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Family ratings of ICU care. Is there concordance within families?

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ABSTRACT

Purpose: To examine heterogeneity of quality-of-care ratings within families and to examine possible predictors of concordance.

Materials and methods: We examined two aspects of agreement within families: response similarity and the amount of exact concordance in responses in a cohort of Danish ICU family members participating in a questionnaire survey (the European Quality Questionnaire: euroQ2).

Results: Two hundred seventy-four family respondents representing 122 patients were included in the study. Identical ratings between family members occurred in 28%–59% of families, depending upon the specific survey item. In a smaller sample of 28 families whose patients died, between 39% and 86% gave identical responses to items rating end-of-life care. There was more response variance within than between families, yielding low estimates of intrafamily correlation. Statistics correcting for chance agreement also suggested modest within-family agreement.

Conclusions: The finding that variance is higher within than between families suggests the value of including multiple participants within a family in order to capture varying points of view.

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1. Introduction

There is increasing awareness of the importance of family-centered care in the Intensive Care Unit (ICU) [1]. This is due to family members' important roles for the patient, such as supporter [1], advocate [2], participant in care [3] and, in some countries, surrogate decision-maker for patients without decision-making capacity [4–6]. In addition, being a family member to a seriously ill ICU patient (e.g. comatose, ventilator dependent, hemodynamically unstable) can have a huge impact on family members themselves, both during and after the ICU admission. Family members may experience poor sleep quality [7–9], anxiety [10], depression [10–12], and post-traumatic stress disorder [10,11,13,14]. The cluster of these negative psychological outcomes has been named “Post-intensive-care-syndrome family” (PICS-F) [10,15] and is analogous to PICS that can occur in patients [16].

Caring for family members of the critically ill is a key recommendation by international research societies such as the Society of Critical Care Medicine [17]. In a recent guideline, evidence-based family-centered care was endorsed in five areas: 1) family presence in the ICU; 2) family support; 3) communication with family members; 4) use of specific consultations and ICU team members; and 5) operational and environmental issues [18]. Although the evidence behind the recommendations was assessed as moderate to very low [18], the guideline is based on the newest and best available evidence. In order to provide high quality family-centered care in the ICU, we must understand family experiences within the above mentioned areas and use validated and responsive measures of that experience. Numerous studies, both quantitative and qualitative, have helped elucidate areas where high-quality family-centered care is provided and also areas for improvement [19–21].

When focusing on family-centered care, it is important to identify who constitutes “family.” Family is commonly defined as “individuals who provide support and with whom the patient has a significant relationship” [18]. This broad category may include persons without blood or marital ties to the patient. Because family is not a homogeneous group, individual family members may have different needs and perceptions. For example, one study found that ICU family members'

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psychological distress (anxiety, depression, or stress) was higher if they or a family member had had an ICU admission within the previous two years [22]. Little is known about agreement within families regarding quality of care. Understanding whether families differ among themselves, as well as from other families, and which factors may influence those differences, may allow clinicians to support and guide families in their care-giving roles. This study evaluates the extent of intra-family homogeneity in quality-of-care ratings, investigates characteristics of families as potential explanations for agreement/disagreement, and suggests possible contributors to heterogeneity in perspective, in order to guide quality improvement and research targeting family members' assessments of quality of care.

2. Materials and methods

2.1. Study design and sample

This study is a secondary investigation of data from a cross-sectional survey which was based on a questionnaire distributed to Danish and Dutch family members of patients who received ICU care [20,23]. Family members of consecutive patients admitted to a participating ICU for 48 h or more were eligible for participation in the original study. Up to three family members per patient could participate. Family members were defined as the persons closest to the patient (identified by the patient if possible, otherwise as stated by the family members), including partners, siblings, children, parents and friends. If more than three family members wanted to participate, the family members themselves chose the participants as instructed in the survey instructions, based on who had spent the most time in the ICU. Family members were excluded if they met one or more of the following criteria: under age 18, cognitively impaired, or unable to read or write Danish or Dutch. The current study is based on data from family members of Danish patients who had multiple participating family members. The Dutch sample had too few multiple-participant families to include.

2.2. Data collection

Eligible family members were approached by ICU nurses during the patient's ICU stay. The family members received oral and written information about the study and, if they agreed to participate, provided their name and home address. Three weeks after the patient's ICU discharge or death, family members received the euroQ2 questionnaire by mail, together with written information and a pre-paid envelope. If the questionnaire was not returned within two weeks, one reminder with a new questionnaire was sent.

