

ORIGINAL WORK



# Predictors of Family Dissatisfaction with Support During Neurocritical Care Shared Decision-Making

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## Abstract

**Background:** There is a critical need to improve support for families making difficult shared decisions about patient care with clinicians in the neuroscience ICU (neuro-ICU). The aim of this study is to identify patient- and family-related factors associated with dissatisfaction with shared decision-making support among families of neuro-critically ill patients.

**Methods:** We conducted a retrospective observational cohort study using survey data that had been collected from a consecutive sample of family members of patients in the neuro-ICU (one family member per patient) at two US academic centers. Satisfaction with shared decision-making support on ICU discharge had been measured among family members using one specific Likert scale item on the Family Satisfaction in the ICU 24 survey, a validated survey instrument for families of patients in the ICU. We dichotomized top-box responses for this particular item as an outcome variable and identified available patient- and family-related covariates associated with dissatisfaction (i.e., less than complete satisfaction) via univariate and multivariate analyses.

**Results:** Among 355 surveys, 180 (49.5%) of the surveys indicated dissatisfaction with support during decision-making. In a multivariate model, no preexisting characteristics of families or patients ascertainable on ICU admission were predictive of dissatisfaction. However, among family factors determined during the ICU course, experiencing three or fewer formal family meetings (odds ratio 1.93 [confidence interval 1.13–3.31];  $p = 0.01$ ) was significantly predictive of dissatisfaction with decisional support in this cohort with an average patient length of stay of 8.6 days (SD 8.4). There was also a trend toward a family's decision to keep a patient as full code, without treatment limitations, being predictive of dissatisfaction (odds ratio 1.80 [confidence interval 0.93–3.51];  $p = 0.08$ ).

**Conclusions:** Family dissatisfaction with neuro-ICU shared decision-making support is not necessarily predicted by any preexisting family or patient variables but appears to correlate with participating in fewer formal family meetings during ICU admission. Future studies to improve family satisfaction with neurocritical care decision-making support should have broad inclusion criteria for participants and should consider promoting frequency of family meetings as a core strategy.

**Keywords:** Intensive care, Decision-making, Ethics, Quality of health care, Patient-centered care, Family caregivers

## Introduction

Families of critically ill adult patients with severe acute brain injury have to make difficult decisions regarding ICU care because their loved ones are nearly always

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incapacitated and are often faced with challenging prognoses regarding functional outcome [1, 2]. Meeting the decision support needs of these families is a professional and moral duty of any ICU, whether a dedicated neuroscience ICU (neuro-ICU) or a general critical care unit [2, 3]. However, studies of family perception of support during shared decision-making in ICUs show significant room for involvement [4, 5]. Only 41% of family members in one prominent general multicenter ICU study reported excellent overall satisfaction with decision-making [4].

Understanding patient and family factors associated with family dissatisfaction with ICU shared decision-making support may help identify high-risk families and provide insight into high-yield strategies for effective future interventions [6, 7]. In the general critical care literature, several well-designed randomized trials of interventions aimed at improving ICU decision-making support—with broad inclusion criteria for enrolling families—have shown that demonstrating the impact of any intervention can be challenging, regardless of selected outcomes [8–10].

Although specific predictors of family dissatisfaction with critical care in general have been previously reported (e.g., living in the same city as the hospital, living in a different household than the patient) [7, 11], studies of factors that specifically predict family dissatisfaction with decision-making support for neurocritically ill patients have been relatively limited [5, 12]. Identifying risk factors associated with dissatisfaction with shared decision-making for families of neurocritical care patients is critical to optimally assist them with making challenging decisions on behalf of their loved ones. Here we tested whether there are distinct patient-level and family-level characteristics that predict dissatisfaction with support during neurocritical care shared decision-making, with hopes that results could guide future high-yield initiatives to improve family satisfaction with decision support.

## Methods

### Study Design, Including Ethics Statement

We conducted a retrospective observational cohort study using a combined database of Family Satisfaction in the ICU 24 (FS-ICU 24) surveys collected from the neuro-ICUs at two US academic medical centers over the past decade [5, 13]. The institutional review boards of both medical centers separately approved the original collection of survey data and patient and family information. Analyses for this study were performed with deidentified patient and family data.

