

ORIGINAL RESEARCH

Primary Care Physician Involvement in Shared Decision Making for Critically Ill Patients and Family Satisfaction with Care

Kevin B. Huang, Urs Weber, BA, Jennifer Johnson, APRN, Nathaniel Anderson, PA-C, Andrea K. Knies, Dr rer. Medic., Belinda Nhunduu, BA, Cynthia Bautista, RN, Kelly Poskus, RN, Kevin N. Sheth, FAAN, FAHA, FANA, FCCM, FNCS, and David Y. Hwang, MD

Purpose: An intensive care unit (ICU) patient's primary care physician (PCP) may be able to assist family with certain ICU shared medical decisions. We explored whether families of patients in nonopen ICUs who nevertheless report involvement of a patient's PCP in medical decision making are more satisfied with ICU shared decision making than families who do not.

Methods: Between March 2013 and December 2015, we administered the Family Satisfaction in the ICU 24 survey to family members of adult neuroscience ICU patients. We compared the mean score for the survey subsection regarding shared decision making (graded on a 100-point scale), as well as individual survey items, between those who reported the patient's PCP involvement in any medical decision making versus those who did not.

Results: Among 263 respondents, there was no difference in mean overall decision-making satisfaction scores for those who reported involvement (81.1; SD = 15.2) versus those who did not (80.1; SD = 12.8; $P = .16$). However, a higher proportion reporting involvement felt completely satisfied with their 1) inclusion in the ICU decision making process (75.9% vs 61.4%; $P = .055$), and 2) control over the care of the patient (73.6% vs 55.6%; $P = .02$), with no difference regarding consistency of clinical information provided by the medical team (64.8% vs 63.5%; $P = 1.00$).

Conclusions: Families who report involvement of a patient's PCP in medical decision making for critically ill patients may be more satisfied than those who do not with regard to specific aspects of ICU decision making. Further research would help understand how best to engage PCPs in shared decisions. (J Am Board Fam Med 2018;31:64–72.)

Keywords: Critical Illness, Family, Intensive Care Units, Medical Decision Making, Personal Satisfaction, Surveys and Questionnaires

The roles that US primary care physicians (PCPs) play when their patients are admitted to intensive care units (ICUs) have evolved as most ICUs have moved from “open” to “nonopen” staffing mod-

els.^{1,2} “Nonopen” models include “closed” models, where all admitted patients have an intensivist as the official attending of record, and “semiclosed” models, where patients may still have official attendings of record who are outside of the ICU but

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From Yale College, New Haven, CT (KBH); Yale School of Medicine, New Haven (UW, NA, BN); Yale–New Haven Hospital, New Haven (JJ, KP); Yale School of Nursing, New Haven (AKK); Fairfield University School of Nursing, Fairfield (CB); Division of Neurocritical Care and Emergency Neurology, Department of Neurology, Yale School of Medicine, New Haven (KNS, DYH); Center for Neuroepidemiology and Clinical Neurological Research, Yale School of Medicine, New Haven (KNS, DYH).

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Corresponding author: David Y. Hwang, MD, Division of Neurocritical Care and Emergency Neurology, Yale School of Medicine, P.O. Box 208018; New Haven, CT 06520 (E-mail: david.hwang@yale.edu).

where all patients are nevertheless automatically cared for by an intensivist. A 2009 survey by the American Hospital Association found that hospitalists or intensivists were present in 89% of hospitals with over 200 beds, having replaced other physicians—including patients' PCPs—as the primary providers of critical care.³ Evidence does suggest that intensivist care may produce better clinical outcomes than nonintensivist care for critically ill patients.⁴ However, modern, nonopen ICU models—in which an intensivist is primarily responsible for admitted patients—do run the risk of “disfranchising” patients' longstanding PCPs in certain situations, especially if communication among services is not prioritized.¹ An example situation may be one where a shared decision regarding acceptable future quality of life needs to be made between a medical team and a surrogate for an ICU patient who lacks decision making capacity and whose prognosis for future survival or functional outcome is likely poor. In such situations where assessing an incapacitated patient's values are important, it is possible that—for some patients—a PCP may be able to consult and to provide insight into what a patient's wishes would have been, could he or she have advocated for him or herself.