2.3. Measures

2.3.1. European quality questionnaire (euroQ2)

The euroQ2 (European Quality Questionnaire) was completed by families and consisted of two sections: The first, the euroFS-ICU, was completed by all participating family members and was a revised version of the "Family Satisfaction in the ICU" (FS-ICU) questionnaire, which solicits family ratings of ICU care, irrespective of the patient's mortality status at discharge [24,25]. The second section, the euroQODD, was completed only by family members of patients who died in the ICU and was a revised version of the "Quality of Dying and Death" (QODD) questionnaire, which considers the quality of events that occur at the end of life [26,27]. Both sections were adapted and validated to accommodate Northern European families of patients in the ICU, as described previously [20,23,28].

2.3.2. Patient and family characteristics

Family member characteristics were obtained from the family member's questionnaire responses: gender, age, and relationship to the patient, which were the only family member characteristics

registered in the questionnaire. Patient characteristics were drawn from the medical record: the patient's gender and age, the specific ICU that treated the patient, that ICU's specialty, the reason for the patient's ICU admission, hours spent in the ICU, and whether mechanical ventilation was provided during the ICU stay.

2.4. Outcomes

We analyzed all rating items in the euroQ2 instrument. They included 20 items assessing general ICU care and 13 items assessing end-of-life care (Table 1). For each aspect of care, the respondent could provide a valid rating, indicate that the aspect was not applicable, or leave the response blank; for end-of-life care items, the respondent could also indicate "Don't know". For each rating we considered two outcomes: (1) complete within-family concordance of response and (2) the extent of intrafamily similarity.

2.4.1. Concordance

For each family, we computed a binary variable for each rating, indicating whether there was exact agreement on the rating among all respondents in the family. For this measure, we included cases with missing data (i.e., failure to respond or a response of "Not applicable" or "Don't know"), but considered all missing data responses to be equivalent. For example, a non-response from one family member was a match with a response of "Not applicable" from another respondent in the same family.

2.4.2. Intrafamily similarity

The raw data for analyses evaluating intrafamily similarity were the family members' responses to the original questions rating quality of care.

2.5. Predictors

For the family concordance outcomes, we tested five patient- or family-level variables as potential predictors. Two were patient characteristics, obtained from the medical record: whether the patient was discharged from the ICU dead or alive and the level of therapy provided to the patient (either full treatment or some/all treatments withheld/withdrawn). Three were based on family members' reports of their age, gender, and relationship to the patient. From these family-member responses we computed for each family the age difference between the family respondents if there were only two (or the maximum age difference if three family members participated), a binary variable indicating whether all family members within the family were of the same or different genders, and a variable measuring whether all respondents within the family had the same relationship to the patient.

2.6. Statistical analyses

We investigated two aspects of agreement within families: exact concordance and response similarity within families.

2.6.1. Exact concordance within families

For each rating, we first provided a descriptive account of within-family concordance (i.e., "exact agreement"). In addition, we regressed each of these binary outcomes on each of the five potential predictors, to assess whether differences in rates of concordance were attributable to known characteristics of the patient or family. Probit regression models used weighted least squares with mean and variance adjustment (WLSMV) for parameter estimation.

2.6.2. Response similarity within families

For each rating, we computed two descriptive statistics related to intrafamily similarity: the intraclass (or intraclass) correlation coefficient (ICC) and Krippendorff's alpha. We limited the analysis of each

Table 1
Aspects of ICU care that were rated by family members^a.

Care of Patient and Family Member, Rated by All Families
Concern and caring (courtesy, respect, and compassion) for patient
Symptom management:
Assessment and treatment of patient's pain
Assessment and treatment of patient's breathlessness
Assessment and treatment of patient's agitation
Atmosphere of the ICU (feeling that family presence was appreciated)
Consideration of family respondent's needs
Emotional support of family respondent
Opportunity to be present at bedside
Ease of getting information (willingness of ICU staff to answer questions)
Provision of understandable explanations
Perceived honesty of information about patient's condition
Completeness of Information:
What was happening with the patient
Why things were being done to the patient
Consistency of information about patient's condition
Overall quality of information:
Information provided by doctors
Information provided by nurses
Inclusion of family respondent in major decision-making processes
Support of family respondent when major decisions were made
Adequate time for family respondent to have concerns addressed and questions answered when decisions were made ^b
Overall quality of care received by all doctors, nurses, and other healthcare professionals during ICU stay ^c
Care of Dying Patients, Rated by Families of Patients Who Died in the ICU
How often patient appeared to have pain under control ^d
How often patient appeared to be comfortable on the ventilator ^d
How often patient appeared to maintain dignity ^d
Patient received any needed emotional support ^e
Patient received any needed spiritual support ^e
Patient received goal-concordant care ^e
Avoided unnecessary prolongation of patient's life ^e
Family member had chance to say goodbye ^e
Patient discussed end-of-life treatment preferences with a doctor before ICU admit ^f
Patient discussed end-of-life treatment preferences with ICU staff during the ICU stay ^f
Extent family member agreed with any decisions made to limit care ^g
Actual roles in decision to limit care ^h
Desired roles in decision to limit care ⁱ

