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## Assessment of Satisfaction with Care Among Family Members of Survivors in a Neuroscience Intensive Care Unit

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### Conflicts of Interest

The authors have no relevant conflicts of interest to declare.

## Abstract

Many prior nursing studies regarding family members specifically of neuroscience intensive care unit (Neuro ICU) patients have focused on identifying their primary needs. A concept related to identifying these needs and assessing whether they have been met is determining whether families explicitly report satisfaction with the care that both they and their loved ones have received. The objective of this study was to explore family satisfaction with care in an academic Neuro ICU and compare results with concurrent data from same hospital's medical ICU (MICU). Over 38 days, we administered the Family Satisfaction-ICU instrument to Neuro ICU and MICU patients' families at time of ICU discharge. Those whose loved ones passed away during ICU admission were excluded. When asked about the respect and compassion that they received from staff, 76.3% (95% CI 66.5–86.1) of Neuro ICU families were completely satisfied, as opposed to 92.7% in the MICU (84.4–101.0,  $p = 0.04$ ). Respondents were less likely to be completely satisfied with the courtesy of staff if they reported participation in zero formal family meetings. Less than 60% of Neuro ICU families were completely satisfied by: (1) frequency of physician communication, (2) inclusion and (3) support during decision making, and (4) control over the care of their loved ones. Parents of patients were more likely than other relatives to feel very included and supported in the decision-making process. Future studies may focus on evaluating strategies for Neuro ICU nurses and physicians to provide better decision-making support and to implement more frequent family meetings even for those patients who may not seem medically or socially complicated to the team. Determining satisfaction with care for those families whose loved ones passed away during their Neuro ICU admission is another potential avenue for future investigation.

## Keywords

Communication; Consumer Satisfaction; Intensive Care Units; Professional-Family Relations

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## Introduction

The provision of medical care that is patient- and family-centered, while certainly not a new idea, is one that has received increasing attention in the general critical care community, especially over the past decade (Davidson et al., 2007). Because of the severity of illnesses treated in intensive care units (ICUs) and the need for shared decision-making when ICU patients are unable to express their own wishes, the ICU community in particular must attend to the experience not only of patients but also of family members (Kentish-Barnes, Lemiale, Chaize, Pochard, & Azoulay, 2009). Tools to measure various aspects of families' experiences are now being added to traditional clinical performance indicators (*e.g.*, mortality rates, length of stay) to assess quality improvement initiatives (Dodek, Heyland, Rucker, & Cook, 2004; Levy, 2007).

For neuroscience ICUs (Neuro ICUs) in particular, the combination of often unclear long-term prognoses and inability for patients to communicate makes improving the family experience especially important. Several studies in the neuroscience nursing literature have compared the needs of family members of critically ill patients with brain injury to those without brain injury, suggesting that indeed differences exist between the two groups. Recent articles by Hinkle, Fitzpatrick, and Oskrochi (2009) and Prachar et al. (2010)

summarized the findings of these studies in detail, noting that the majority of them used either a version of Molter's Critical Care Family Needs Inventory (CCFNI) (Molter, 1979) as the survey instrument of choice or qualitative interview methods. We would like to highlight a study using the CCFNI by Engli and Kirsivali-Farmer (1993), who reported that knowing the prognosis was a more pressing need among families of patients with acute brain injury compared with those families of patients without brain injury. A complementary qualitative study by Bond et al. (2003) reported that among the top needs of families of patients with traumatic brain injury were simply to know the truth about their loved ones' conditions.

