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Author: Brunsveld-Reinders, A.H.

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Chapter 9

Questionnaires on family satisfaction in the adult ICU; a systematic review including psychometric properties

Anja H. Brunsveld-Reinders Janneke M. van den Broek Aglaia M.E.E. Zedlitz Armand R.J. Girbes Evert de Jonge M. Sesmu Arbous

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Abstract

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 until 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 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 CCFNI and the FS-ICU 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.

Introduction

In recent years, quality of care has become a central issue in healthcare systems worldwide. Particularly, the quality 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 Since 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 not clearly defined.

In the current body of literature, different aspects of family satisfaction are considered important for family members but 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 well-being. 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 family related 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 on the internet: 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 parent-patient 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 manuscripts. All studies that on full text 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, timeframe 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 (i.e. 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 (e.g. complete item list and means must be published) and (C) substantial data is 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 α was > 0.70 for all factors) and good reliability (Spearman Brown or Split half > 0.8 of scale and subscales both, or K < 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, 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. Lastly, 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 (e.g. 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 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 α >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 α). 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 α , 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 K 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 standard deviation (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, non-parametric test should be applied. In these cases, the interpretability of high or low scores is limited substantially.

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 wellestablished 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 (+)	
III	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	Ne	gative sore in A, B, and/or C (-)	Unconfirmed quality

Validity and reliability were assessed and scored as follows:

[&]quot;++" in category C was scored when both validity (either face-, content- or construct -) and reliability (either internal consistency, inter-rater reliability, 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 α was >0.70 for all factors), and good reliability (Spearman Brown or Split half > 0.8 of scale and subscales both, or K < 0.061 or Pearson's r > 0.8).

[&]quot;+" in category C was scored when both validity (either face-, content- or construct-) and reliability (either internal consistency, inter-rater reliability, 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).

[&]quot;+/-" in category C was scored when either validity (either face-, content- or construct-) or reliability (either internal consistency, inter-rater reliability, test-retest reliability) were named but not precisely defined, or when no values were presented, or when low values were presented (Cronbach α < 0.70 for all factors), or reliability (Spearman Brown < 0.8).

[&]quot;--" in category C was scored when validity or reliability were not mentioned or when no data on validity or reliability was reported.

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 (e.g., 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 (i.e., 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.

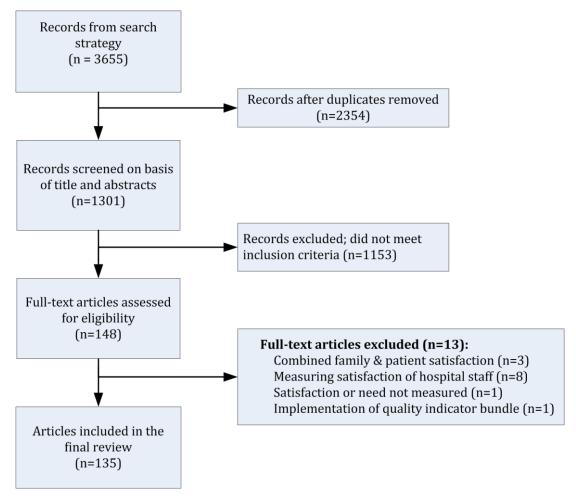


Figure 1. Study selection flow diagram

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 Appendix A.

Table 2. Level of Evidence

			Level of	Evidence		
Instrument	Year	A. Literature	B. Sufficient Details	C. Validity/ Reliability	Overall quality (I,II,III,IV)	Mode of assessment
Critical care Family Needs Inventory				-		
5,32-82, 90,92,109,114,116,119,124,125	1979-2013	++	++	++	I	Questionnaire
Society of Critical Care Medicine Family Needs Assessment 7,133,137,140,143,157	1998-2012	++	++	++	I	Questionnaire
Critical Care Family Satisfaction Survey 8,83,85,86,95,97,98,111,115,120	2001-2013	++	++	++	I	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	++	++	++	I	Questionnaire
Quality Of Death and Dying communication 103,122	2004-2007	+	+	+	II	Questionnaire
Myhren ^{129,136}	2004-2011	++	+/-	++	III	Questionnaire
Family members perception of nurses roles ¹¹⁷	2005	+/-	+	+	III	Questionnaire
Quality Of Communication 101	2006	+/-	+	+/-	III	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 a
Kirchhoff et al ¹³⁷	2002	-	-	-	IV	Interview a
Kutash et al 149	2007	-	+	-	IV	Interview a
Sacco et al ¹⁶⁴	2009	+/-	-	++	IV	Interview a
Nelson et al ¹³²	2010	+/-	++	-	IV	Interview a
Siddiqui et al ¹²⁸	2011	+/-	+		IV	Interview a