### Database Descriptions

The Massachusetts General Hospital (MGH) neuro-ICU FS-ICU 24 database contains data from 76 family members that were collected from July to August 2011. Families of all patients admitted to the neuro-ICU with a minimum ICU length of stay (LOS) of 24 h were approached in person at the time of or up to 48 h after ICU discharge or transfer and asked to complete paper surveys. One family member per patient was recruited, with a focus on health care proxies. Minors, non-English speakers, and all families of patients who received comfort measures only (CMO) were excluded. The capture rate of eligible participants in this database has been previously reported as 63% [5].

The Yale New Haven Hospital (hereinafter “Yale”) neuro-ICU FS-ICU 24 database contains data from 288 family members that were collected from March to December 2015. Families of patients admitted to the neuro-ICU for longer than 72 h were eligible, with one family member per patient recruited. Minors and non-English speakers were excluded. Families of patients who did not receive CMO were approached in person at the time of or up to 48 h after ICU discharge or transfer, whereas families of patients who received CMO were contacted by mail 1 month after ICU discharge to respect the time to cope with a loved one’s death and minimize recall bias [14]. In-house surveys were conducted via an online form, and mailed surveys were completed on paper. The capture rate of eligible participants in this database has been previously reported as 49.3% (51.9% for families of patients who did not receive CMO and 40.4% for families of patients who did receive CMO) [13].

### Settings

Both the MGH and Yale neuro-ICUs operate as closed-collaborative units. For neurology patients, intensivists are the primary attendings of record. For neurosurgical patients, neurosurgeons remain the primary attendings of record, but intensivists see all patients in the unit and are responsible for all orders and day-to-day management. Family meetings are also scheduled on an ad hoc basis to provide updates and discuss management of care. Some of the meetings are informal, and others are more formal, with representatives from multiple services, including nursing, social work, and case management.

In both neuro-ICUs, multidisciplinary morning rounds are led by the attending intensivist at the patient’s bedside and include all patients within the unit. Prior to the coronavirus disease 2019 (COVID-19) pandemic, when the data for our study was conducted, families were invited to participate actively in these morning rounds.

## Variables

We divided covariates into three categories: (1) family characteristics at the time of hospital admission, (2) patient characteristics at the time of hospital admission, and (3) patient and family factors determined during the ICU course. Family covariates in both databases were captured directly from surveys, whereas patient covariates were abstracted from medical records.

Family characteristics at the time of hospital admission included age, sex, race, level of education, English as a first language, relationship with patient, prior ICU experience, health care proxy status (self-identified), and size of family. Information regarding whether the family member lived with the patient and whether the family member lived in the same town as the hospital was also obtained. The demographic questions for the family survey at both sites, including those with multiple-choice answers, are listed in Supplementary Digital Content 1. Collected patient characteristics at the time of hospital admission included age, sex, race, and primary diagnosis.

Patient and family factors determined during the ICU course included average hours per day spent by the family at bedside, number of formal family meetings the family reported participating in during the ICU admission (definition of “formal family meeting” was left to the judgment of the survey respondent), decision made by the family to limit code status (limitation defined as do not resuscitate, do not intubate, do not resuscitate/do not intubate, or CMO), patient LOS, and patient modified Rankin Scale at the time of discharge from the ICU. We included the modified Rankin Scale at discharge because we were concerned over the possibility that a patient’s final functional outcome could be associated with the outcome of interest.

## Outcome

The primary outcome was family dissatisfaction with item eight on the “Satisfaction with Decision-Making” section of the FS-ICU 24 questionnaire. The FS-ICU 24 survey has been extensively validated and used to study family satisfaction in the ICU setting around the world [4, 6, 13, 15–21]. It is a 24-item survey consisting of two subsections: “Satisfaction With Care” (14 items) and “Satisfaction With Decision-Making” (10 items). Items from the latter subsection have been used extensively in studies measuring satisfaction with ICU decision-making [6, 22, 23]. Item eight of the decision-making section reads, “Did you feel supported during the decision-making process?” and prompts respondents to indicate their satisfaction with the support provided on a Likert scale (five-point ranking scale; Supplementary Digital Content 2). We selected this single item as our outcome of

interest as opposed to a composite score of the decision-making subsection of the questionnaire because this subsection itself has a wide variety of questions, each of which may be influenced by different sets of covariates in clinical practice. For this study, we defined dissatisfaction with decision-making support as less than complete satisfaction on this particular survey item, including all the options other than the top-box response. We chose this approach to mirror that way in which the Centers for Medicare and Medicaid Services report patient satisfaction data [7].