Related to identifying these needs and assessing whether they have been met is determining whether families report satisfaction with the care that both they and their loved ones have received. While assessing needs and satisfaction are clearly intertwined (Rothen, Stricker, & Heyland, 2010), Heyland et al. have pointed out that the two concepts are not quite synonymous because "... unmet needs do not always translate into dissatisfaction. In addition, meeting needs does not guarantee satisfaction (2002, p. 1413)." In the critical care literature, a number of validated survey instruments have been developed for the purposes of assessing family satisfaction within the ICU (Kentish-Barnes et al., 2009; Rothen et al., 2010). Each of these instruments has different areas of emphasis with regards to the assessment of overall family satisfaction with care. The Family Satisfaction-ICU (FS-ICU) is one satisfaction survey that has now been extensively validated in the general critical care population (Heyland et al., 2002; Heyland & Tranmer, 2001). It is unique and has become popular because nearly half of the survey has a particular focus on families' perceptions of the shared decision-making process (Henrich et al., 2011; Hunziker et al., 2012; Stricker et al., 2007; Wall, Engelberg, Downey, Heyland, & Curtis, 2007b).

In this article, we present data of family satisfaction from an observational study in a hospital's dedicated Neuro ICU over a period of slightly greater than one month. The goals of the study were to discover aspects of the family experience in the Neuro ICU that could be improved and identify patient and family covariates that might be associated with satisfaction ratings for these aspects. Because updating families on the prognosis of their loved ones and making shared decisions with patients' health care proxies have been previously identified as important family needs in the Neuro ICU, we used the FS-ICU as our survey instrument for satisfaction. For comparison, the survey was also administered concurrently to families of patients in the hospital's medical intensive care unit (MICU). We decided to compare survey results from the Neuro ICU to those from the MICU in particular (1) to assess whether differences in satisfaction exist among families of brain-injured patients versus critically ill patients without brain injury and (2) to explore whether variations in family satisfaction might arise between two ICUs with organizational structures that differ in important manners.

## Methods

This study was conducted over a consecutive 38-day period in the Neuro ICU and MICU at an academic medical center and was approved by the hospital's Human Studies Committee. Work was carried out with the ethical standards set forth in the Helsinki Declaration of

1975. The length of the study was determined by the availability of a full-time research assistant to ensure that as many families in both ICUs were enrolled as possible.

At the time of the study, both the Neuro ICU and MICU were comprised of 18 patient beds. The structure of morning rounds in both ICUs is multidisciplinary, with nurses and physicians discussing patients together, along with pharmacists and therapists.

The nurse-to-patient ratio in both the Neuro ICU and the MICU is based on patient acuity needs; nurses care for one to two patients with emphasis on continuity of patient care. Nursing leadership in both units consists of a nursing director and a unit-based clinical nurse specialist. The operational flow of admissions and discharges in both units is facilitated by a rotating resource nurse, with bedside nurses instrumental in supporting family and assisting with communication and coordination of care plans. Both the clinical nurse specialist and resource nurse in their respective units often join the bedside nurse and physician team on morning rounds to participate in information sharing and to offer support to staff, patients, and families. Both units also have a dedicated social worker and case manager available to provide support as needed.

The neurointensivists and neurocritical care fellows staffing the Neuro ICU are all graduates of neurology residencies, with all residents on service rotating from neurology and neurosurgery training programs. On a typical day, the Neuro ICU team is comprised of nursing, an attending neurointensivist, three neurocritical care fellows, two residents, and support staff. The intensivists and critical care fellows staffing the MICU are all graduates of internal medicine residencies, with all residents on service rotating from the hospital's internal medicine training program. The standard daily MICU team is comprised of nursing, two attending intensivists, two critical care fellows, two third-year residents, four second-year residents, six first-year interns, and support staff.

All family members of patients admitted to the participating units during the study period were potential participants, regardless of gender, race, or the medical conditions of their loved ones. A research coordinator identified patients for inclusion by consulting with the resource nurses of the two participating ICUs on each weekday during the study period. Families of patients with planned discharges within 24 hours of this resource nurse consultation were eligible for the study. Only one family member per patient was allowed to complete the survey; when possible, the person serving as the patient's health care proxy was selected among various family members for inclusion. Minors, non-English speakers, and subjects whose loved ones either passed away during ICU admission or whose goals of care had been changed to intensive comfort measures (ICM) were excluded during the screening process. In the general ICU literature, the satisfaction of family members in end-of-life situations has received distinct attention as a particular area for quality improvement, especially since the process of directing goals of care towards comfort can involve intense discussions that are different in nature from other decision making in the ICU (Gries, Curtis, Wall, & Engelberg, 2008; Heyland, Rocker, O'Callaghan, Dodek, & Cook, 2003). While we recognize the importance of understanding factors that contribute to family satisfaction or dissatisfaction with end-of-life care, we felt that, for the purposes of drawing clear

conclusions from the data, limiting the current study to ICU survivors only would have merit.

