al: Clinician statements and family satisfaction with family conferences in the intensive care unit. *Crit Care Med* 2006; 34:1679–1685
- 102. Dowling J, Vender J, Guilianelli S, et al: A model of family-centered care and satisfaction predictors: The Critical Care Family Assistance Program. Chest 2005; 128:81S–92S
- 103. McDonagh JR, Elliott TB, Engelberg RA, et al: Family satisfaction with family conferences about end-of-life care in the intensive care unit: Increased proportion of family speech is associated with increased satisfaction. *Crit Care Med* 2004; 32:1484–1488
- 104. Heyland DK, Rocker GM, O'Callaghan CJ, et al: Dying in the ICU: Perspectives of family members. *Chest* 2003; 124:392–397
- Heyland DK, Cook DJ, Rocker GM, et al: Decision-making in the ICU: Perspectives of the substitute decision-maker. *Intensive Care Med* 2003; 29:75–82

#### 1742 www.ccmjournal.org

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- 106. 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; 16:142–149
- 107. Cuthbertson SJ, Margetts MA, Streat SJ: Bereavement follow-up after critical illness. *Crit Care Med* 2000; 28:1196–1201
- 108. Dockter B, Black DR, Hovell MF, et al: Families and intensive care nurses: Comparison of perceptions. *Patient Educ Couns* 1988; 12:29–36
- Garrouste-Org, Willems V, Timsit J-F, et al: Opinions of families, staff, and patients about family participation in care in intensive care units. *J Crit Care* 2010; 25:634–640
- 110. Dowling J, Wang B: Impact on family satisfaction: The Critical Care Family Assistance Program. *Chest* 2005; 128:76S–80S
- 111. Wasser T, Matchett S, Ray D, et al: Validation of a total score for the critical care family satisfaction survey. *JCOM* 2004; 11:502–507
- Dixon JJ, Manara AR, Willats SM: Patient and relative satisfaction with intensive care. Importance of duration and quality of life. *Clinical Intensive Care* 1997; 8:63–68
- 113. Kross EK, Engelberg RA, Shannon SE, et al: Potential for response bias in family surveys about end-of-life care in the ICU. *Chest* 2009; 136:1496–1502
- 114. Hinkle JL, Fitzpatrick E: Needs of American relatives of intensive care patients: Perceptions of relatives, physicians and nurses. *Intensive Crit Care Nurs* 2011; 27:218–225
- 115. Hickman RL Jr, Daly BJ, Douglas SL, et al: Informational coping style and depressive symptoms in family decision makers. *Am J Crit Care* 2010; 19:410–420
- 116. Kinrade T, Jackson AC, Tomnay JE: The psychosocial needs of families during critical illness: Comparison of nurses' and family members' perspectives. Aust J Adv Nurs 2009; 27:82–88
- 117. Fox-Wasylyshyn SM, El-Masri MM, Williamson KM: Family perceptions of nurses' roles toward family members of critically ill patients: A descriptive study. *Heart Lung* 2005; 34:335–344
- 118. Deitrick L, Ray D, Stern G, et al: Evaluation and recommendations from a study of a critical-care waiting room. J Healthc Qual 2005; 27:17–25
- 119. Al-Mutair AS, Plummer V, Clerehan R, et al: Needs and experiences of intensive care patients' families: A Saudi qualitative study. *Nurs Crit Care* 2014; 19:135–144
- 120. Huffines M, Johnson KL, Smitz Naranjo LL, et al: Improving family satisfaction and participation in decision making in an intensive care unit. *Crit Care Nurse* 2013; 33:56–69
- LeClaire MM, Oakes JM, Weinert CR: Communication of prognostic information for critically ill patients. *Chest* 2005; 128:1728–1735
- 122. White DB, Braddock CH 3<sup>rd</sup>, Bereknyei S, et al: Toward shared decision making at the end of life in intensive care units: Opportunities for improvement. *Arch Intern Med* 2007; 167:461–467
- 123. Keenan A, Joseph L: The needs of family members of severe traumatic brain injured patients during critical and acute care: A qualitative study. *Can J Neurosci Nurs* 2010; 32:25–35
- Obringer K, Hilgenberg C, Booker K: Needs of adult family members of intensive care unit patients. J Clin Nurs 2012; 21:1651–1658
- 125. Chatzaki M, Klimathianaki M, Anastasaki M, et al: Defining the needs of ICU patient families in a suburban/rural Greek population: A prospective cohort study. J Clin Nurs 2012; 21:1831–1839
- 126. Sundararajan K, Sullivan TR, Sullivan TS, et al: Determinants of family satisfaction in the intensive care unit. *Anaesth Intensive Care* 2012; 40:159–165
- 127. Lewis-Newby M, Curtis JR, Martin DP, et al: Measuring family satisfaction with care and quality of dying in the intensive care unit: Does patient age matter? *J Palliat Med* 2011; 14:1284–1290
- 128. Siddiqui S, Sheikh F, Kamal R: "What families want an assessment of family expectations in the ICU". *Int Arch Med* 2011; 4:21
- 129. Myhren H, Ekeberg Ø, Stokland O: Satisfaction with communication in ICU patients and relatives: Comparisons with medical staffs' expectations and the relationship with psychological distress. *Patient Educ Couns* 2011; 85:237–244
- Curtis JR, Nielsen EL, Treece PD, et al: Effect of a quality-improvement intervention on end-of-life care in the intensive care unit: A randomized trial. Am J Respir Crit Care Med 2011; 183:348–355