## Statistical Analysis

We analyzed the covariates of dissatisfied and completely satisfied families and their corresponding patients using standard descriptive statistics and collapsed several levels of variables included in the original questionnaires on the basis of the relatively smaller percentages of responses received for certain levels. We then compared family and patient covariates between dissatisfied and completely satisfied families using the  $\chi^2$  test for categorical variables and the Mann–Whitney  $U$  test for continuous variables. We then performed a multivariate logistic regression analysis to identify independent predictors of decision-making support dissatisfaction among all family covariates and among family and patient covariates combined. IBM SPSS Statistics 26 (IBM Corp, Armonk, NY) was used for the analysis. Missing data were excluded [24].

## Results

### Subjects Selected from Databases

On the basis of those participants in the data sets who had responses recorded for FS-ICU 24 item eight (“Did you feel supported during the decision-making process?”), we included 73 of the 76 respondents in the existing MGH database and 282 of the 288 respondents in the existing Yale database (355 of 364 total respondents). The overall characteristics of patients and families in the MGH and Yale data sets have been reported in prior publications [5, 13]. We found that 50.7% (180 of 355) of all survey respondents indicated dissatisfaction with support during decision-making: 56.1% (41 of 73) at MGH and 49.3% (139 of 282) at Yale ( $p=0.30$ ).

### Family Characteristics at the Time of ICU Admission

Overall, family survey respondents included in the analysis were predominantly White (291 of 337 completed question responses [86.4%]) and received a college education or higher (245 of 339 [72.3%]). The majority had prior ICU experience (197 of 352 [56.0%]).

Table 1 reports a univariate comparison of family characteristics ascertainable at the time of ICU admission between those who were dissatisfied with shared

**Table 1** Univariate comparison of family characteristics at the time of ICU admission

Family characteristics	Dissatisfied (n = 180)	Completely satisfied (n = 175)	p
Age, mean (SD) (yr)	52.1 (14.5) <sup>a</sup>	51.3 (14.3) <sup>b</sup>	0.59
Female sex, n (%)	118 (65.6)	111 (63.4)	0.76
Race, n (%)			0.88
White Caucasian	151/172 (87.8)	140/165 (84.8)	–
Black	9/172 (5.2)	11/165 (6.7)	–
Asian	2/172 (1.2)	2/165 (1.2)	–
Other	10/172 (5.8)	12/165 (7.3)	–
Highest level of education, n (%)			0.71
High school	35/170 (20.6)	41/169 (24.3)	–
College	75/170 (44.1)	74/169 (43.8)	–
Graduate	52/170 (30.6)	44/169 (26.0)	–
Other	8/170 (4.7)	10/169 (5.9)	–
Native English speaker, n (%)	163/174 (93.7)	152/169 (90.0)	0.29
Relation to patient, n (%)			0.71
Spouse	73/179 (40.8)	63 (36.0)	–
Child	59/179 (33.0)	65 (37.1)	–
Parent	25/179 (14.0)	28 (16.0)	–
Other	22/179 (12.3)	19 (10.9)	–
Prior ICU experience, n (%)	95/178 (53.4)	102/174 (58.6)	0.38
Health care proxy, n (%)	122/169 (72.2)	114/166 (68.7)	0.56
Living with patient, n (%)	94/180 (52.2)	95/174 (54.6)	0.73
Living in the town where the hospital is located, n (%)	19 (10.6)	22 (12.6)	0.67
Size of family visiting patient regularly in ICU, n (%)			0.03
1–3 people	80/173 (46.2)	59/169 (34.9)	–
4–6 people	68/173 (39.3)	69/169 (40.8)	–
>6 people	25/173 (14.5)	41/169 (24.3)	–

All categorical variables are reported as n (%). Percentages were calculated amongst completed data fields whereas indicated

<sup>a</sup> n = 177

<sup>b</sup> n = 171

decision-making support and those who were completely satisfied. The cohort of family respondents who were dissatisfied had smaller-sized families (e.g., “Size of family visiting patient regularly in ICU > 6 people,” 14.5% vs. 24.3%; *p* = 0.03). Other covariates did not significantly differ between dissatisfied and completely satisfied family members.