We used the FS-ICU 24 as the survey instrument in this study (Wall et al., 2007b). We selected the FS-ICU as our survey instrument because the survey has been extensively and internationally validated in the general critical care population and because half of the survey has a particular focus on families' perceptions of the shared decision-making process (Henrich et al., 2011; Hunziker et al., 2012; Stricker et al., 2007; Wall et al., 2007b).

Attached to the questionnaire was a cover sheet with language of informed consent. A family member who returned the questionnaire to the research coordinator was considered to have formally consented to participate in the study. In addition, a supplemental form for the collection of family demographic information was also provided. Of note, one question on the supplemental form asked respondents to indicate the number of formal family meetings that they participated in while their loved ones were admitted; for this particular question, the definition of "formal" was based upon the judgment of the respondents.

After survey distribution, the research coordinator remained available, though not immediately present in the room, to answer questions while family members completed the questionnaire. The research coordinator returned to each family to collect the questionnaires based on a mutually agreed upon time. Surveys needed to be completed within 48 hours after patient discharge in order to be included in the study. Participants in the survey who expressed discomfort were withdrawn at their request. If needed, a social worker was provided to assist families with any emotional discomfort emerging from survey completion.

Data from completed surveys were transferred and stored in an electronic, HIPAA-compliant REDCap database. All members of the research team were trained in protecting patient confidentiality.

Patient and family characteristics were described using means with standard deviations and percentages. Twenty-three of the 24 items on the FS-ICU 24 ask respondents to rate their satisfaction with specific aspects of the ICU experience on a 5-point Likert-type response scale, with possible choices ranging from selections similar to "Excellent" to "Poor." (17) For the statistical analysis of each of these twenty-three items, we dichotomized the outcome variable into those who were "completely satisfied" (*i.e.*, the highest rating on the Likert response scale) and those who were not (*i.e.*, any of the remaining rating choices on the scale). We patterned this method of data analysis after the recent article by Hunziker et al. (2012); the authors argued that this dichotomization of FS-ICU item responses, while arbitrary, is familiar to patients, families, clinicians, and administrators, since it is the approach that the Centers for Medicare and Medicaid Services has taken with public reporting of patient satisfaction. Of note, the last item on the FS-ICU 24 ("When making decisions, did you have adequate time to have your concerns addressed and questions answered?") only has two possible responses on the original version of the survey. The percentages of these dichotomized responses from the Neuro ICU and MICU cohorts were compared using the Fisher's exact test. Logistic regression analysis with regards to collected patient and family covariates was performed on Neuro ICU and MICU responses to FS-ICU

questions of interest using *Stata Statistical Software: Release 11* (StataCorp LP, College Station, TX, 2009).

## Results

Over the study period, 121 total non-ICM patients were marked by a resource nurse for discharge on weekdays from the Neuro ICU, compared to 72 from the MICU. Of the 121 patients discharged from the Neuro ICU, the research team was able to meet with a representative from 106 families (87%). Seventy-nine surveys (63% of the total) were subsequently returned to the team and included in the study analysis. Of the 72 patients discharged from the MICU, the research team was able to meet with a representative from 60 families (83%). Forty-five (62.5% of the total) surveys were returned to the team and included in the study analysis.

Table 1 outlines demographics of the patients whose family members were enrolled in the study. Twenty-six (32.9%) Neuro ICU patients were scheduled neurosurgical admissions for routine monitoring following elective operations. Table 2 outlines demographics of the survey respondents for the Neuro ICU and MICU. The mean age of survey respondents in the Neuro ICU and MICU were 48.3 (SD 14.5) and 52.7 (12.9) years, respectively. In addition to respondents from both ICUs being well-educated, nearly 56% of our survey participants in the Neuro ICU and 60.0% in the MICU indicated that they had prior experiences with family members admitted to an ICU.