^a All aspects of care were coded so that higher score indicated better-quality care. Except where otherwise noted, evaluations were on 5-point scale: 0 (poor), 1 (fair), 2 (good), 3 (very good), 4 (excellent). In computing concordance, we considered blanks and responses of "inapplicable" or "don't know" to be concordant with one another; however, these responses were excluded from computation of intraclass correlation coefficients and analysis of mean absolute differences between ratings within families.

^b Coded on a binary scale: 0 (could have used more time), 1 (had adequate time).

^c Coded on an 11-point scale: 0 (worst care possible) to 10 (best care possible).

^d Coded on a 6-point scale: 0 (none of the time), 1 (a little bit of the time), 2 (some of the time), 3 (a good bit of the time), 4 (most of the time), 5 (all the time).

^e Coded on a 3-point scale: 0 (no), 1 (partially), 2 (yes).

^f Coded on a 2-point scale: 0 (no), 1 (yes).

^g Coded on a 5-point scale: 0 (not at all), 1 (mostly not), 2 (partially), 3 (mostly), 4 (totally).

^h Coded on 6-point scale: 0 (patient made decision), 1 (doctors made decision alone), 2 (doctors made decision after discussing with family), 3 (decision made jointly between doctors and family), 4 (family made decision after getting information from doctors), 5 (family made decision alone).

ⁱ Coded on 5-point scale: 0 (doctors made decision alone), 1 (doctors made decision after discussing with family), 2 (decision made jointly between doctors and family), 3 (family made decision after getting information from doctors), 4 (family made decision alone).

rating's response similarity to data from families for which there were at least two valid (i.e., non-missing) ratings.

The ICC is a measure of the similarity (or relatedness) of clustered data [29–32] and – in this study – described how strongly the answers provided by respondents *within* families resembled one another, relative to their resemblance to responses provided by other families. For each rating we ran an unconditional two-level random effects logistic regression model (family respondents at level 1; patient clusters at level 2). The models for ordinal outcomes were estimated with

restricted penalized-quasi-likelihood (PQL); models for binary outcomes were estimated using full maximum likelihood with adaptive Gauss-Hermite quadrature. The ICC was then computed as the ratio of between-family variance to total variance. Several methods are available for estimating the level-1 (respondent-level) variance for ordinal and binary outcomes. Of these, we used a latent variable approach, which assumes that observed ordinal or binary outcomes are imperfect measurements of underlying continuous latent variables; level-1 variance is uniformly estimated as $\pi^2/3$, the variance of the logistic distribution [33,34].

Krippendorff's alpha [35,36] is a "kappa-like" statistic that assesses agreement within clusters of raters. It allows clusters of variable size, different raters in each cluster, and ordinal weighting of ratings (thus assigning greater similarity to ratings that are close together than to ratings that are further apart). A frequently used set of benchmarks for evaluating this and similar statistics [37] has suggested the following interpretations for ranges of values: poor agreement ($\alpha < 0.00$), slight agreement ($0.00 < \alpha \leq 0.20$), fair agreement ($0.20 < \alpha \leq 0.40$), moderate agreement ($0.40 < \alpha \leq 0.60$), substantial agreement ($0.60 < \alpha \leq 0.80$), almost perfect agreement ($0.80 < \alpha \leq 1.00$).

We used the following software for analyses: SPSS Version 19 for descriptive statistics; the *KappaEtc* module in Stata Version 12.1 for calculation of Krippendorff's alpha; HLM for Windows, Version 7.01 for multi-level modeling and computation of ICCs; and Mplus Version 8.1 for regression models testing the associations between predictors and the concordance outcomes, [38–41]. A two-sided *p*-value $< .05$ was considered statistically significant.

2.7. Ethics

In accordance with Danish law, the study did not need (and therefore could not obtain) permission from the Regional Ethics Committees, but permission to access patient files was obtained from the Danish National Health Authorities (3-3013-353/1/), and the study was registered with the Danish Data Protection Agency. All family participants provided written consent to receive the questionnaire.