#### Patient Characteristics at the Time of ICU Admission

The majority of patients whose families were included in the analysis were admitted with nontraumatic subarachnoid hemorrhage (21.1%), intraparenchymal and/or intraventricular brain hemorrhage (18.9%), or ischemic stroke (18.0%). Table 2 reports a univariate comparison of patient characteristics ascertainable at the time of ICU admission between those who had family members who were dissatisfied with decision-making support and those who had family members who were completely satisfied. There were no significant differences in the recorded

patient characteristics between those whose family members were dissatisfied and those whose family members were satisfied.

#### Patient and Family Factors Determined During the ICU Course

Overall, the majority of family respondents included in the analysis reported spending more than 3 h a day at the patient’s bedside (272 of 341 [79.8%]). We found that 18.9% (67 of 354) of families made a decision to limit patient code status during the ICU admission; among the Yale surrogates, 16.7% (47 of 282) requested CMO for their relatives. The average LOS for patients was 8.6 (standard deviation 8.4) days, and 32.1% (113 of 352) of patients were bedridden or dead at the time of discharge.

Table 3 reports univariate comparisons of both family and patient factors determined during the ICU course between dissatisfied and completely satisfied families. A higher proportion of dissatisfied families reported

**Table 2 Univariate comparison of patient characteristics at the time of ICU admission**

Patient characteristics	Dissatisfied family (n = 180)	Completely satisfied family (n = 175)	p
Age, mean (SD) (yr)	61.0 (16.6)	62.0 (17.7)	0.57
Female sex, n (%)	86 (47.8)	96 (54.9)	0.22
Race, n (%)			0.43
Caucasian White	153/178 (86.0)	143/174 (82.2)	–
Black	11/178 (6.2)	13/174 (7.5)	–
Asian	3/178 (1.7)	1/174 (0.6)	–
Other	11/178 (6.2)	17/174 (9.8)	–
Primary diagnosis, n (%)			0.51
SAH, non-traumatic	37 (20.6)	38 (21.7)	–
IPH/IVH	33 (18.3)	34 (19.4)	–
Ischemic stroke	28 (15.6)	36 (20.6)	–
Tumor	22 (12.2)	24 (13.7)	–
Status epilepticus / seizure	16 (8.9)	10 (5.7)	–
SDH	16 (8.9)	8 (4.6)	–
Other	28 (15.6)	25 (14.3)	–

All categorical variables are reported as n (%). Percentages were calculated amongst completed data fields aswhere indicated.

IPH/IVH, intraparenchymal brain hemorrhage/intraventricular haemorrhage.

SAH, subarachnoid haemorrhage.

SDH, subdural hemorrhage

experiencing only three formal family meetings or fewer during the ICU admission, compared with completely satisfied families (75.1% vs. 59.0%;  $p = 0.002$ ). Of dissatisfied families, 15.6% made decisions to limit

patient code status, compared with 22.3% of satisfied families ( $p = 0.11$ ).

### Multivariate Analysis of Family Predictors of Decision-Making Support Dissatisfaction

Table 4 contains the results of a multivariate logistic regression analysis of family characteristics predicting dissatisfaction with decision-making support. None of the family characteristics ascertainable at the time of ICU admission were predictive of dissatisfaction, including family size. Among family factors determined during the ICU course, experiencing three or fewer formal family meetings (odds ratio 1.93 [confidence interval 1.13–3.31];  $p = 0.01$ ) was a significant predictor of family dissatisfaction with support during shared decision-making. There was also a trend toward a family's decision to keep a patient as full code, without treatment limitations, being predictive of dissatisfaction (odds ratio 1.80 [confidence interval 0.93–3.51];  $p = 0.08$ ). A multivariate regression that included patient characteristics in addition to family characteristics did not change the results of the analysis.

### Discussion

In this retrospective observational cohort study of a database of FS-ICU 24 surveys from two academic neuro-ICUs over the past decade, we were unable to confirm any specific characteristics of families or patients ascertainable on ICU admission that reliably predicted family dissatisfaction with shared decision-making support at the time of ICU discharge. We did find that among our cohort with an average patient LOS of approximately 9 days, families who reported