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

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) $^{4,8,35,43,56,60,71,83,86,97-99,102,111,115,120,141}$, inter-rater 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 (see Appendix B for a detailed overview) (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 four-point 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, ten varieties of the CCFNI with a total number of questions varying between 14 and 90 items were reported. 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. Means 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 (see Appendix B for a detailed overview).

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: 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

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

			Va	Validity		Reliability		
		Sample	Content	Construct validity, of scales/	Internal	Inter-Rater/	Measures of Central	
Instrument	Version	size	/Face	subscales	Consistency	Test-Retest	Tendency	Responsiveness
Critical Care	48 item French 65,66	+	+	0	+	0	0	0
Family Needs	46 item French & English ⁵⁸	+	+	0	+	0	0	0
Inventory	46 item 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	ı	0	-/+	0
	45 item Greek ¹²⁵	+	+	0	0	0	+	-/+
	43 item English ⁴⁶	+	+	0	0	0	-/+	0
	43 item Portugese 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	+	-/+	1	+	0	-/+	0
	60 item English (+NMI) 71	1	+	ı	+	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	14 item French ^{7,137,143}	+	+		0	+	0	0
Assessment	14 item Arabic 157,133	+	+	0		•	0	0
Critical Care Family	20 item English 8,83,86,97,98,111,115,120	+	+	+	+	C	-/+	-/+
Satisfaction	20 item Arahic 95		+		+	0	· 0	0
Survey				Þ)	ò	>
	20 item Swedish 85		+	0	+	0	0	0

Table 3. (cont.)

				Responsiveness		·	0	0	0	+	-/+	+	0	0	0	0
	3 · · · · · · · · · · · · · · · · · · ·	Measures or		Tendency Res	-/+	,	-/+	0	-/+	0	-/+	-/+	-/+	0	-/+	-/+
Reliability			_	Test-Retest '	0		+	0	•	0	0	ı	0	+	0	0
			Internal	Consistency	1		+	+	+	+		+	+	+	0	+
Validity	Construct,	vandity, or	Scales/	Subscales	ı	ć	0	0	-/+	0	•	-/+	0	0	0	0
Va			Content	/Face	+		+	+	+	+	+	+	+	+	+	+
		,	Sample	size	+		+		+	+	+	+		+	+	
				Version	37 item English 102,110	34 item English 6,93,94,104-	106,113,130,146	34 item English +2 ¹²¹	34 item German 91,96,99,131	34 item Dutch ⁵¹	26 item Modified English 160,161	Z4 item English 4,84,87,100,127,141,147-149	24 item Hebrew ¹⁵³	24 item German 159	24 item Greek 150	24 item Filipino ¹⁵⁸
				Instrument	Family Satisfaction in the	Intensive Care	Unit									

Sample size and psychometric properties of well-established assessment tools. To improve legibility, sensitivity was not included in the table since 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, '-' = 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 α < 0.70 $\,$

Internal consistency: '+' = Cronbach α , Spearman Brown or Split Half > 0.80 of the scale and subscales both, '+/-' = Cronbach α is > 0.80 for either the scale or the subscales, but not both, '-' = Cronbach α < 0.80 for the scale and the subscales Reliability (inter-rater/test-retest): + = K > 0.61 or Pearson's r > 0.80, - = K < 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

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 Responsiveness: '+' = scale shows to be able to detect differences over timer or between before and after measurements, '+/-' = differences in before and after intervention before and after measurements.

oerore and arter measur '0' = no data =available. measures of central tendency. Means and SD of the items, as well as completion time of the questionnaire, were not reported (see Appendix B for a detailed overview).

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 means and SD 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 (see Appendix B for a detailed overview).

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 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 (see Appendix B for a detailed overview). 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 means 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 (see Appendix B for a detailed overview).

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 since 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 to members of less educated families for whom the questionnaire was filled out by the investigator in 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 means 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 e.g., globally satisfied or globally not satisfied. With a four-or 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, e.g., 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.