Regarding general aspects of care in both the Neuro ICU and the MICU (Table 3), satisfaction was particularly low with the atmosphere in the waiting room (47.3%, 95% CI 35.6–59.0), highlighting an area to target for improvement. Of note, when asked to rate their satisfaction with the courtesy, respect, and compassion that they themselves were given as family members, a smaller percentage of survey participants in the Neuro ICU (76.3%, 95% CI 66.5–86.1) were completely satisfied, compared with the MICU (92.7%, 84.4–101.0,  $p = 0.04$ ). Significant findings from bivariate analyses of all collected patient and family characteristics with regards to family impressions of the courtesy of the Neuro ICU staff are presented in Table 4. Respondents who did not report participation in any formal family meetings were less likely to feel completely satisfied with the concern and caring shown to them as family members by ICU staff (OR 0.28, 95% CI 0.094–0.85, 0.03).

Less than 75% of all participating family members in the Neuro ICU were completely satisfied with 9 of the 10 aspects of decision making covered in the survey (Table 5), with the lone exception being adequate time to have concerns addressed and questions answered by Neuro ICU staff (an item with an originally dichotomized response scale in the FS-ICU). In particular, less than 60% of the family members participating in the study from the Neuro ICU were completely satisfied with these four domains: (1) frequency of communication by Neuro ICU doctors (46.6%, 95% CI 34.9–58.3), (2) inclusion in decision making (52.6%, 41.2–63.9), (3) support during decision making (44%, 32.5–55.5), and (4) control as patient's family over the care of their loved one (54%, 42.5–65.5).



Bivariate analyses of all collected patient and family characteristics identified a few significant family covariates associated with complete satisfaction regarding these four particular aspects of the decision-making experience that scored less than 60% among Neuro ICU participants (Table 6). These bivariate analyses included the Neuro ICU and MICU survey responses as a single cohort, given that there was no significant difference between the two units with regards to performance in these four domains. Of note, survey respondents who were parents of ICU patients were possibly more likely to feel very included (OR 5.19, 95% CI 1.09–24.80,  $p = 0.04$ ) and very supported (3.91, 1.002–15.28, 0.05) in the decision-making process. This correlation was not seen for respondents who reported being patients' children, spouses, or partners.

## Discussion

The purpose of this observational study was to explore the satisfaction of family members with the care that their surviving loved ones' received at time of discharge in an academic Neuro ICU, using a standardized survey previously validated in general medical and surgical units (Henrich et al., 2011; Heyland et al., 2002; Heyland & Tranmer, 2001; Hunziker et al., 2012; Stricker et al., 2007; Wall et al., 2007b) and comparing results with concurrently collected survey data from families in the same hospital's MICU. We found that our Neuro ICU's families were possibly less satisfied with the concern and caring of the staff for their needs compared to families in the MICU. Those survey participants who lived with the patient prior to admission and whose families numbered four to six people in size were significantly more likely to be completely satisfied by the Neuro ICU staff's courtesy, respect, and compassion for their family. Conversely, those participants who were not living with the patient before admission and who reported not having a single family meeting during their loved ones' Neuro ICU stay were significantly less likely to be completely satisfied from this regard.

We also found that parents of admitted patients were more likely to be very satisfied with feeling included and supported during key decisions, a correlation not seen for other family relationships to the patient (e.g., spouse, child, etc.). Furthermore, families who did not participate in a single family meeting during their loved one's admission were less likely to feel complete control over patient care, while families who participated in more than three formal family meetings were more likely to be completely satisfied with the frequency of physician communication. Finally, the actual percentage of respondents in the Neuro ICU who reported complete satisfaction with the atmosphere of the waiting room, where many important decisions with families are made, was low in our study.