**Table 3 Univariate comparison of patient and family factors determined during the ICU course**

Factors	Dissatisfied (n = 180)	Completely satisfied (n = 175)	p
Family factors, n (%)			
Hours spent per day by respondent in the ICU			0.20
> 3	134/174 (77.0)	138/167 (82.6)	–
≤ 3	40/174 (23.0)	29/167 (17.4)	–
Number of formal family meetings with ICU staff			0.002
> 3	42/169 (24.9)	68/166 (41.0)	–
≤ 3	127/169 (75.1)	98/166 (59.0)	–
Decision made by family to limit code status	28/179 (15.6)	39/175 (22.3)	0.11
Patient factors			
LOS, days, mean (SD) (d)	8.0 (7.8)	9.1 (9.0)	0.34
Discharge mRS of patient, n (%)			0.67
0–4	119/178 (66.9)	120/174 (69.0)	–
5–6	59/178 (33.1)	54/174 (31.0)	–

All categorical variables are reported as n (%). Percentages were calculated amongst completed data fields aswhere indicated

Discharge mRS, patient's modified Rankin Scale assessed at time of discharge from the ICU.

LOS, length of stay

**Table 4 Multivariate logistic regression analysis of family characteristics predicting dissatisfaction with decision-making support**

Family characteristics	Odds ratio	95% confidence interval	p
At the time of ICU admission			
Age	1.01	0.99–1.03	0.50
Female sex	1.05	0.63–1.77	0.84
Race			
White	–	–	–
Black	0.78	0.25–2.45	0.67
Asian	1.10	0.13–9.40	0.93
Other	0.97	0.30–3.14	0.96
Highest level of education			
High school	–	–	–
College	1.08	0.56–2.09	0.82
Graduate	1.47	0.71–3.04	0.31
Other	1.29	0.35–4.83	0.70
Native English speaker	1.06	0.36–3.16	0.91
Relation to patient			
Spouse	–	–	–
Child	0.56	0.23–1.37	0.20
Parent	0.79	0.33–1.82	0.55
Other	0.70	0.25–1.97	0.50
Prior ICU experience			
No prior ICU experience	1.14	0.69–1.87	0.62
Health care proxy	–	–	–
Not a health care proxy	0.81	0.44–1.47	0.49
Living with patient	–	–	–
Not living with patient	1.62	0.80–3.30	0.18
Living in the town where hospital is located	–	–	–
Not living in the town where hospital is located	0.94	0.42–2.07	0.87
Size of family visiting patient regularly in ICU			
1–3 people	–	–	–
4–6 people	0.90	0.52–1.54	0.69
>6 people	0.66	0.32–1.39	0.28
Determined during ICU course			
Hours spent per day by respondent in the ICU			
>3	–	–	–
≤3	1.41	0.74–2.69	0.30
Number of formal family meetings with ICU staff			
>3	–	–	–
≤3	1.93	1.13–3.31	0.01
Decision made by family to limit code status			
Yes	–	–	–
No	1.80	0.93–3.51	0.08

LOS, length of stay

experiencing three or fewer formal family meetings during ICU admission were twice as likely to be dissatisfied with decisional support. There was a trend toward families who kept patients full code being more dissatisfied with decisional support compared with

those who did decide on treatment limitations over the course of ICU admission.

Several groups have attempted to identify predictors of satisfaction or dissatisfaction with the overall general care provided in ICUs [7, 25], but only a couple of general

ICU studies have homed in on predictors of satisfaction with ICU decision-making processes [25, 26], and only one to our knowledge has focused on a neurocritical care population [12]. A retrospective analysis of survey responses from 457 family members of patients admitted to general ICUs in two hospitals did previously report that participating in at least one family meeting predicted satisfaction with overall decision-making processes (i.e., the composite score of ten items related to decision-making on the FS-ICU 24 survey) [26]. Approximately 60% of patients in this analysis had an ICU LOS of less than 4 full days. Our data suggest that in neurocritical care environments, for those patients with longer LOS on average, the actual frequency of formal family meetings may be critical, specifically regarding the satisfaction with support provided during shared decision-making (i.e., a specific single item within the FS-ICU 24 survey). Another recent study of 48 surrogates of patients with nontraumatic intracerebral hemorrhage examined predictors of higher family satisfaction with overall ICU decision-making (i.e., again, the ten-item composite FS-ICU 24 decision-making subscore) and concluded that among other factors, younger patient age and the respondent being the spouse of the patient were independent predictive factors [12]. Our larger cohort of patients with a wider array of neurocritical care diagnoses did not replicate these findings, but, again, our study used a single specific FS-ICU 24 item regarding support provided during shared decision-making as the outcome of interest.