The movement away from open ICU models has occurred concomitantly with increasing attention in the ICU community focused on assessing and improving patient- and family-centered care.⁵ Because most patients admitted to ICUs do not possess the capacity for decision making, surrogate decision making plays an important role in the ICU, and the experience of family members has been recognized as a crucial ICU outcome.⁶ New tools related to the family experience, such as validated family satisfaction surveys, are starting to be assessed regularly, in conjunction with traditional ICU clinical performance indicators such as mortality rates and lengths of stay, to measure critical care quality.^{4,7}

Despite the rise of intensivist-led ICU care and family-centeredness in ICU practice, exactly how PCP involvement in surrogate decision making impacts family satisfaction with decision-making processes in modern, nonopen ICUs models has not been explored in depth. Thus, in this study conducted in a nonopen subspecialty ICU, we used a validated family satisfaction survey to explore whether families of ICU patients who report involvement of a patient's PCP in medical decision

making are more satisfied with ICU shared decision making than families who do not. We hypothesized that families reporting PCP involvement in medical decision making would report higher satisfaction with decision making processes in the ICU than families who did not report any PCP involvement during patient ICU admission.

Methods

Study Design and Setting

This prospective observational single-center survey study was conducted between March 2013 and December 2015 in a 14-bed neuroscience intensive care unit (NICU) at an academic medical center. At time of patient ICU discharge or following patient death, we asked 1 family member for each eligible patient whether to his or her knowledge the patient's PCP had been involved in any medical decision making during the admission and also had each family member complete the FS-ICU 24⁸, an extensively used and validated survey that evaluates family satisfaction with care in the ICU using Likert scales.^{8–11} The 2 subsections of this 24-item survey assess the satisfaction of a family respondent with various aspects of 1) general ICU care, and 2) shared decision making. We compared the score for the survey subsection regarding shared decision making and responses to its individual survey items between those who reported the patient's PCP involvement in any medical decision making versus those who did not.

Of note, all patients admitted to the NICU where this study was conducted have either a neurointensivist or neurosurgeon as the attending of record, with a neurointensivist coordinating care for nonelective neurosurgical admissions. PCPs are not allowed to be the attending of record and simply consult neurological subspecialists for their patients who are admitted to the NICU. The decision whether (and how much) to engage a patient's PCP when his or her patient is admitted to the NICU is not only at the discretion of the neurointensivist and his or her team of residents and advanced providers, but also the patient and his or her family via their own direct outreach.

Ethics Statement

This study was approved by the hospital's equivalent of an Institutional Review Board. Work was

conducted with the ethical standards set forth in the Helsinki Declaration of 1975.

Participants

Adult, English-speaking family members of patients who had a NICU length of stay longer than 72 hours or who were made comfort measures only (CMO) in the NICU during the study period were considered eligible for this survey study. One family member per patient was recruited into the study, with preference given to the patient's health care proxy.

Variables

Patient Covariates

Patient data we collected included demographic information such as age, sex, race/ethnicity, and length of stay; as well as clinical data such as diagnosis, Apache II score, and code status at time of discharge.

Family Covariates

In addition to surveying directly whether the patient's PCP had been involved in any medical decision making during the NICU admission, we

collected data from enrolled families including age, sex, race, ethnicity, health care proxy status, relationship to patient, native language, education level, home location, prior ICU experience, cohabitation status with the patient and frequency of seeing the patient before admission, number of regular visitors to the patient, hours spent by respondent per visit, and number of formal family meetings.

Primary Outcome

Because this study focused on the impact of PCP involvement in medical decision making on family satisfaction, the primary outcome used in this study was the decision making subsection score of the FS-ICU 24. The FS-ICU 24⁸ is an extensively used and validated survey that evaluates family satisfaction with care in the ICU using Likert scales.^{8–11} Two subsections of this 24-item survey assess the satisfaction of a family respondent with various aspects of 1) general ICU care and 2) shared decision making. Answers to the majority of items on the survey are provided on a 5-point Likert-scale, with available responses converted to a continuous 100-point scale for computation of global score, as