Beside 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 impact 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.

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Appendix A. General quality and global psychometric properties of tools to assess family satisfaction with intensive care

				Le	vel of Eviden	ce
Author	Year	Instrument	Version	A. Literature	B.Sufficient Detail	C. Validity/ Reliability
Chartier 66	1989	CCFNI	48 item French	++	+/-	++
Coutu-Wakulczyk 65	1990	CCFNI	48 item French	++	+/-	++
Rukholm 58	1991	CCFNI	46 item French & English	++	+/-	++
Daley 77	1984	CCFNI	46 item English	-	++	-
Lynn-McHale ⁶⁷	1988	CCFNI	46 item English	++	++	++
Rukholm ⁷⁸	1991	CCFNI	46 item +2 English	++	+/-	++
Rukholm ⁵⁶	1992	CCFNI	46 item +2 English	++	+/-	++
Molter 69	1979	CCFNI	45 item English	++	++	+/-
Rodgers 68	1983	CCFNI	45 item English	++	++	++
Leske 5	1986	CCFNI	45 item English	++	++	+
Macey 59	1991	CCFNI	45 item English	++	++	++
Leske 60	1991	CCFNI	45 item English	++	++	++
Koller 61	1991	CCFNI	45 item English	++	+	++
Kahn 55	1991	CCFNI	_			
			45 item English	++	+	++
Kleinpell 57	1992	CCFNI	45 item English	++	+/-	++
Engli 53	1993	CCFNI	45 item English	++	+/-	++
Lopez-Fagin 51	1995	CCFNI	45 item English	++	+/-	-
Mendonca ⁴⁷	1998	CCFNI	45 item English	++	+/-	++
Hunsucker 45	1999	CCFNI	45 item English	++	++	++
Higgins 75	1999	CCFNI	45 item English	++	++	++
Hinkle 32	2009	CCFNI	45 item English	++	++	++
Kinrade 116	2009	CCFNI	45 item English	++	++	++
Bailey 90	2010	CCFNI	45 item English	++	+/-	++
Hinkle 114	2011	CCFNI	45 item English	++	++	++
Noor Siah 81	2012	CCFNI	45 item English	++	+/-	++
Obringer 124	2012	CCFNI	45 item English	++	+/-	++
Warren 52	1993	CCFNI + NMI	90 item English	++	+/-	+/-
Kosco 39	2000	CCFNI + NMI	90 item English	++	+/-	++
Bijttebier ⁴³	2000	CCFNI	45 item Dutch	++	++	++
Bijttebier 40	2001	CCFNI	45 item Dutch	++	++	++
Delva 74	2002	CCFNI	45 item Dutch	++	++	++
Tin Mi-kuen 44	1999	CCFNI	45 item Chinese	++	++	++
Lee 42	2000	CCFNI	45 item Chinese	++	+/-	++
Leung 41	2001	CCFNI	45 item Chinese	++	+/-	++
Chiu ⁷⁶	2004	CCFNI + C-SAI	45 item Chinese	+/-	-	_
Chien 35	2005	CCFNI	45 item Chinese	++	++	++
Chien ³⁶	2006	CCFNI	45 item Chinese	++	+/-	++
Al Hassan ³⁸	2004	CCFNI	45 item Arabic	++	+/-	++
Omari ³³	2009	CCFNI	45 item Arabic	++	+/-	++
Al-Mutair ¹¹⁹	2013	CCFNI	45 item Arabic	++	++	++
Moreau ⁸⁰	2004	CCFNI (RCT)	45 item French	++	+/-	++
Garrouste-Orgeas ¹⁰⁹	2010	CCFNI	45 item French	++	+/-	-
Hoghaug 82	2010	CCFNI	45 item Swedisch	++	+/-	++
Chatzaki ¹²⁵	2011	CCFNI	45 item Greek	++	++	-
Burr ⁴⁶	1998	CCFNI	43 item English	++		<u>-</u>
Fumis ³⁴			•		+/-	-
Freitas ⁷³	2006	CCENI	43 item Portugese	++	+/-	
	2007	CCFNI	43 item Portugese	++	++	++
Fumis 70	2008	CCFNI	43 item Portugese	++	-	-

Appendix A. (cont.)