To our knowledge, this study is the first to test the FS-ICU instrument with a focus on a Neuro ICU population and perhaps highlights some challenges typical of modern Neuro ICU practices. Several hypotheses exist as to why there was a possibly significant difference between the Neuro ICU and MICU with regards to families' satisfaction with the courtesy and compassion that they received. For example, the neurosurgical patients in the study Neuro ICU are co-managed by both neurointensivists and neurosurgeons, the latter of which serve as the attendings of record. The MICU is a completely "closed" unit. Multiple prior studies comparing open and closed ICUs in the general medical and surgical ICU literature

have reported improved outcomes such as care efficiency and reduced patient mortality in a closed model where an intensivist assumes complete responsibility for patient care upon admission to the ICU (Multz et al., 1998; van der Sluis et al., 2011). Our study raises the possibility that improved satisfaction with courtesy and respect shown by ICU staff to families may be another outcome advantage of a closed Neuro ICU model, although further study is clearly needed to show a causal relationship.

Another hypothesis, supported more by our logistic regression analysis, relates to the organization of often limited Neuro ICU nursing and physician staff to ensure that both patients and their families have their needs addressed. At the time that the survey was administered, our Neuro ICU was comprised of 18 beds, primarily staffed at any given time by only one neurology-trained attending neurointensivist. Given that the number of physician trainees (e.g., residents and fellows) in our unit ranges from 3 to 5 during business hours and 1 to 2 on nights and weekends, oftentimes triaging resources among available nurses and physicians to ensure that all 18 families have access to team members becomes important. We speculate from our bivariate analyses that there might be certain types of family situations that may capture the collective attention of a Neuro ICU staff with limited manpower; e.g., a patient with a large number of family members (e.g., 4–6) in their “core” group of visitors, a younger patient—perhaps unexpectedly ill—whose primary family representatives are his or her parents (as opposed to older, chronically ill patients accompanied by their spouses and/or children), or a patient whose main family spokesperson has been living with him or her for years and is very emotionally attached. While it is possible that these situations may contain high emotional valence and thus require multiple meetings among family and staff to mediate, they may also inadvertently result in less attention being paid by a busy staff to more “routine” patients and their families. This phenomenon may correlate with reports in the general medical ICU literature that (1) family members whose loved ones pass away during admission report higher level of satisfaction with ICU care than those whose loved ones survive (Wall, Curtis, Cooke, & Engelberg, 2007a) and that (2) a longer duration for decision making regarding withdrawal of life support is also associated with higher levels of family satisfaction (Gerstel, Engelberg, Koepsell, & Curtis, 2008).

Our study has several limitations. It is a single-center study, and thus it is uncertain how the results might generalize to other Neuro ICUs, especially since many different models and environments for Neuro ICUs exist (i.e., with regards to nurse and physician staffing, architectural design, patient and family demographics, etc.). Our hope is that as the field of neurocritical care evolves, more data will become available regarding family satisfaction with care in Neuro ICUs different from our own. It is unclear to us whether those potential study participants who did not return surveys they were given did not do so at random or if either a positive or negative selection bias could have been a possibility. Also, because our study is exploratory in nature, we collected a large number of covariates for our family participants and used a survey designed with many questions in a relatively small cohort of families. The value of applying an established survey such as the FS-ICU in a novel population such as a dedicated Neuro ICU is that one can identify possible areas for quality improvement and design more hypothesis-driven, targeted studies in the future.



## Summary

We have shown using a previously validated survey that, in our Neuro ICU, our patients' families could be more satisfied with several aspects of care, including the atmosphere in the waiting room and the respect that we as staff show to them. Shared decision making with families could also be improved in many areas; in particular, increasing frequency of communication by ICU doctors, ensuring that patients' families feel included and supported throughout the process, and keeping in mind that families appreciate control over their loved ones' care as much as possible. Our analysis of patient and family covariates suggest that efforts to improve the experience of families in the Neuro ICU could be made not only for the more intense family discussions but also for those more routine.