The finding in our study that a higher proportion of euro-ICU families who chose to keep patients full code trended toward reporting dissatisfaction with decisional support compared with those who decided on treatment limitations does complement prior general critical care family satisfaction literature [27, 28]. Family members whose loved ones passed away during ICU admission report higher levels of overall satisfaction with ICU care than those whose loved ones survived [27]. Although our study cannot prove causation, we speculate that this correlation could be in part a by-product of increased amount of attention devoted to families of patients given do-not-intubate/do-not-resuscitate orders or CMO.

This study had limitations. Nonresponse bias is a concern for survey studies; to minimize this bias, we drew data from two previously published data sets with good response rates for survey research [5, 13]. The response rates for these previous data sets were achieved by attempting to survey families in person while patients were still admitted to the hospital and calling those families who received mailed surveys to make them more aware of the survey request. Also, there were differences in participant inclusion/exclusion criteria between the two data sets that were combined, including the exclusion

of families of patients who received CMO at MGH. Regarding concerns of differences in response rates and inclusion/exclusion at our two centers, we note that the percentage of families reporting they were dissatisfied with decision-making was similar in each cohort.

We did not capture family levels of psychological distress and coping resources as predictor variables. The phrase "formal family meeting" was not explicitly defined and could therefore have been interpreted differently by different respondents. Additionally, we did not include initial disease-specific severity scores or data regarding urgent procedures for patients because of the heterogeneity of our patient population; however, we did not find any differences in dissatisfaction among families with respect to patient functional outcome at the time of ICU discharge. The databases that we used did not include information about whether individual patients were incapacitated during their neuro-ICU admissions or not, raising the question of whether their surrogates were actually required to make critical decisions on their behalf while they were admitted. Of note, although we recognize the heterogeneous makeup of neuro-ICU populations in different settings, prior literature does suggest high rates of patients who lack capacity in ICUs in general [29].

For our outcome, we used a single item on an older version of the FS-ICU 24 survey. However, a newly revised version has now been recently developed [30]. The exact wording of the question regarding decision-making support that we used as our outcome of interest is slightly different in the newest version of the FS-ICU 24 survey; in the newest version, respondents are now asked if they felt "unsupported," as opposed to "overwhelmed." It is possible that repeating the study with the new FS-ICU 24 item wording could lead to different results. The decision to dichotomize our selected survey question's Likert responses into "completely satisfied" and "less satisfied," as opposed to considering each individual level of satisfaction, was made to make the data more readily interpretable. Although this approach risks missing some more nuanced differences within the "less satisfied" group, as noted earlier, it closely mirrors the standard way in which the Centers for Medicare and Medicaid Services report patient satisfaction data [7].

Of note, the databases we used do not include specific data on the exact decisions that families were asked to make during patient admissions (e.g., consent for surgery, goals of care, etc.), nor do they quantify the number of decisions made during each admission. Although we did not collect this detailed information, the "Satisfaction With Decision-Making" subsection of the FS-ICU 24 survey is validated as a tool to measure families' overall impressions with aspects of decision-making in the ICU at or following the time of ICU discharge, as opposed to

immediately after individual moments during an ICU admission.

Although our intention in this study was to focus on perceptions of decision-making support among surrogates of neuro-critically ill patients—given the difficult decisions that many of these surrogates have to grapple with when their incapacitated relatives are projected to have long-term disability—the fact that this study recruited only in neuro-ICUs may limit its generalizability to other areas of critical care. Additionally, findings from a pre-COVID-19 database may be difficult to generalize to an era with visitor restriction policies [31, 32].

## Conclusions

We found that family dissatisfaction with neuro-ICU shared decision-making support was not correlated with any patient or family characteristics ascertainable on ICU admission. However, among our cohort with an average LOS of 8.6 days, family dissatisfaction correlated with participating in three or fewer formal family meetings during ICU admission, and there was a nonsignificant trend of higher dissatisfaction levels among families of patients who were kept full code.

Designing interventions that improve the decision-making experience of ICU families has proven to be a challenging task [8–10]. To optimize future trials of interventions for improving decisional support among neuro-ICU families, understanding factors that may be predictive of family dissatisfaction with support could, in theory, be important for study design and participant selection. However, our study suggests that such studies should cast a broad net regarding surrogates of patients with brain injury who are selected for study enrollment because we were unable to identify reliable covariate predictors of dissatisfaction with decision-making support.