				Le	evel of Evidenc	
Author	Year	Instrument	Version	A. Literature	B.Sufficient Detail	C. Validity/ Reliability
Fumis 92	2009	CCFNI	43 item Portugese	++	-	+/-
Zazpe 48	1997	CCFNI	34 item Spanish	+/-	++	-
Forrester 63	1990	CCFNI	30 item English	++	++	++
Price 62	1991	CCFNI	30 item English	++	++	++
Murphy 79	1992	CCFNI	30 item English	++	+/-	++
Quinn 49	1996	CCFNI	30 item English	-	++	-
Quinn 50	1996	CCFNI	30 item English	++	+/-	-
Gelling 72	1999	CCFNI	30 item English	+/-	++	-
Maxwell 71	2007	CCFNI + NMI	60 item English	++	++	++
Halm 64	1990	CCFNI	15 item English	++	++	-
Henneman 54	1992	CCFNI	15 item English	+/-	++	++
Auerbach 37	2005	CCFNI	14 item English	++	++	++
Azoulay ¹³⁷	2001	SCCMFNA	14 item French			
•			14 item French	++	++	++
Azoulay 143	2003	SCCMFNA		++	+/-	-
Azoulay ⁷	2004	SCCMFNA	14 item French	++	+/-	-
Yousefi 157	2012	SCCMFNA	14 item Arabic	++	+/-	-
Johnson 140	1998	SCCMFNA	14 item English	++	+	++
Damghi ¹³³	2008	SCCMFNA	14 item Arabic	++	++	+/-
Wasser ⁸	2001	CCFSS	20 item English	++	++	++
Wasser 111	2004	CCFSS	20 item English	++	+	++
Gajic ⁹⁷	2008	CCFSS	20 item English	++	++	++
Steel 98	2008	CCFSS	20 item English	++	+/-	++
Roberti 86	2010	CCFSS	20 item English	++	++	++
Hickman 115	2010	CCFSS	20 item English	++	+	++
Hickman 83	2012	CCFSS	20 item English	++	+	++
Huffines 120	2013	CCFSS	20 item English	++	+	++
Brown 95	2008	CCFSS	20 item Arabic	++	+/-	++
Karlsson 85	2011	CCFSS	20 item Swedish	++	+	++
Dowling 102	2005	FS-ICU	37 item English	++	_	?
Dowling 110	2005	FS-ICU	37 item English	++	_	-
Heyland ¹⁰⁶	2001	FS-ICU	34 item English	++	+	++
Heyland ⁶	2002	FS-ICU	34 item English	++	+/-	+
Heyland ¹⁰⁴	2003	FS-ICU	34 item English	++	+/-	+
Heyland ¹⁰⁵	2003	FS-ICU	34 item English	++	+/-	+
Gerstel ⁹³	2008	FS-ICU	34 item English	++	+/-	++
Kaufer 94	2008	FS-ICU	34 item English	++	+/-	++
Kross 113	2009	FS-ICU	34 item English	++	+/-	++
Curtis 130	2011	FS-ICU	34 item English	++	+/-	++
Hunziker 146	2012	FS-ICU	34 item English	++	+/-	++
LeClaire 121	2005	FS-ICU	34 +2 item English	++	+/-	++
Stricker 99	2007	FS-ICU	34 item German	++	+/-	++
Gries ⁹⁶	2008	FS-ICU	34 item German	++	+/-	++
Stricker 91	2009	FS-ICU	34 item German	++	+/-	++
Stricker ¹³¹	2011	FS-ICU	34 item German	++	+/-	++
Jongerden 51	2013	FS-ICU	34 item Dutch	++	++	++
Shelton ¹⁶¹	2010	FS-ICU	26 item modified English	++	-	-
Moore 160	2012	FS-ICU	26 item modified English	++	+/-	_
Wall 100	2012	FS-ICU	24 item English	++	++	++

Appendix A. (cont.)