## Conclusion

Future studies may focus on evaluating strategies for Neuro ICU nurses and physicians to provide better decision-making support—in a variety of different unit organizational structures—and to implement more frequent family meetings even for those patients who may not seem medically or socially complicated to the team. Instituting a system in which members of the nursing and physician Neuro ICU team regularly meet with all available families of patients daily, either as a part of morning work rounds or separately later in the day, may represent one potential strategy for improvement. Also, determining satisfaction with care for those families whose loved ones passed away during their Neuro ICU admission is another potential avenue for future investigation. Our hope is that the field of neurocritical care pursues Neuro ICU-specific, multi-center intervention studies to improve overall family satisfaction and in particular their experience with decision making, as the general critical care community has recently done (Dodek et al., 2004; Lederer, Goode, & Dowling, 2005; Radwin, Ananian, Cabral, Keeley, & Currier, 2011; Scheunemann, McDevitt, Carson, & Hanson, 2011; Shelton, Moore, Socaris, Gao, & Dowling, 2010).

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## References

- Bond AE, Draeger CRL, Mandleco B, Donnelly M. Needs of family members of patients with severe traumatic brain injury. Implications for evidence-based practice. *Critical Care Nurse*. 2003; 23(4): 63–72. [PubMed: 12961784]
- Davidson JE, Powers K, Hedayat KM, Tieszen M, Kon AA, Shepard E, et al. Clinical practice guidelines for support of the family in the patient-centered intensive care unit: American College of

- Critical Care Medicine Task Force 2004–2005. *Critical Care Medicine*. 2007; 35(2):605–622. [PubMed: 17205007]
- Dodek PM, Heyland DK, Rocker GM, Cook DJ. Translating family satisfaction data into quality improvement. *Critical Care Medicine*. 2004; 32(9):1922–1927. [PubMed: 15343023]
- Engli M, Kirsivali-Farmer K. Needs of family members of critically ill patients with and without acute brain injury. *Journal of Neuroscience Nursing*. 1993; 25(2):78–85. [PubMed: 8478558]
- Gerstel E, Engelberg RA, Koepsell T, Curtis JR. Duration of withdrawal of life support in the intensive care unit and association with family satisfaction. *American Journal of Respiratory and Critical Care Medicine*. 2008; 178(8):798–804. [PubMed: 18703787]
- Gries CJ, Curtis JR, Wall RJ, Engelberg RA. Family member satisfaction with end-of-life decision making in the ICU. *Chest*. 2008; 133(3):704–712. [PubMed: 18198256]
- Henrich NJ, Dodek P, Heyland D, Cook D, Rocker G, Kutsogiannis D, et al. Qualitative analysis of an intensive care unit family satisfaction survey. *Critical Care Medicine*. 2011; 39(5):1000–1005. [PubMed: 21283004]
- Heyland DK, Tranmer JE. Measuring family satisfaction with care in the intensive care unit: The development of a questionnaire and preliminary results. *Journal of Critical Care*. 2001; 16(4):142–149. [PubMed: 11815899]
- 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. *Critical Care Medicine*. 2002; 30(7):1413–1418. [PubMed: 12130954]
- Heyland DK, Rocker GM, O'Callaghan CJ, Dodek PM, Cook DJ. Dying in the ICU: perspectives of family members. *Chest*. 2003; 124(1):392–397. [PubMed: 12853551]
- Hinkle JL, Fitzpatrick E, Oskrochi GR. Identifying the perception of needs of family members visiting and nurses working in the intensive care unit. *Journal of Neuroscience Nursing*. 2009; 41(2):85–91. [PubMed: 19361124]
- Hunziker S, McHugh W, Sarnoff-Lee B, Cannistraro S, Ngo L, Marcantonio E, Howell MD. Predictors and correlates of dissatisfaction with intensive care. *Critical Care Medicine*. 2012; 40(5):1554–1561. [PubMed: 22511136]
- Kentish-Barnes N, Lemiale V, Chaize M, Pochard F, Azoulay E. Assessing burden in families of critical care patients. *Critical Care Medicine*. 2009; 37(10 Suppl):S448–S456. [PubMed: 20046134]
- Lederer MA, Goode T, Dowling J. Origins and development: the Critical Care Family Assistance Program. *Chest*. 2005; 128(3 Suppl):65S–75S. [PubMed: 16174809]
- Levy M. Including families in quality measurement in critical care. *Critical Care Medicine*. 2007; 35(1):324–325. [PubMed: 17197788]
- Molter NC. Needs of relatives of critically ill patients: a descriptive study. *Heart & Lung : the Journal of Critical Care*. 1979; 8(2):332–339. [PubMed: 253712]
- Multz AS, Chalfin DB, Samson IM, Dantzker DR, Fein AM, Steinberg HN, et al. A "closed" medical intensive care unit (MICU) improves resource utilization when compared with an "open" MICU. *American Journal of Respiratory and Critical Care Medicine*. 1998; 157(5 Pt 1):1468–1473. [PubMed: 9603125]
- Prachar TL, Mahanes D, Arceneaux A, Moss BL, Jones S, Conaway M, Burns SM. Recognizing the needs of family members of neuroscience patients in an intensive care setting. *Journal of Neuroscience Nursing*. 2010; 42(5):274–279. [PubMed: 20968223]
- Radwin LE, Ananian L, Cabral HJ, Keeley A, Currier PF. Effects of a patient/family-centered practice change on the quality and cost of intensive care: research protocol. *Journal of Advanced Nursing*. 2011; 67(1):215–224. [PubMed: 21077929]
- Rothen HU, Stricker KH, Heyland DK. Family satisfaction with critical care: measurements and messages. *Current Opinion in Critical Care*. 2010; 16(6):623–631. [PubMed: 20736823]
- Scheunemann LP, McDevitt M, Carson SS, Hanson LC. Randomized, controlled trials of interventions to improve communication in intensive care: a systematic review. *Chest*. 2011; 139(3):543–554. [PubMed: 21106660]