Our study does support the idea that, when designing neuro-ICU interventions to improve families' perception of decision-making support, those strategies that promote a family's perception of a high frequency of family meetings during the ICU admission may have a solid theoretical foundation. However, in the COVID-19 era of strict visitor restrictions, whether an association exists between frequent virtual meetings over the phone or via video-conferencing technology and family satisfaction with decision-making support is an open question. As visitor restrictions remain in place, neurocritical care physicians must work to adapt to meet family communication needs in new, creative ways [31].

## Supplementary Information

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## Author contributions

DYH and JR conceived the study idea and methods, with consultation from AMV. JJ, NA, AKK, BN, CB, and KBH collected data for the study. DO cleaned the data, and DO and JG provided statistical support. UW and QZ drafted the manuscript. All listed authors reviewed the manuscript, provided edits, and approved the final manuscript draft.

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## Conflict of interest

JR reports receiving consulting fees from Boehringer Ingelheim, unrelated to the present work. A-MV reports receiving consulting fees from Calm.com, unrelated to the present work. The other authors declare no conflicts of interest.

## Ethical approval/informed consent

The institutional review boards of both medical centers separately approved the original collection of survey data and patient and family information. Analyses for this study were performed with deidentified patient and family data.

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## References

- Rid A, Wendler D. Can we improve treatment decision-making for incapacitated patients? *Hastings Cent Rep.* 2010;40(5):36–45.
- Cai X, Robinson J, Muehlschlegel S, White DB, Holloway RG, Sheth KN, et al. Patient preferences and surrogate decision making in neuroscience intensive care units. *Neurocrit Care.* 2015;23(1):131–41.
- Kon AA, Davidson JE, Morrison W, Danis M, White DB. American College of Critical Care Medicine; American Thoracic Society. Shared decision making in ICUs: an American College of Critical Care Medicine and American Thoracic Society policy statement. *Crit Care Med.* 2016;44(1):188–201.
- Heyland DK, Rocker GM, Dodek PM, Kutsogiannis DJ, Konopad E, Cook DJ, et al. Family satisfaction with care in the intensive care unit: results of a multiple center study. *Crit Care Med.* 2002;30(7):1413–8.
- Hwang DY, Yagoda D, Perrey HM, Tehan TM, Guanci M, Ananian L, et al. Assessment of satisfaction with care among family members of survivors in a neuroscience intensive care unit. *J Neurosci Nurs.* 2014;46(2):106–16.
- Stricker KH, Kimberger O, Schmidlin K, Zwahlen M, Mohr U, Rothen HU. Family satisfaction in the intensive care unit: what makes the difference? *Intensive Care Med.* 2009;35(12):2051–9.