				Le	vel of Eviden	ce
Author	Year	Instrument	Version	A. Literature	B.Sufficient Detail	C. Validity/ Reliability
Wall ⁴	2007	FS-ICU	24 item English	++	++	++
Jacobowski 87	2010	FS-ICU	24 item English	++	+/-	++
Henrich 84	2011	FS-ICU	24 item English	++	+/-	++
Lewis-Newby 127	2011	FS-ICU	24 item English	++	++	++
Dodek 141	2012	FS-ICU	24 item English	++	+/-	+/-
Osborn 148	2012	FS-ICU	24 item English	++	++	++
Shaw 147	2013	FS-ICU	24 item English	++	+/-	++
Higginson 149	2013	FS-ICU	24 item English	++	+/-	++
Khalaila 153	2013	FS-ICU	24 item Hebrew	++	+	++
Schwarzkopf 159	2013	FS-ICU	24 item German	++	++	++
Gerasimou-Angelidi ¹⁵⁰	2013	FS-ICU	24 item Greek	++	+	+/-
Dalisay-Gallardo 158	2012	FS-ICU	24 item Fillipino	++	++	++
McDonagh 103	2004	QODD-comm	5 item English	+	+	+
White 122	2007	QODD-comm	5 item English			
Myhren ¹³⁶	2004	Myhren	78 item Norwegian	+	+/-	-
Myhren 129	2011	Myhren	29 item Norwegian	++	+/-	++
Fox-Wasylyshyn 117	2005	Family members perception of nurses roles	14 item English	+/-	+	+
Stapleton 101	2006	QOC	7 item English	+/-	+	+/-
Liddle 158	1988	Liddle	10 item, English	-	-	-
Dockter ¹⁰⁸	1988	Dockter	44 item English	+/-	-	-
Dixon 112	1997	Dixon	12 item English	+/-	+	-
Malacrida 140	1998	Malacrida	43 item	+/-	+	-
Keenan 139	2000	Keenan	English, not listed	+/-	-	-
Roland 151	2001	Roland	Not listed	+/-	-	-
Deitrick ¹¹⁸	2005	Deitrick	18 item English	+/-	+	-
Kirchhoff 137	2002	Kirchhoff	2 item English	-	-	-
Kjerulf ¹³⁴	2005	Kirchhoff	9 item English	+/-	-	-
Humble 144	2009	Humble	10 item English	+/-	+	-
Whitcomb 156	2010	Whitcomb	19 item English	+/-	+	-
Cheung 89	2010	Cheung	Undescribed	-	-	-
Keenan 133	2010	FNQ	9 item English	+/-	-	-
Sundararajan 126	2012	Sundararajan	10 item English	+/-	+	-
Cuthbertson ¹⁰⁷	2000	Cuthbertson	18 item English 26 item Modified Dutch	++	+	-
Klink 88	2010	Cuthbertson	version	+	++	-
Kutash 149	2007	Interviews	English, not listed	-	+	-
Sacco 164	2009	Sacco	7 item English	+/-	-	++
Nelson ¹³²	2010	Interview	32 item English	+/-	++	-
Siddiqui ¹²⁸	2011	Siddiqui	25 item Pakistani	+/-	+	-

Appendix B. Psychometric criteria of level I tools to assess family satisfaction with intensive care