- Shelton W, Moore CD, Socaris S, Gao J, Dowling J. The effect of a family support intervention on family satisfaction, length-of-stay, and cost of care in the intensive care unit. *Critical Care Medicine*. 2010; 38(5):1315–1320. [PubMed: 20228678]
- Stricker KH, Niemann S, Bugnon S, Wurz J, Rohrer O, Rothen HU. Family satisfaction in the intensive care unit: cross-cultural adaptation of a questionnaire. *Journal of Critical Care*. 2007; 22(3):204–211. [PubMed: 17869970]
- van der Sluis FJ, Slagt C, Liebman B, Beute J, Mulder JWR, Engel AF. The impact of open versus closed format ICU admission practices on the outcome of high risk surgical patients: a cohort analysis. *BMC Surgery*. 2011; 11:18. [PubMed: 21861878]
- Wall RJ, Curtis JR, Cooke CR, Engelberg RA. Family satisfaction in the ICU: differences between families of survivors and nonsurvivors. *Chest*. 2007a; 132(5):1425–1433. [PubMed: 17573519]
- 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. *Critical Care Medicine*. 2007b; 35(1):271–279. [PubMed: 17133189]

**Table 1**

## Participating patient demographics

Characteristic	Neuro ICU	MICU
Number	79	45
Mean age (SD)	58.1 (17.1)	62.5 (16.7)
Number of females (%)	45 (57.0)	17 (38.0)
Race		
White	71 (90.0)	36 (80.0)
Black	2 (2.5)	2 (4.4)
Asian	2 (2.5)	2 (4.4)
Other	1 (1.3)	2 (4.4)
Unavailable	3 (3.8)	3 (6.7)
Mean length of admission in days (SD)	3.4 (4.4)	5.4 (6.8)
Neuro ICU diagnoses (%)		
Ischemic stroke	18 (22.8)	
Brain tumor	17 (21.5)	
Unruptured aneurysm	11 (13.9)	
Subarachnoid hemorrhage	9 (11.4)	
Subdural/epidural hemorrhage	6 (7.6)	
Intraparenchymal hemorrhage	5 (6.3)	
Seizure	5 (6.3)	
Spinal cord disease	3 (3.8)	
Infection	1 (1.3)	
Other	4 (5.1)	
MICU diagnoses (%)		
Pulmonary		14 (31.1)
Gastrointestinal		9 (20.0)
Infectious Disease		7 (15.6)
Hematologic/oncologic		4 (8.9)
Cardiac		3 (6.7)
Endocrine		3 (6.7)
Other		5 (11.1)
*Number of major co-morbid conditions (%)		
None	24 (30.4)	16 (35.6)
One	23 (29.1)	12 (26.7)
Two	15 (19.0)	6 (13.3)
Three or more	17 (21.5)	11 (24.4)