3. Results

The response rate for the entire Danish sample (573 family members, where 299 were sole respondents within a family) was 75% [19]. Our secondary study was based on 274 respondents from 122 multi-respondent families who completed the euroFS-ICU portion of the questionnaire (92 families with two participants and 30 with three participants) and 63 respondents from 28 multi-respondent families who completed the euroQODD (21 families with two participants and 7 with three participants). Patients were drawn from 11 adult ICUs, representing university affiliated and regional ICUs with different specialties and with the number of participating families per ICU ranging from 1 to 19. Most of the patients (71.1%) were male. Median patient age was 70. The patients spent an average of 232 h (almost 10 days) in the ICU, and 23% died during their ICU stay. Family respondents had median age of 52 years. They were predominantly female (70.8%), with almost half (46.7%) of the families represented entirely by female family members (Table 2). The 28 family respondents whose patients died in the ICU were similar to the full sample of patients except that their patients were significantly more likely to have had some or all therapies withdrawn ($p < .001$). Further details such as ICU specialties and reasons for ICU admission can be found in supplementary material Table S1.

In general, the full cohort of family members gave very high ratings for all of the aspects of care (Table 3). The concentration of the responses at the upper end of the rating scales sharply reduced the total variability in responses among those who provided valid ratings.

Table 2
Characteristics of individual participants and families.

Characteristics	All families		Families of decedents	
	Valid n ^a	Statistic ^b	Valid n ^a	Statistic ^b
Family members:				
Male	267	78 (29.2)	61	21 (34.4)
Age, median (IQR)	266	52 (21)	61	52 (18)
Relationship to Patient	267		61	
Spouse/partner		67 (25.1)		14 (23.0)
Child of patient		142 (53.2)		38 (62.3)
Sibling		14 (5.2)		2 (3.3)
Parent of patient		18 (6.7)		1 (1.6)
Other relative		13 (4.9)		3 (4.9)
Friend		2 (0.7)		0 (0.0)
Other relationship		11 (4.1)		3 (4.9)
Patients:				
Male	121	86 (71.1)	28	18 (64.3)
Age, median (IQR)	121	70 (16)	28	73 (13)
Hours in ICU, median (IQR)	121	232(301)	28	192 (290)
Therapy level	121		28	
No limits on treatment		95 (78.5)		8 (28.6)
Some or all therapies withhold or withdrawn		26 (21.5)		20 (71.4)
Patient status at discharge	121		28	
Alive		91 (75.2)		0 (0.0)
Dead		30 (24.8)		28 (100.0)
Mechanical ventilation provided	121	109 (90.1)	28	27 (96.4)
Families:				
Maximum age difference between respondents within families, median (IQR)	116	23 (21)	26	23 (25)
Gender	122		28	
All male		13 (10.7)		3 (10.7)
All female		57 (46.7)		9 (32.1)
Mixed		52 (42.6)		16 (57.1)
Relationship to patient	115		26	
Patient's children		25 (21.7)		8 (30.8)
Patient's siblings		2 (1.7)		0 (0.0)
Patient's parents		3 (2.6)		0 (0.0)
Mixture of relationships to patient		85 (73.9)		18 (69.2)

^a The number of individuals (or families) with valid data for the characteristic.

^b Except where noted otherwise, the statistic shown is the number (%) of individuals (or families) with the characteristic.

3.1. Exact concordance in responses within families

When non-response, "Not applicable" and "Don't know" were treated as identical to one another, the percentage of families for whom all respondents provided identical ratings varied from 27.9% for inclusion of the family respondent in major decision-making processes to 85.7% for avoiding unnecessary prolongation of the patient's life (Table 4). In the full sample of 122 families, identical ratings occurred in 28%–59% of families, with 3 aspects of care concordant for over 50% of families. In the smaller sample of 28 families whose patients died, identical ratings on end-of-life items occurred in 39%–86% of families, with 9 items showing complete agreement in at least 50% of the families.

The five variables tested as potential predictors of family concordance involved 165 associations with the 33 study outcomes. Of these, only five associations were significant at 0.05 or beyond. Families having all participants of the same gender showed greater agreement than mixed-gender families on three items: opportunity to be present at the bedside ($b = 0.719, p = .002, 95\% \text{ CI} = 0.255, 1.182$); ease of getting information ($b = 0.634, p = .007, 95\% \text{ CI} = 0.176, 1.093$); and obtaining complete information about why things were being done ($b = 0.522, p = .028, 95\% \text{ CI} = 0.057, 0.987$). Family members of

patients who died were more likely than family respondents of surviving patients to provide concordant responses on two items: inclusion of the family respondent in major decision-making processes ($b = 0.727, p = .008, 95\% \text{ CI} = 0.192, 1.262$); and adequate time for the family respondent to have concerns addressed and questions answered when decisions were made ($b = 0.676, p = .014, 95\% \text{ CI} = 0.138, 1.214$). Concordance levels on none of the ratings were significantly associated with the level of therapy provided to the patient, age differences between family respondents, or whether all family respondents had the same relationship to the patient.