			1	Validity		Reliability			ı		
					Construct		Interrater	. Measures of			
Author	ır İnstrument	Version	Sample size	Content face	validity of scale/subscales	Internal consistency	/ test- retest	central tendency	Sensitivity	Respon- siveness	Time to administer
Chartier 66 1989	39 CCFNI	48 item French	+	+	0	0	0	0	0	0	unknown
Coutu-Wakulszyk 65 1990	00 CCFNI	48 item French	+	+	0	+	0	0	0	0	25 min
Rukholm ⁵⁸ 1991	1 CCFNI	46 item French + English	+	+	0	+	0	0	0	0	unknown
Rukholm ⁷⁸ 1991	1 CCFNI	46 + 2 item English	+	+	0	0	0	0	0	0	unknown
Rukholm 56 1992	2 CCFNI	46 + 2 item English		+	+	+	0	-/+	0	0	unknown
Daley 77 1984	34 CCFNI	46 item English	ı	+	0	0	0	0	0	0	unknown
Lynn-McHale ⁶⁷ 1988	38 CCFNI	46 item English	•	+	0	+	0	0	0	0	unknown
Molter 69 1979	79 CCFNI	45 item English		+	0	0	0	0	0	0	20-60 min.
Rodgers ⁶⁸ 1983	33 CCFNI	45 item English	1	+	0	+	0	0	0	0	20-60 min.
Leske ⁵ 1986	36 CCFNI	45 item English	•	+	0	+	0	0	0	0	30 min
Macey ⁵⁹ 1991	1 CCFNI	45 item English		+	0	0	+	0	0	0	unknown
Leske 60 1991	1 CCFNI	45 item English	+	+	+	0	0	0	0	0	unknown
Koller ⁶¹ 1991	1 CCFNI	45 item English	ı	+	0	0	0	-/+	0	0	unknown
Kahn 55 1992	CCFNI	45 item English		+	0	0	0	0	0	0	unknown
Kleinpell 57 1992	CCFNI	45 item English	+	+	0	+	0	0	0	0	unknown
Engli ⁵³ 1993	3 CCFNI	45 item English	ı	+	0	+	0	0	0	0	unknown
Lopez-Fagin ⁵¹ 1995	5 CCFNI	45 item English	0	+	0	0	0	0	0	0	unknown
Mendonca 47 1998	98 CCFNI	45 item English	ı	+	0	0	0	0	0	0	unknown
Higgins 75 1999	99 CCFNI	45 item English	ı	+	0	0	0	0	0	0	unknown
Hunsucker ⁴⁵ 1999	99 CCFNI	45 item English	1	+	0	0	0	-/+	0	0	unknown
Hinkle ³² 2009	9 CCFNI	45 item English	+	+	0	+	0	-/+	0	0	unknown
Kinrade ¹¹⁶ 2009	9 CCFNI	45 item English	ı	+	0	0	0	-/+	0	0	unknown
Bailey 90 2010	O CCFNI	45 item English	•	+	0	0	0	-/+	0	0	unknown
Hinkle ¹¹⁴ 2011	11 CCFNI	45 item English	+	+	0	ı	0	-/+	0	0	30 min
Noor Siah 81 2012	2 CCFNI	45 item English	+	+	0	0	0	-/+	0	0	unknown
Obringer ¹²⁴ 2012	CCFNI	45 item English		+	0	0	0	-/+	0	0	unknown
Warren ⁵² 1993	3 CCFNI + NMI	90 item English	1	+	0	0	0	0	0	0	unknown
Kosco ³⁹ 2000	00 CCFNI + NMI	90 item English	ı	+	0	0	0	-/+	0	0	30 min
Bijttebier ⁴³ 2000	00 CCFNI	45 item Dutch	+	+	-/+	ı	0	-/+	0	0	unknown
Bijttebier ⁴⁰ 2001	1 CCFNI	45 item Dutch	+	+	0	0	0	-/+	0	0	unknown

Appendix B. (cont.)

					,	Validity		Reliability				
				Sample	Content	Construct validity of	Internal	Interrater / test-	Measures of central		Resnon-	Time to
Author	Year	Instrument	Version	size	face	scale/subscales	consistency	retest	tendency	Sensitivity	siveness	administer
Delva 74	2002	CCFNI	45 item Dutch	+	+	0	0	0	-/+	0	0	unknown
Tin Mi-kuen 44	1999	CCFNI	45 item Chinese		+	0	0	+	-/+	0	0	unknown
Lee ⁴²	2000	CCFNI	45 item Chinese		+	0	0	0	-/+	0	0	unknown
Leung ⁴¹	2001	CCFNI	45 item Chinese		+	0	i	0	-/+	0	0	unknown
Chiu ⁷⁶	2004	CCFNI + C-SAI	45 item Chinese	•	+	0	0	0	0	0	0	unknown
Chien 35	2002	CCFNI	45 item Chinese	+	+	+	+	0	-/+	0	0	unknown
Chien ³⁶	2006	CCFNI	45 item Chinese	•	+	0	+	0	-/+	0	+	unknown
Al Hassan ³⁸	2004	CCFNI	45 item Arabic	+	+	0	+	0	-/+	0	0	unknown
Omari ³³	2009	CCFNI	45 item Arabic	+	+	0	+	0	-/+	0	0	unknown
Al-Mutair ¹¹⁹	2013	CCFNI	45 item Arabic	+	+	0	+	0	-/+	0	-/+	unknown
Moreau 80	2004	CCFNI (RCT)	45 item French	+	0	0	0	0	0	0	0	unknown
Garrouste-Orgeas 109	2010	CCFNI	45 item French	+	0	0	0	0	0	0	0	unknown
Hoghaug ⁸²	2011	CCFNI	45 item Swedish	+	+	0	ı	0	-/+	0	0	unknown
Chatzaki ¹²⁵	2012	CCFNI	45 item Greek	+	+	0	0	0	+	0	-/+	unknown
Burr 46	1998	CCFNI	43 item English	+	+	0	0	0	-/+	0	0	unknown
Fumis 34	2006	CCFNI	43 item Portugese	+	+	0	ı	0	0	0	0	unknown
Freitas 73	2007	CCFNI	43 item Portugese	•	+	0	ı		-/+	0	0	unknown
Fumis 70	2008	CCFNI	43 item Portugese	+	+	0	0	0	0	0	0	unknown
Fumis ⁹²	2009	CCFNI	43 item Portugese	+	+	0	0	0	0	0	0	unknown
Zazpe 48	1997	CCFNI	34 item Spanish	1	0	0	0	0	0	0	0	unknown
Forrester ⁶³	1990	CCFNI	30 item English	•	+	0	+	0	0	0	0	unknown
Price 62	1991	CCFNI	30 item English	+	+	0	+	0	0	0	0	unknown
Murphy 79	1992	CCFNI	30 item English	1	+	0	+	0	0	0	0	unknown
Quinn 49	1996	CCFNI	30 item English	+	+	0	0	0	0	0	0	16 min
Quinn 50	1996	CCFNI	30 item English	+	+	0	0	0	-/+	0	0	16 min
Gelling 72	1999	CCFNI	30 item English	•	+	0	0	0	0	0	0	unknown
Maxwell 71	2007	CCFNI + NMI	60 item English	1	+	ı	+	0	0	0	0	20-30 min
Halm 64	1990	CCFNI	15 item English	+	-/+	0	0	0	0	0	0	unknown
Henneman ⁵⁴	1992	CCFNI	15 item English	+	-/+	0	+	0	-/+	0	0	unknown
Auerbach ³⁷	2002	CCFNI	14 item English		0	0	+	0	-/+	0	0	unknown
Azoulay 137	2001	SCCMFNA	14 item French	+	0	0	0	0	0	0	0	unknown