- Stricker KH, Kimberger O, Brunner L, et al: Patient satisfaction with care in the intensive care unit: Can we rely on proxies? Acta Anaesthesiol Scand 2011; 55:149–156
- 132. Nelson JE, Puntillo KA, Pronovost PJ, et al: In their own words: Patients and families define high-quality palliative care in the intensive care unit. *Crit Care Med* 2010; 38:808–818
- 133. Damghi N, Khoudri I, Oualili L, et al: Measuring the satisfaction of intensive care unit patient families in Morocco: A regression tree analysis. *Crit Care Med* 2008; 36:2084–2091
- Kjerulf M, Regehr C, Popova SR, et al: Family perceptions of end-oflife care in an urban ICU. *Dynamics* 2005; 16:22–25
- 135. Agård AS, Harder I: Relatives' experiences in intensive care-finding a place in a world of uncertainty. *Intensive Crit Care Nurs* 2007; 23:170–177
- 136. Myhren H, Ekeberg Ø, Langen I, et al: Emotional strain, communication, and satisfaction of family members in the intensive care unit compared with expectations of the medical staff: Experiences from a Norwegian University Hospital. *Intensive Care Med* 2004; 30:1791–1798
- 137. Kirchhoff KT, Walker L, Hutton A, et al: The vortex: Families' experiences with death in the intensive care unit. Am J Crit Care 2002; 11:200–209
- 138. Azoulay E, Pochard F, Chevret S, et al; French FAMIREA Group: Meeting the needs of intensive care unit patient families: A multicenter study. *Am J Respir Crit Care Med* 2001; 163:135–139
- 139. Keenan SP, Mawdsley C, Plotkin D, et al: Withdrawal of life support: How the family feels, and why. *J Palliat Care* 2000; 16:S40–S44
- Malacrida R, Bettelini CM, Degrate A, et al: Reasons for dissatisfaction: A survey of relatives of intensive care patients who died. *Crit Care Med* 1998; 26:1187–1193
- Johnson D, Wilson M, Cavanaugh B, et al: Measuring the ability to meet family needs in an intensive care unit. *Crit Care Med* 1998; 26:266–271
- 142. Coulter MA: The needs of family members of patients in intensive care units. *Intensive Care Nurs* 1989; 5:4-10
- 143. Dodek PM, Wong H, Heyland DK, et al; Canadian Researchers at the End of Life Network (CARENET): The relationship between organizational culture and family satisfaction in critical care. *Crit Care Med* 2012; 40:1506–1512
- Humble SR, Antoniewicz P, Colvin JR: Communication with the relatives of critically ill patients. Br J Intensive Care 2009; 19:13–17
- 145. Fry S, Warren NA: Perceived needs of critical care family members: A phenomenological discourse. *Crit Care Nurs* Q 2007; 30:181–188
- 146. Azoulay E, Pochard F, Chevret S, et al; French Famirea Group: Family participation in care to the critically ill: Opinions of families and staff. *Intensive Care Med* 2003; 29:1498–1504
- 147. McKiernan M, McCarthy G: Family members' lived experience in the intensive care unit: A phemenological study. *Intensive Crit Care Nurs* 2010; 26:254–261
- 148. Plakas S, Cant B, Taket A: The experiences of families of critically ill patients in Greece: A social constructionist grounded theory study. *Intensive Crit Care Nurs* 2009; 25:10–20
- 149. Kutash M, Northrop L: Family members' experiences of the intensive care unit waiting room. *J Adv Nurs* 2007; 60:384–388
- 150. Verhaeghe ST, van Zuuren FJ, Defloor T, et al: How does information influence hope in family members of traumatic coma patients in intensive care unit? *J Clin Nurs* 2007; 16:1488–1497
- 151. Roland P, Russell J, Richards KC, et al: Visitation in critical care: Processes and outcomes of a performance improvement initiative. *J Nurs Care Qual* 2001; 15:18–26
- Hunziker S, McHugh W, Sarnoff-Lee B, et al: Predictors and correlates of dissatisfaction with intensive care. *Crit Care Med* 2012; 40:1554–1561
- 153. Shaw DJ, Davidson JE, Smilde RI, et al: Multidisciplinary team training to enhance family communication in the ICU. *Crit Care Med* 2013; 42:265–271
- 154. Osborn TR, Curtis JR, Nielsen EL, et al: Identifying elements of ICU care that families report as important but unsatisfactory: Decisionmaking, control, and ICU atmosphere. *Chest* 2012; 142:1185–1192