Table 1. Characteristics of Patients Whose Families Were Surveyed

Characteristic	Family Reporting PCP Involvement in Decision Making	Family Reporting no PCP Involvement in Decision Making	P
n	54	209	
Mean age (SD) (years)	59.7 (17.2)	63.5 (17.2)	.16
No. of females [n, (%)]	27 (50.0)	105 (50.2)	.98
Race/ethnicity [n, (%)]			.16
Caucasian	39 (72.2)	177 (84.7)	
Latino	7 (13.0)	17 (8.1)	
African American	7 (13.0)	12 (5.7)	
Asian	0 (0.0)	2 (1.0)	
Other	1 (1.8)	1 (0.5)	
Mean length of stay [days, (SD)]	9.8 (8.5)	9.8 (8.7)	.99
Diagnosis [n, (%)]			.1
Subarachnoid hemorrhage	8 (14.8)	55 (26.3)	
Stroke	10 (18.5)	35 (16.7)	
Seizure	4 (7.4)	15 (7.2)	
Intraparenchymal hemorrhage	10 (18.5)	47 (22.5)	
Subdural/epidural hemorrhage	7 (13.0)	11 (5.3)	
Brain tumor	7 (13.0)	19 (9.1)	
Other	8 (14.8)	27 (12.9)	
Mean Apache II Score [n, (%)]	14.2 (4.9)	15.5 (6.0)	.29
Made comfort measures only [n, (%)]	10 (18.5)	34 (16.3)	.69

PCP, primary care physician; SD, standard deviation.

Table 2. Characteristics of Survey Respondents (Families)

Characteristic	Family Reporting PCP Involvement in Decision Making	Family Reporting no PCP Involvement in Decision Making	P
n	54	209	
Mean age (SD) (years)	54.8 (15.9)	52.4 (13.9)	.31
Number of females [n, (%)]	31 (57.4)	138 (66.0)	.24
Race [n, (%)]			.24
Caucasian	40 (78.4)	175 (87.1)	
African American	6 (11.8)	10 (5.0)	
Asian	0 (0.0)	2 (1.0)	
Ethnicity [n, (%)]			.95
Non-Hispanic	44 (86.3)	162 (86.6)	
Hispanic	7 (13.7)	25 (13.4)	
Healthcare proxy [n, (%)]	36 (69.2)	144 (70.6)	.85
Relationship to patient [n, (%)]			.37
Child	13 (23.6)	72 (34.6)	
Spouse	23 (41.8)	84 (40.4)	
Parent	11 (20.0)	31 (14.9)	
Sibling	3 (5.5)	9 (4.3)	
Partner	0 (0.0)	7 (3.4)	
English as first language [n, (%)]	48 (88.9)	188 (90.8)	.67
Highest level of education attained [n, (%)]			.72
High school	15 (28.3)	50 (24.3)	
College	18 (34.0)	88 (42.7)	
Graduate degree	17 (32.1)	57 (27.7)	
Home location [n, (%)]			.07
In town	11 (20.4)	23 (11.0)	
Out of town	43 (79.6)	186 (89.0)	
Prior ICU experience [n, (%)]	31 (58.5)	118 (56.7)	.82
Living with patient prior to admission [n, (%)]	33 (62.3)	113 (54.1)	.28
Frequency of seeing patient prior to admission [n, (%)]			.13
More than weekly	17 (73.9)	51 (48.6)	
Weekly	2 (8.7)	31 (29.5)	
Monthly	3 (13.1)	18 (17.1)	
Yearly	1 (4.3)	5 (4.8)	
Number of regular visitors to patient [n, (%)]			.21
1	5 (9.3)	10 (4.8)	
2 to 3	12 (22.2)	72 (34.8)	
4 to 6	22 (40.7)	82 (39.6)	
Greater than 6	15 (27.8)	43 (20.8)	
Hours spent by respondent per visit [n, (%)]			.16
<1	0 (0.0)	0 (0.0)	
1	3 (5.7)	3 (1.5)	
2	3 (5.7)	12 (5.9)	
3	2 (3.7)	21 (10.2)	
>3	45 (84.9)	169 (82.4)	
Number of formal family meetings [n, (%)]			.97
0	12 (22.6)	46 (22.8)	
1	6 (11.3)	28 (13.9)	
2	7 (13.2)	26 (12.8)	
3	9 (17.0)	28 (13.9)	
>3	19 (35.9)	74 (36.6)	

Responses of "Other" and blank responses are not shown in this table.

ICU, intensive care unit; PCP, primary care physician; SD, standard deviation.

well as the option to compute general ICU and shared decision making satisfaction subscores, each on a continuous 100-point scale as well.