Appendix B. (cont.)

					•	Validity		Reliability				
				Sample	Content	Construct validity of	Internal	Interrater / test-	Measures of central		Respon-	Time to
Author	Year	Instrument	Version	size	face	scale/subscales	consistency	retest	tendency	Sensitivity	siveness	administer
Azoulay ¹⁴³	2003	SCCMFNA	14 item French	+	+	0	0	0	0	0	0	unknown
Azoulay 7	2004	SCCMFNA	14 item French	+	+	0	0	0	0	0	0	unknown
Yousefi 157	2012	SCCMFNA	14 item Arabic		0	0	0	0	0	0	0	unknown
Johnson ¹⁴⁰	1998	SCCMFNA	14 item English	+	0		0	+	0	0	0	unknown
Damghi ¹³³	2008	SCCMFNA	14 item Arabic	+	+	0			0	0	0	unknown
Wasser 8	2001	CCFSS	20 item English	+	+	+	+	0	0	0	0	unknown
Wasser 111	2004	CCFSS	20 item English	+	+	+	,	0	0	0	0	unknown
Gajic ⁹⁷	2008	CCFSS	20 item English	+	+	+	1	0	0	0	0	unknown
Steel 98	2008	CCFSS	20 item English	+	+	+	+	0	0	0	0	unknown
Roberti 86	2010	CCFSS	20 item English		+	+	+	0	-/+	0	0	unknown
Hickman ¹¹⁵	2010	CCFSS	20 item English	+	+	+	,	0	0	0	0	unknown
Hickman ⁸³	2012	CCFSS	20 item English	+	+	+	,	0	0	0	0	unknown
Huffines ¹²⁰	2013	CCFSS	20 item English		+	+	+	0	0	0	-/+	unknown
Brown 95	2008	CCFSS	20 item Arabic		+	0	+	0	0	0	0	unknown
Karlsson 85	2011	CCFSS	20 item Swedish	ı	+	0	0	0	0	0	0	unknown
Dowling 102	2002	FS-ICU	37 item English	+	+	•	ı	0	-/+	0	•	unknown
Dowling 1110	2002	FS-ICU	37 item English	+	+	0	0	0	-/+	0	0	unknown
$Heyland^{106}$	2001	FS-ICU	34 item English	,	+	0	+	+	-/+	0	0	unknown
Heyland ⁶	2002	FS-ICU	34 item English	+	+	0	0	0	0	0	0	unknown
Heyland 104	2003	FS-ICU	34 item English	+	+	0	0	0	0	0	0	unknown
Heyland 105	2003	FS-ICU	34 item English	+	+	0	0	0	0	0	0	unknown
Gerstel ⁹³	2008	FS-ICU	34 item English	+	+	0	0	0	0	0	0	unknown
Kaufer ⁹⁴	2008	FS-ICU	34 item English		+	0	0	0	0	0	0	unknown
Kross ¹¹³	2009	FS-ICU	34 item English	+	+	0	0	0	0	0	0	20 min
Curtis 130	2011	FS-ICU	34 item English	+	+	0	0	0	0	0	0	unknown
Hunziker ¹⁴⁶	2012	FS-ICU	34 item English	+	+	0	0	0	0	0	0	unknown
LeClaire ¹²¹	2002	FS-ICU	34 + 2 item English		+	0	+	0	0	0	0	unknown
Stricker 99	2007	FS-ICU	34 item German	+	+	-/+	+	•	0	0	0	unknown
Gries ⁹⁶	2008	FS-ICU	34 item German	+	+	0	0	0	0	0	0	unknown