3.2. Response similarity within families

For all 33 aspects of care, most of the response variance was within, rather than between families, thus yielding low ICCs, and low estimates of within-family similarity (Table 4). For all except one item (amount of time the patient appeared comfortable on the ventilator), substantially <50% of the estimated total variance in response was between families. ICCs ranged from a low of 0.020 for family members' desired role in decision-making to a high of 0.610 for the amount of time the patient appeared to be comfortable on the ventilator.

Krippendorff's alpha values were similarly low for most aspects of care, particularly for items presented to all families. Based on the standard benchmarks, of the 20 items presented to all families, 2 (10%) showed slight agreement, and the remaining 18 (90%) showed only fair agreement. Ratings of the 12 items that families of decedents rated showed somewhat greater agreement: 1 (8%) with poor agreement, 1 (8%) with slight agreement, 3 (25%) with fair agreement, 5 (42%) with moderate agreement and 2 (17%) with substantial agreement.

4. Discussion

In prior studies examining family ratings of care, results have sometimes been reported for families as if families were homogeneous groups [42]. To our knowledge, this study is the first to use a variety of approaches to explore intrafamily homogeneity regarding ratings of the quality of ICU care. We examined exact concordance of responses at the family level, assessed intrafamily correlation of responses with models that partitioned response variance within and between families, and calculated a weighted kappa-type statistic that simultaneously adjusted for agreement attributable to chance and acknowledged differences in the magnitude of disagreements by taking into account the ordinal character of most of our ratings.

Exact concordance within families was higher than we expected with 12 items showing complete agreement in 50% of more of families and an additional 14 items showing agreement in 40% of families. However, when examined via estimated response variance within vs. between families, variance within families represented an unexpectedly high proportion of the total response variance for almost all ratings. For all 20 aspects of general ICU care, and for 11 of the 12 aspects of end-of-life care for which ICCs could be computed, estimated intrafamily variance was greater than estimated interfamily variance, leading to relatively low ICCs. Similarly, Krippendorff's alpha suggested relatively low within-family similarity, particularly for general ICU care. None of those 20 items showed better than "fair" agreement within families. There was considerably greater similarity in responses to the items related to end-of-life care, with more than half of the items showing "moderate" or "substantial" within-family agreement. This association, combined with the finding that on two of the general-ICU-care items there was greater concordance among families whose patients died in the ICU than among families of surviving patients, suggests that the death of a patient may contribute to increased cohesion among family members regarding their perceptions of the quality of care. This may be because ICU staff is particularly attentive to those family members' needs.

Table 3
Ratings of specific aspects of quality of care^a.