Secondary Outcome

Secondary outcomes included the FS-ICU 24 general ICU subsection scores, the FS-ICU 24 global scores, and “top-box” analysis of each item within the decision making subsection. A “top-box” response for an FS-ICU item is the highest possible response on the Likert scale; the reporting of top-box responses mirrors the method by which the Centers for Medicare and Medicaid Services discloses public patient experience data.¹⁰

Data Sources and Measurement

Data Collection from Families of ICU Survivors

Eligible family members for patients surviving their ICU admission were approached in person during a time window starting 24 hours before known scheduled patient discharge or transfer from the ICU and ending at 1) time of direct hospital discharge from the ICU, or 2) 48 hours after transfer from the ICU to a different hospital unit. We selected this timing of data collection to minimize recall bias on satisfaction surveys. A study team member invited each family member into a hospital conference room, explained the purpose of the study, and obtained informed consent. The survey was completed on-line using a deidentifying unique study identification number for each participant.

Data Collection from Families of Patients Made CMO

Eligible health care proxies of CMO patients were mailed a study packet containing a sympathy letter,

informed consent information sheet, survey, and return envelope after their willingness to participate had been established through a phone call 4 weeks following the patient’s death, transfer, or discharge. Based on prior studies of families of ICU nonsurvivors, we judged that waiting 1 month before study recruitment balanced respect for personal loss with minimizing recall bias.¹²

Patient Data Collection

Descriptive information for all patients whose families participated in the study was abstracted from review of medical records.

Survey Analysis, Statistical Methods, and Study Size

We compared patient and family covariate data between the cohort reporting PCP involvement and the cohort reporting no PCP involvement using descriptive statistics, *t*-tests for continuous variables, and the χ^2 test for categorical variables. We compared mean FS-ICU 24 scores between groups using the Mann-Whitney *U* test. We compared dichotomized top-box individual FS-ICU item responses using Fisher’s exact test.

Regarding study sample size, we calculated that to detect a difference of at least 8 points on the mean FS-ICU 24 decision-making subsection score between groups, we needed at least 50 respondents in each group to achieve a power of 0.80 and α of 0.05, assuming a variance of approximately 200 for the FS-ICU score in each group based off of prior multicenter FS-ICU observational data.^{12,13}

Table 3. FS-ICU 24 Scores of Survey Respondents

	Families Reporting PCP Involvement in Decision Making				Families Reporting no PCP Involvement in Decision Making				<i>P</i>
	Mean	SD	Median	IQR	Mean	SD	Median	IQR	
Decision making subsection score	81.06	15.1	87.5	17.5	80.07	12.76	83.33	17.5	.16
General ICU care subsection score	90.22	12.68	94.64	11.81	88.38	14.15	92.86	14.29	.28
Global score	86.4	11.76	91.49	12.77	84.91	12.17	88.1	12.75	.16

The FS-ICU 24 has two sections, one regarding satisfaction with decision making, and the other regarding satisfaction with general ICU care.

Both subsections produce a composite subsection score graded from zero to 100, with the complete survey also producing a composite global score representing overall satisfaction. The *P*-values compare the mean scores for each subsection, as well as the composite score.

FS-ICU 24, Family Satisfaction in the ICU 24-item survey; ICU, intensive care unit; IQR, interquartile range; PCP, primary care physician; SD, standard deviation.

Results

During the study period, 263 of 582 eligible families completed the survey, with 54 (20.5%) self-reporting PCP involvement.

Table 1 shows the demographics for patients whose family members were enrolled onto the study. Statistical analysis by χ^2 and t -tests did not reveal any significant differences between patients in the 2 groups.

Table 2 shows the demographics for survey respondents themselves. Again, statistical analysis did not reveal any significant differences between survey respondents in the 2 groups.

Regarding our primary outcome, the mean composite FS-ICU 24 scores for the survey's decision-making subsection did not vary significantly between the 2 groups (Table 3). In addition, no difference between groups was seen for either the mean general ICU care subsection scores or for the global FS-ICU 24 scores. Of note, 14 of the 66 family members of CMO patients (21%) and 40 of the 143 family members of non-CMO patients (28%) reported PCP involvement in decision making. For both the cohorts of 1) families of CMO patients and 2) families of non-CMO patients (ie, examined separately), there was no difference in either mean FS-ICU 24 overall or subsection scores between those families who reported PCP involvement and those who did not (Table 4).

With regard to individual survey items in the decision-making section of the FS-ICU 24 survey, less than 80% of respondents of all survey respondents reported complete satisfaction with 9 out of 10 survey items (Table 5). However, a higher proportion reporting PCP involvement felt completely satisfied with their 1) inclusion in the ICU decision making process (75.9% vs 61.4%; $P = .055$), and 2) control over the care of the patient (73.6% vs 55.6%; $P = .02$), with no difference between groups regarding satisfaction with the consistency of clinical information provided by the medical team (64.8% vs 63.5%; $P = 1.00$).