7. Hunziker S, McHugh W, Sarnoff-Lee B, Cannistraro S, Ngo L, Marcantonio E, et al. Predictors and correlates of dissatisfaction with intensive care. *Crit Care Med.* 2012;40(5):1554–61.
8. Curtis JR, Treece PD, Nielsen EL, Gold J, Ciechanowski PS, Shannon SE, et al. Randomized trial of communication facilitators to reduce family distress and intensity of end-of-life care. *Am J Respir Crit Care Med.* 2016;193(2):154–62.
9. White DB, Angus DC, Shields A-M, Buddadhumaruk P, Pidro C, Paner C, et al. A randomized trial of a family-support intervention in intensive care units. *N Engl J Med.* 2018;378(25):2365–75.
10. Cox CE, White DB, Hough CL, Jones DM, Kahn JM, Olsen MK, et al. Effects of a personalized web-based decision aid for surrogate decision makers of patients with prolonged mechanical ventilation: a randomized clinical trial. *Ann Int Med.* 2019;170(5):285–97.
11. Hinkle LJ, Bosslet GT, Torke AM. Factors associated with family satisfaction with end-of-life care in the ICU: a systematic review. *Chest.* 2015;147(1):82–93.
12. Sahgal S, Yande A, Thompson BB, Chen EP, Fagerlin A, Morgenstern LB, et al. Surrogate satisfaction with decision making after intracerebral hemorrhage. *Neurocrit Care.* 2021;34(1):193–200.
13. Weber U, Johnson J, Anderson N, Knies AK, Nhundu B, Bautista C, et al. Dedicated afternoon rounds for ICU patients' families and family satisfaction with care. *Crit Care Med.* 2018;46(4):602–11.
14. Wall RJ, Curtis JR, Cooke CR, Engelberg RA. Family satisfaction in the ICU: differences between families of survivors and nonsurvivors. *Chest.* 2007;132(5):1425–33.
15. Heyland DK, Tranmer JE, Kingston General Hospital ICU Research Working Group. Measuring family satisfaction with care in the intensive care unit: the development of a questionnaire and preliminary results. *J Crit Care.* 2001;16(4):142–9.
16. Curtis JR, Patrick DL, Engelberg RA, Norris K, Asp C, Byock I. A measure of the quality of dying and death. Initial validation using after-death interviews with family members. *J Pain Symptom Manage.* 2002;24(1):17–31.
17. Hodde NM, Engelberg RA, Treece PD, Steinberg KP, Curtis JR. Factors associated with nurse assessment of the quality of dying and death in the intensive care unit. *Crit Care Med.* 2004;32(8):1648–53.
18. Mularski R, Curtis JR, Osborne M, Engelberg RA, Ganzini L. Agreement among family members in their assessment of the quality of dying and death. *J Pain Symptom Manage.* 2004;28(4):306–15.
19. Levy CR, Ely EW, Payne K, Engelberg RA, Patrick DL, Curtis JR. Quality of dying and death in two medical ICUs: perceptions of family and clinicians. *Chest.* 2005;127(5):1775–83.
20. Wall RJ, Engelberg RA, Downey L, Heyland DK, Curtis JR. Refinement, scoring, and validation of the Family Satisfaction in the Intensive Care Unit (FS-ICU) survey. *Crit Care Med.* 2007;35(1):271–9.
21. Schwarzkopf D, Behrend S, Skupin H, Westermann I, Riedemann NC, Pfeifer R, et al. Family satisfaction in the intensive care unit: a quantitative and qualitative analysis. *Intensive Care Med.* 2013;39(6):1071–9.
22. Frivold G, Slettebo Å, Heyland DK, Dale B. Family members' satisfaction with care and decision-making in intensive care units and post-stay follow-up needs—a cross-sectional survey study. *Nurs Open.* 2018;5(1):6–14.
23. Maxim T, Alvarez A, Hojberg Y, Antoku D, Moneme C, Singleton A, et al. Family satisfaction in the trauma and surgical intensive care unit: another important quality measure. *Trauma Surg Acute Care Open.* 2019;4(1):e000302.
24. IBM Corp. IBM SPSS Statistics for Windows [computer program]. Version 26.0. Armonk (NY): IBM Corp; 2019.
25. Osborn TR, Curtis JR, Nielsen EL, Back AL, Shannon SE, Engelberg RA. Identifying elements of ICU care that families report as important but unsatisfactory: decision-making, control, and ICU atmosphere. *Chest.* 2012;142(5):1185–92.
26. Kodali S, Stametz RA, Bengier AC, Clarke DN, Layon AJ, Darer JD. Family experience with intensive care unit care: association of self-reported family conferences and family satisfaction. *J Crit Care.* 2014;29(4):641–4.
27. Gries CJ, Curtis JR, Wall RJ, Engelberg RA. Family member satisfaction with end-of-life decision making in the ICU. *Chest.* 2008;133(3):704–12.
28. Gerstel E, Engelberg RA, Koepsell T, Curtis JR. Duration of withdrawal of life support in the intensive care unit and association with family satisfaction. *Am J Respir Crit Care Med.* 2008;178(8):798–804.
29. Ely EW, Margolin R, Francis J, May L, Truman B, Dittus R, et al. Evaluation of delirium in critically ill patients: validation of the Confusion Assessment Method for the Intensive Care Unit (CAM-ICU). *Crit Care Med.* 2001;29(7):1370–9.
30. Heyland DK, Tranmer JE. Introducing the new FS-ICU 24R. <https://fsicu.com/professionals/about/#introducing>. Accessed 17 July 2020.
31. Hart JL, Turnbull AE, Oppenheim IM, Courtright KR. Family-centered care during the COVID-19 era. *J Pain Symptom Manage.* 2020;60(2):e93–7.
32. Morris SE, Moment A, Thomas JD. Caring for bereaved family members during the COVID-19 pandemic: before and after the death of a patient. *J Pain Symptom Manage.* 2020;60(2):e70–4.