Aspect of care, all families (n = 274)	(poor)	(fair)	(good)	(very good)	(excellent)	Inap	Blank		
Concern and caring for patient	0 (0.0)	0 (0.0)	11 (4.0)	89 (32.5)	172 (62.8)	0 (0.0)	2 (0.7)		
Pain management	0 (0.0)	2 (0.7)	19 (6.9)	108 (39.4)	132 (48.2)	10 (3.6)	3 (1.1)		
Breathlessness management	0 (0.0)	4 (1.5)	14 (5.1)	81 (29.6)	145 (52.9)	22 (8.0)	8 (2.9)		
Agitation management	1 (0.4)	6 (2.2)	29 (10.6)	102 (37.2)	107 (39.1)	23 (8.4)	6 (2.2)		
Atmosphere of the ICU	1 (0.4)	5 (1.8)	21 (7.7)	89 (32.5)	156 (56.9)	1 (0.4)	1 (0.4)		
Consideration of family needs	1 (0.4)	11 (4.0)	30 (10.9)	94 (34.3)	134 (48.9)	1 (0.4)	3 (1.1)		
Emotional support of family	2 (0.7)	11 (4.0)	46 (16.8)	86 (31.4)	117 (42.7)	9 (3.3)	3 (1.1)		
Opportunity to be present at bedside	3 (1.1)	10 (3.6)	18 (6.6)	85 (31.0)	157 (57.3)	0 (0.0)	1 (0.4)		
Ease of getting information	0 (0.0)	5 (1.8)	28 (10.2)	82 (29.9)	158 (57.7)	0 (0.0)	1 (0.4)		
Provision of understandable explanations	3 (1.1)	10 (3.6)	20 (7.3)	114 (41.6)	126 (46.0)	0 (0.0)	1 (0.4)		
Perceived honesty about patient's condition	0 (0.0)	10 (3.6)	20 (7.3)	88 (32.1)	155 (56.6)	0 (0.0)	1 (0.4)		
Complete information re: what was happening	3 (1.1)	12 (4.4)	25 (9.1)	109 (39.8)	123 (44.9)	0 (0.0)	2 (0.7)		
Complete information re: why being done	1 (0.4)	8 (2.9)	31 (11.3)	108 (39.4)	124 (45.3)	1 (0.4)	1 (0.4)		
Consistent information about patient's condition	4 (1.5)	17 (6.2)	35 (12.8)	100 (36.5)	112 (40.9)	3 (1.1)	3 (1.1)		
Overall quality of information from doctors	5 (1.8)	11 (4.0)	30 (10.9)	100 (36.5)	119 (43.4)	4 (1.5)	5 (1.8)		
Overall quality of information from nurses	2 (0.7)	6 (2.2)	26 (9.5)	95 (34.7)	142 (51.8)	0 (0.0)	3 (1.1)		
Inclusion of family in decision-making	4 (1.5)	19 (6.9)	36 (13.1)	85 (31.0)	79 (28.8)	41 (15.0)	10 (3.6)		
Support of family in decision-making	2 (0.7)	7 (2.6)	25 (9.1)	84 (30.7)	91 (33.2)	35 (12.8)	30 (10.9)		
Aspect of care, families of patients who died (n = 63)	(never)	(a little bit)	(some)	(a good bit)	(most)	(all)	DK	Inap	Blank
Amount of time patient's pain under control	0 (0.0)	0 (0.0)	0 (0.0)	1 (1.6)	23 (36.5)	36 (57.1)	0 (0.0)	3 (4.8)	0 (0.0)
Amount of time patient comfortable on ventilator	2 (3.2)	2 (3.2)	2 (3.2)	4 (6.3)	20 (31.7)	21 (33.3)	6 (9.5)	4 (6.3)	2 (3.2)
Amount of time patient maintained dignity	0 (0.0)	3 (5.7)	1 (1.6)	5 (7.9)	15 (23.8)	29 (46.0)	9 (14.3)	0 (0.0)	1 (1.6)
Patient received emotional support	(no) 0 (0.0)	(partially) 6 (9.5)	(yes) 37 (58.7)				DK 19 (30.2)	Inap 0 (0.0)	Blank 1 (1.6)
Patient received spiritual support	0 (0.0)	2 (3.2)	34 (54.0)				25 (37.1)	0 (0.0)	2 (3.2)
Patient received goal-concordant care	0 (0.0)	8 (12.7)	31 (49.2)				23 (36.5)	0 (0.0)	1 (1.6)
Avoided unnecessary prolongation of patient's life	2 (3.2)	7 (11.1)	53 (84.1)				1 (1.6)	0 (0.0)	0 (0.0)
Chance to say goodbye	0 (0.0)	5 (7.9)	57 (90.5)				1 (1.6)	0 (0.0)	0 (0.0)
Patient discussed wishes before ICU stay	(no) 36 (57.1)	(yes) 12 (19.0)					DK 15 (23.8)	Inap 0 (0.0)	Blank 0 (0.0)
Patient discussed wishes during ICU stay	18 (28.6)	10 (15.9)					10 (15.9)	25 (39.7)	0 (0.0)
Extent agreed with decision about limiting care ^b	(not at all) 0 (0.0)	(mostly not) 0 (0.0)	(partially) 4 (6.3)	(mostly) 17 (27.0)	(totally) 39 (61.9)		DK 0 (0.0)	Inap 3 (4.8)	Blank 0 (0.0)
Actual roles in decision to limit care	(patient decided) 1 (1.6)	(doctors alone) 2 (3.2)	(doctors with family input) 25 (39.7)	(joint doctor/family) 25 (39.7)	(family with doctor input) 5 (7.9)	(family alone) 1 (1.6)	DK 1 (1.6)	Inap 0 (0.0)	Blank 3 (4.8)
Desired roles in decision to limit care		0 (0.0)	22 (34.9)	33 (52.4)	4 (6.3)	0 (0.0)	1 (1.6)	0 (0.0)	3 (4.8)

Abbreviations: Inap (not applicable), DK (don't know).

^a Each entry shows the number (%) of respondents giving this response.

^b The "Inap" column for this item corresponds to a response of "not able to."

Family ratings are important outcome measures for evaluating the quality of patient- and family-centered care [43]. The ratings provide information about whether family members' individual needs are met, and allow discriminating between areas where the perceived quality of care is high and areas where improvement is needed [19,44]. In addition to each family's average evaluation, the extent to which family members' ratings agree or disagree may also provide valuable information for quality improvement or research efforts. For example, future guidelines for quality improvement might include recommendations for "mapping" the patient's family so that all of the family members' needs (e.g., adult children, parent) can be more adequately addressed. Our results showing substantial intrafamily variability also suggest the

importance of collecting data from multiple family members per patient in future research.