Discussion

The purpose of this study was to investigate the association of PCP involvement in medical decision making with family perception of satisfaction with care in a subspecialty ICU with a nonopen model, in which intensivists manage all patients. We found no difference in standardized survey scores regard-

Table 4. FS-ICU 24 Scores of Survey Respondents Stratified by Patient CMO Status

	CMO Families Reporting PCP Involvement in Decision Making				CMO Families Reporting no PCP Involvement in Decision Making				Non-CMO Families Reporting PCP Involvement in Decision Making				Non-CMO Families Reporting no PCP Involvement in Decision Making				<i>P</i>
	Mean	SD	Median	IQR	Mean	SD	Median	IQR	Mean	SD	Median	IQR	Mean	SD	Median	IQR	
Decision making subsection score	84.19	7.24	84.17	8.75	77.26	16.77	82.5	18.13	86.81	15.7	87.5	17.5	80.71	11.84	83.33	15	.33
General ICU care subsection score	91.68	8.2	93.75	13.15	86.38	16.34	91.37	16.16	94.52	13.15	95.4	10.95	89.02	13.23	93.3	14.22	.36
Global score	88.57	7.35	90.96	8.14	82.54	15.91	87.8	14.09	91.26	12.16	91.67	11.9	85.55	11	88.54	12.01	.23

The FS-ICU 24 has two sections, one regarding satisfaction with decision making and the other regarding satisfaction with general ICU care.

Both subsections produce a composite subsection score graded from zero to 100, with the complete survey also producing a composite global score representing overall satisfaction. The P -values compare the mean scores for each subsection, as well as the composite score.

CMO, comfort measures only; FS-ICU 24, Family Satisfaction in the ICU 24-item survey; IQR, interquartile range; PCP, primary care physician; SD, standard deviation.

Table 5. Responses to Individual FS-ICU 24 Survey Items Regarding Aspects of Decision Making

Survey item	Number of Responses (n)		Proportion Reporting Complete Satisfaction (%)		<i>P</i>
	PCP Involvement	No PCP Involvement	PCP Involvement	No PCP Involvement	
Frequency of communication by doctors	54	198	58.5	52.0	.44
Ease of getting information	54	205	74.1	75.1	.86
Understanding of information	54	193	74.1	76.2	.72
Honesty of information	54	198	66.7	71.2	.51
Completeness of information	53	206	79.2	70.4	.23
Consistency of information	54	203	64.8	63.5	1.00
Inclusion in decision making	54	207	75.9	61.4	.06
Support during decision making	54	207	50.0	50.7	1.00
Control over care	53	207	73.6	55.6	.02
Time to address questions and concerns	51	202	92.2	93.6	.76

The FS-ICU 24 has two sections, one regarding satisfaction with decision making and the other regarding satisfaction with general ICU care. The table shows the breakdown in responses for each question in the decision making subsection. ICU, intensive care unit; FS-ICU 24, Family Satisfaction in the ICU 24-item survey; PCP, primary care physician.

ing overall satisfaction with ICU decision making between families who self-reported PCP involvement in ICU decision making (approximately 1 in 5 families in our cohort) and families who self-reported no PCP involvement. This finding was independently true both for families of patients made CMO and families of patients who survived their ICU admissions. However, on closer examination of the individual item responses within the standardized survey, we found that family members who reported PCP involvement in medical decision making were more likely to be completely satisfied specifically with their own inclusion in the decision-making process and control over care of the patient than those families who reported that the patient's PCP was not involved. In addition, satisfaction with consistency of communication was not significantly different between the 2 groups. Taken together, these results highlight how exact choice of an outcome measure and specific questions for a survey study of ICU family satisfaction can influence conclusions.