# Critical Care Medicine

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- 155. Higginson IJ, Koffman J, Hopkins P, et al: Development and evaluation of the feasibility and effects on staff, patients, and families of a new tool, the Psychosocial Assessment and Communication Evaluation (PACE), to improve communication and palliative care in intensive care and during clinical uncertainty. *BMC Med* 2013; 11:213
- 156. Gerasimou-Angelidi S, Myrianthefs P, Chovas A, et al: Nursing Activities Score as a predictor of family satisfaction in an adult Intensive Care Unit in Greece. J Nurs Manag 2014; 22:151–158
- 157. Jongerden IP, Slooter AJ, Peelen LM, et al: Effect of intensive care environment on family and patient satisfaction: A before-after study. *Intensive Care Med* 2013; 39:1626–1634
- 158. Liddle K: Reaching out. to meet the needs of relatives in intensive care units. *Intensive Care Nurs* 1988; 4:146–159
- 159. Jamerson PA, Scheibmeir M, Bott MJ, et al: The experiences of families with a relative in the intensive care unit. *Heart Lung* 1996; 25:467–474
- Warren NA: Critical care family members' satisfaction with bereavement experiences. Crit Care Nurs Q 2002; 25:54–60
- 161. Khalaila R: Patients' family satisfaction with needs met at the medical intensive care unit. *J Adv Nurs* 2013; 69:1172–1182
- 162. Selph RB, Shiang J, Engelberg R, et al: Empathy and life support decisions in intensive care units. J Gen Intern Med 2008; 23:1311–1317
- 163. Samuels O: Redesigning the neurocritical care unit to enhance family participation and improve outcomes. *Cleve Clin J Med* 2009; 76 Suppl 2:S70–S74
- 164. Sacco TL, Stapleton MF, Ingersoll GL: Support groups facilitated by families of former patients: Creating family-inclusive critical care units. *Crit Care Nurse* 2009; 29:36–45

- 165. Whitcomb JJ, Roy D, Blackman VS: Evidence-based practice in a military intensive care unit family visitation. *Nurs Res* 2010; 59:S32–S39
- 166. Yousefi H, Karami A, Moeini M, et al: Effectiveness of nursing interventions based on family needs on family satisfaction in the neurosurgery intensive care unit. *Iran J Nurs Midwifery Res* 2012; 17:296–300
- 167. Dalisay-Gallardo MI, Perez E: Family members' satisfaction in the end-of-life care in the ICU in a tertiary hospital setting. *Phillipp J Intern Med* 2012; 50
- Schwarzkopf D, Behrend S, Skupin H, et al: Family satisfaction in the intensive care unit: A quantitative and qualitative analysis. *Intensive Care Med* 2013; 39:1071–1079
- 169. Moore CD, Bernardini GL, Hinerman R, et al: The effect of a family support intervention on physician, nurse, and family perceptions of care in the surgical, neurological, and medical intensive care units. *Crit Care Nurs* Q 2012; 35:378–387
- 170. Azoulay E, Chevret S, Leleu G, et al: Half the families of intensive care unit patients experience inadequate communication with physicians. *Crit Care Med* 2000; 28:3044–3049
- 171. Shelton W, Moore CD, Socaris S, et al: The effect of a family support intervention on family satisfaction, length-of-stay, and cost of care in the intensive care unit. *Crit Care Med* 2010; 38:1315–1320
- 172. Family Satisfaction Survey. http://www.thecarenet.ca/. May 1, 2014
- 173. Smeeth L, Fletcher AE, Stirling S, et al: Randomised comparison of three methods of administering a screening questionnaire to elderly people: Findings from the MRC trial of the assessment and management of older people in the community. *BMJ* 2001; 323:1403–1407
- 174. Latour JM, Hazelzet JA, van der Heijden AJ: Parent satisfaction in pediatric intensive care: A critical appraisal of the literature. *Pediatr Crit Care Med* 2005; 6:578–584