Families having all participants of the same gender showed greater agreement than mixed-gender families on opportunity to be present at the bedside, ease of getting information, and obtaining complete information about why things were being done. We don't have any insights for the reason for this association and think it is an important area for future study.

Responses to questionnaire items may differ for many reasons, among them measurement error (e.g., respondents' misreading or misunderstanding of questions or marking of responses). However, there are other, more systematic reasons for differing responses. One

Table 4
Amount of concordance and response similarity within families.

Aspect of care, all families	Proportion of families concordant ^a	Valid cases: families (Respondents) ^b	Intrafamily similarity	
			Intraclass correlation ^c	Krippendorff's α
Concern and caring for patient	0.590	121 (271)	0.275	0.312
Pain management	0.385	113 (253)	0.216	0.217
Breathlessness management	0.426	104 (231)	0.230	0.245
Agitation management	0.410	104 (230)	0.308	0.314
Atmosphere of the ICU	0.443	120 (270)	0.233	0.241
Consideration of family needs	0.451	118 (266)	0.243	0.260
Emotional support of family	0.418	114 (254)	0.352	0.359
Opportunity to be present at bedside	0.467	121 (272)	0.127	0.217
Ease of getting information	0.508	122 (273)	0.237	0.246
Provision of understandable explanations	0.418	122 (273)	0.280	0.317
Honesty of information about patient's condition	0.475	122 (273)	0.335	0.369
Complete information about what was happening	0.434	121 (271)	0.354	0.361
Complete information about why things were being done	0.402	121 (271)	0.313	0.308
Consistency of information about patient's condition	0.369	118 (264)	0.258	0.317
Overall quality of information from doctors	0.336	115 (258)	0.238	0.250
Overall quality of information from nurses	0.467	121 (270)	0.324	0.355
Inclusion of family in decision-making	0.279	87 (196)	0.168	0.152
Support of family in decision-making	0.328	82 (183)	0.232	0.194
Adequate time during decision-making	0.500	70 (156)	0.239	0.220
Overall quality of care	0.459	120 (269)	0.358	0.322
Aspect of Care, Families of Patients Who Died				
Amount of time patient's pain under control	0.571	25 (57)	0.348	0.428
Amount of time patient comfortable on ventilator	0.500	21 (47)	0.610	0.647
Amount of time patient maintained dignity	0.500	23 (51)	0.445	0.501
Patient received emotional support	0.679	17 (36)	0.451	0.774
Patient received spiritual support ^d	0.607	13 (27)		
Patient discussed wishes before ICU stay	0.464	21 (43)	0.130	0.210
Patient discussed wishes during ICU stay ^e	0.393	23 (50)	0.183	0.203
Patient received goal-concordant care	0.571	14 (30)	0.344	0.597
Avoided unnecessary prolongation of patient's life	0.857	27 (61)	0.370	0.441
Chance to say goodbye	0.821	27 (61)	0.207	0.143
Extent agreed with decision about limiting care	0.571	26 (59)	0.422	0.455
Actual roles in decision to limit care	0.464	26 (58)	0.336	0.243
Desired roles in decision to limit care	0.464	25 (57)	0.020	-0.011

^a Proportion of families (of all 122 families, or of 28 families whose patients died) for which all participants gave identical responses. (Blank, "don't know," and "inapplicable" were considered identical responses in computing family concordance.)

^b Number of families (respondents) contributing to the similarity statistics by virtue of having 2+ respondents with valid ratings (i.e., with responses other than "no response," "don't know," or "inapplicable").

^c Intraclass correlation coefficient (ICC) was based on an unconditional multi-level logistic regression model (family members clustered under patients). For each aspect of care, the analysis included only families with at least two family members providing valid responses. Variance at the respondent level (level 1) was estimated uniformly as $\pi^2/3$, the variance of the logistic distribution. Ordinal outcome parameters were estimated with restricted penalized-quasi-likelihood (PQL); binary outcome parameters were estimated with full maximum likelihood and adaptive Gauss-Hermite quadrature.

^d Variance of the outcome variable = 0.000. Similarity statistics could not be computed.