Appendix B. (cont.)

Reliability

Validity

						Construct		Interrater	Measures of			
Author	Year	Year Instrument	Version	Sample size	Content face	validity of scale/subscales	Internal consistency	/ test- retest	central tendency	Sensitivity	Respon- siveness	Time to administer
Stricker 91	2009	FS-ICU	34 item German	+	+	0	0	0	0	0	0	unknown
Stricker 131	2011	FS-ICU	34 item German	+	+	0	0	0	-/+	0	0	unknown
Jongerden ⁵¹	2013	FS-ICU	34 item Dutch	+	+	0	+	0	0	0	+	unknown
Shelton 161	2010	FS-ICU	26 item modified English	+	+	0	0	0	-/+	0	-/+	unknown
Moore 160	2012	FS-ICU	26 item modified English	+	+	0	0	0	-/+	0	-/+	unknown
Wall 100	2007	FS-ICU	24 item English	+	+	-/+	+	0	-/+	0	0	unknown
Wall 4	2007	FS-ICU	24 item English	+	+	0	0	0	0	0	+	unknown
Jacobowski ⁸⁷	2010	FS-ICU	24 item English	+	+	0	0	0	0	0	0	unknown
Henrich 84	2011	FS-ICU	24 item English	+	+	0	0	0	0	0	0	unknown
Lewis-Newby 127	2011	FS-ICU	24 item English	+	+	0	0	0	-/+	0	0	unknown
Dodek 141	2012	FS-ICU	24 item English	+	+	0	0		0	0	0	unknown
Osborn 148	2012	FS-ICU	24 item English	+	+	0	0	0	0	0	0	unknown
Shaw 147	2013	FS-ICU	24 item English	+	+	0	0	0	-/+	0	-/+	unknown
Higginson ¹⁴⁹	2013	FS-ICU	24 item English	+	+	0	0	0	0	0	-/+	unknown
Khalaila ¹⁵³	2013	FS-ICU	24 item Hebrew	,	+	0	+	0	-/+	0	0	30 min
Schwarzkopf 159	2013	FS-ICU	24 item German	+	+	0	+	+	0	-/+	0	unknown
Gerasimou-Angelidi ¹⁵⁰	2013	FS-ICU	24 item Greek	+	+	0	0	0	-/+	0	0	unknown
Dalisay-Gallardo 158	2012	2012 FS-ICU	24 item Filipino		+	0	+	0	-/+	0	0	unknown

Cronbach $\alpha > 0.70$, but not all, '-'= factor analysis shows poor quality with most factors Cronbach $\alpha < 0.70$. Internal consistency: '+' = Cronbach α , Spearman Brown or Split Half > 0.80Sample size: +' = n > 100, -' = n < 100. Content/face validity: +' = assesses intended construct, +' -' = aoes not match the original tool, but assesses intended construct, -' = aoes 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 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 Reliability (inter-rater/test-retest): + = K > 0.61 or Pearson's r > 0.80, - = K < 0.61; Pearson's r < 0.80, or proven change of scores when filled in by junior versus senior staff. of the scale and subscales both, '+/-' = Cronbach α is > 0.80 for either the scale or the subscales, but not both, '-' = Cronbach α < 0.80 for the scale and the subscales between before and after measurements. '0' = no data =available. sensitivity was reported.