To our knowledge, this study is one of the first to document an estimated percentage of ICU families reporting PCP involvement at an academic medical center and to examine the possible association of PCP involvement in medical decision making and ICU family satisfaction. Prior related studies have mostly instead focused on patient (as opposed to family) experiences of inpatient care in non-ICU hospital wards, direct PCP communication with inpatient clinicians, and continuity of

outpatient care following inpatient hospitalization. One study found that patients who perceived direct communication between their hospital team and their PCP were more satisfied with care.¹⁴ Another study estimated that only 33% of patients admitted to a teaching hospital actually had contact with their PCPs; of those, the majority of these patients were satisfied with communication and believed that having a physician they have known for a long time involved would lead to better care.¹⁵ With regard to inpatient-outpatient provider communication, severe communication deficits have been shown to exist between PCPs and hospitalists (with direct communication occurring infrequently if at all)¹⁶, with some evidence of impact on both patient safety and satisfaction.^{17–18} Notably, even though hospitalists and PCPs share the challenge of proper care coordination following patient discharge from the hospital¹⁹, only 56% of PCPs report satisfaction with communication with hospitalists.²⁰

Although these known data regarding patient and clinician perceptions of hospital care are important, we argue that understanding how family satisfaction with care in an ICU is impacted by PCP involvement is uniquely important in several ways. The majority of patients admitted to an ICU lack capacity for medical decision making themselves.²¹ Thus, most medical decisions in ICUs that involve value judgments (ie, changing a patient's code status or deciding to limit life support for a patient with poor prognosis) put families and surrogate decision makers in the difficult position of

attempting to respect a patient's perceived wishes, when such wishes may not have been previously discussed.²² In this sense, PCPs may play a more important role for patients admitted to the ICU than in other hospital units because their longitudinal relationships with their patients can give them unique perspectives regarding patient values and preferences when uncertainty exists in critical situations (especially when patients themselves lack decision making capacity). PCPs may also provide reassurance and confidence in the ICU team for families meeting inpatient clinicians for the first time and still building trust.

In addition to being single-center, this study has several limitations. Although the FS-ICU is one of the most commonly used survey tools for assessing family satisfaction with ICU care, all self-reporting surveys are subject to several biases. With regard to self-reporting bias, we note that our survey was administered at the time of or following patient discharge; this timing meant that respondents in theory had minimal incentive to bias their responses toward expressing more satisfaction (out of concern that their responses might impact ongoing patient care). We proactively sought to enroll all families of ICU survivors while they were still in the hospital (as opposed to by mail) to minimize any possible influence of nonresponse bias as well. Although our survey cohort was large and spanned several years, the study size may still have been too small to detect subtle but significant differences between groups with regard to the calculated overall and subsection FS-ICU scores. Furthermore, the sample size of family members who contacted their PCPs (54) is relatively small when compared with the rest of the cohort (209). However, this statistic in itself is an interesting finding—only 20% of family members of patients admitted to the ICU reported consulting with patients' PCPs during admission.

We disclose as well that our ICU instituted a new practice protocol around halfway through our data collection period whereby the attending intensivist on service and the ICU nurse manager visited all families of patients at the bedside every Tuesday and Thursday afternoon to provide them with an opportunity to discuss their impressions of clinical care with the ICU leadership. However, conducting the analysis we described in this article in the time periods before and after this practice change separately revealed no significant difference in FS-

ICU scores during either time period (online Appendix).

Based on the data from the individual items in our survey, we do conclude that PCP involvement in medical decision making may be associated with improved family satisfaction with several specific components of the shared decision making process. Given the enormous transformation that has occurred in the practice of intensive care within the past few decades, surprisingly little is known about the impact PCP involvement has on family satisfaction with care in modern, nonopen ICUs. Future studies may test proactive interventions designed to encourage PCP involvement in the ICU to increase family satisfaction with shared decision making. As this study demonstrates, these studies will need to consider carefully the specific survey instruments and individual questions that will be used to assess outcomes.

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Appendix. Pre- and Post-Intervention FS-ICU 24 Scores of Survey Respondents

Scores	Pre-Intervention									Post-Intervention																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																									
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FS-ICU 24 = Family Satisfaction in the ICU 24-item survey; p-values compare mean FS-ICU 24 scores.

The FS-ICU 24 has two sections, one regarding satisfaction with decision making and the other regarding satisfaction with general ICU care. Both subsections produce a composite subsection score graded from zero to 100, with the complete survey also producing a composite global score representing overall satisfaction. The p-values compare the mean scores for each subsection, as well as the composite score.

“Intervention” refers to a new practice protocol instituted halfway through the data collection period whereby the attending intensivist on service and the NICU nurse manager visited all families of patients at the bedside each Tuesday and Thursday afternoon, at a specific time that was advertised to families in advance, as an opportunity to discuss with the NICU leadership their impressions with clinical care.

ICU, intensive care unit; IQR, interquartile range; PCP, patient’s primary care physician; SD, standard deviation.