^e The response ("patient not able") was merged with response ("no") before computing similarity statistics.

factor that is particularly relevant to differences in family members' ratings of *their own* care is the fact that they may have differing needs or needs that were differentially addressed by ICU staff. Domains with low intrafamily similarity may signal areas where better assessment of, and response to, individual needs *during the ICU stay* could have resulted in improved clinical care and higher and more homogeneous family ratings. Our data suggested particularly low agreement on ratings of family members' inclusion and roles in decision-making, support during decision-making, and opportunities to be present at the bedside and to say goodbye. These domains of disagreement may be a function of the specific ICUs that were included in our study. As Danish family members do not have legal rights (or duties) to act as surrogate decision-maker for a decisionally incapacitated patient, involvement in decision-making in a Danish context means speaking on behalf of the patient to represent his/her wishes and values and receiving ongoing information about treatment plans, but not making the actual decisions. Therefore, experiences of level of involvement and support during the process may differ between family members if their expectations regarding information and involvement are not similar. However, use of the euroQ2 by individual ICUs as a tool for debriefing family members after patient discharge or death might provide insights more relevant for improving their own processes of care. Areas with high intrafamily

disagreement may suggest areas worthy of attention during the ICU stay.

Another important factor, related to differences regarding ratings of care provided to the *patient*, concerns family respondents' differential access to the patient's healthcare experiences. Family members do not necessarily visit together, meet the same members of the ICU team, or observe the patient in the same condition. Exposure to specific episodes of care-giving may render some family members better able than others to replicate patients' own assessments of the quality of their care. A study of patients with lung cancer and their families in Sweden suggested the family members were reliable evaluators of patient care: patients and family members had similar ratings of perceived reality (although significant differences in ratings of the subjective importance of various aspects of care) [45]. One difficulty in evaluating disparate patient-care ratings within families is in determining the most reliable judge. A Scandinavian study of ICU patients and family members reported statistics suggesting only "fair" patient-family agreement overall, but considerably higher agreement when the family respondent was the patient's next-of-kin [46]. A change to the euroQ2 questionnaire that might enhance its usefulness for evaluating family members' evaluations of care would be to add questions assessing the respondent's access to the patient's healthcare experiences (e.g., the amount of time

spent with the patient in the ICU). This might allow greater weight to be placed on responses from family members with better access.

4.1. Limitations

Our study has several limitations. First, a maximum of three family members could participate in the original study, thus limiting the cluster sizes for families included in the current analyses. Had the assessment of family members' similarity of response been a goal of the original study, additional family respondents could have been recruited, so as to obtain the broadest possible range of attitudes. The use of larger family clusters in future work to assess differing points of view will be useful for additional insights. Second, the only family characteristics collected in the original study were age, gender and relationship with the patient. Other factors, such as education, health literacy, and race/ethnicity, may also play a role regarding concordance of response and should be pursued in future research. Third, although the study was multicenter, all centers were in one country. This may decrease generalizability to other regions. Fourth, our use of the intracluster (or intraclass) correlation coefficient to measure family similarity should be evaluated with caution, especially for the end-of-life ratings by families whose patients died in the ICU. Researchers have noted uncertainties about the accuracy of multilevel variance estimates in general and, more specifically, about the implications for accuracy rates of small samples and outcome distributions that do not match distributional assumptions. We estimated level-1 variance with an approach that assumes that each observed outcome is an imperfect measurement of an underlying continuous normally-distributed latent variable. Another estimation method (based on an assumption that observed ordinal or binary responses are normally-distributed continuous variables) yielded ICC results similar to those reported in Table 4 (data not shown). Both estimation methods, along with other more complex methods, have been endorsed by statisticians [33,34]. However, the assumption that either the observed response or an underlying variable that it represents is normally distributed is somewhat suspect in this sample given the concentration of the observed responses near the upper end of the ordinal response scale. Our estimates were based on small cluster sizes and a relatively small number of groups – the latter particularly noteworthy for outcomes related to end-of-life care. Only a few studies evaluating the impact of sample size on variance estimates in multilevel models have studied models with categorical outcomes, and those have considered only binary outcomes.

5. Conclusion

Our findings indicate that there is considerable within-family disagreement in family members' perceptions of the quality of ICU care. This suggests that persons within the same family may have different needs regarding the care provided to the patient and themselves, thus warranting an individual approach to family centered care. Our results also imply that if one is attempting to evaluate the "true" quality of patient care from ratings provided by family and friends of the patient, assessing a larger number of persons within the patient's circle will produce a wider range of opinions, thus increasing the likelihood that quality of care will be accurately assessed, particularly when the information relies on the respondent's access to the patient's healthcare experiences. Studies that use a single family member as proxy for the patient in evaluating quality of care may produce unreliable findings, as quality-of-care ratings may depend on which family member one queries. Further research is needed to understand intrafamily variability and its influence on use of family ratings to assess quality of care.

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Declaration of Competing Interest

The authors declare that they have no competing interests.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.jcrc.2019.10.011>.

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