SD = standard deviation.

\* Major co-morbid conditions: atrial fibrillation; chronic obstructive pulmonary disease; cancer; congestive heart failure; coronary artery disease; diabetes mellitus; hypercholesterolemia; hypertension; history of ischemic stroke, transient ischemic attack, or intracerebral hemorrhage.

**Table 2**

## Survey respondent demographics

Characteristic	Neuro ICU	MICU
	<i>n</i> (%)	<i>n</i> (%)
Total	79	45
Female	50 (63.3)	29 (64.4)
Race		
White	67 (84.8)	34 (75.6)
Black	1 (1.3)	2 (4.4)
Asian	1 (1.3)	1 (2.2)
Health care proxy	50 (63.3)	28 (62.2)
Relationship to patient		
Child	34 (43.0)	17 (37.8)
Spouse	26 (32.9)	17 (37.8)
Parent	10 (12.7)	4 (8.9)
Sibling	5 (6.3)	2 (4.4)
Partner	1 (1.3)	4 (8.9)
English as first language	69 (87.3)	37 (82.2)
Level of education		
High school	9 (11.4)	8 (17.8)
College	41 (51.9)	17 (37.8)
Graduate degree	17 (21.5)	12 (26.7)
Commute time to hospital		
Less than 30 minutes	26 (32.9)	17 (37.8)
30 minutes to 1 hour	26 (32.9)	16 (35.6)
Greater than 1 hour	20 (25.3)	4 (8.9)
Prior experience with family member admitted to an ICU	44 (55.7)	27 (60.0)
Living with patient prior to admission	39 (49.4)	26 (57.8)
If respondent not living with patient, frequency of seeing patient prior to admission		
More than weekly	12 (30.0)	7 (36.8)
Weekly	10 (25.0)	3 (15.8)
Monthly	8 (20.0)	3 (15.8)
Yearly	7 (17.5)	4 (21.1)
Number of "core" family members visiting patient in hospital		
1 (respondent only)	4 (5.1)	6 (13.3)
2-3	34 (43.0)	15 (33.3)
4-6	26 (32.9)	15 (33.3)
Greater than 6	7 (8.9)	3 (6.7)
Hours per day spent by respondent with patient in hospital		
Less than 1	0 (0)	1 (2.2)
1	3 (3.8)	1 (2.2)
2	8 (10.1)	4 (8.9)

	<b>Neuro ICU</b>	<b>MICU</b>
3	8 (10.1)	5 (11.1)
Greater than 3	53 (67.1)	28 (62.2)
Number of formal family meetings during patient's ICU admission		
0	36 (45.6)	16 (35.6)
1	8 (10.1)	9 (20.0)
2	8 (10.1)	1 (2.2)
3	6 (7.6)	2 (4.4)
Greater than 3	12 (15.2)	10 (22.2)

Responses of "Other" and blank responses are not shown in table. This percentage for any given question did not exceed 18.0%.

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**Table 3**

Family satisfaction with general care

Variable	Number of responses to item (n)		Complete satisfaction (%)		p
	Neuro ICU (total = 79)	MICU (total = 45)	Neuro ICU	MICU	
<i>Patient care perceived by family members</i>					
Concern and caring by ICU staff	75	44	80.0	90.9	0.13
Management of pain	76	43	71.1	76.7	0.53
Management of breathlessness	54	35	79.6	85.7	0.58
Management of agitation	58	36	67.2	83.3	0.10
Coordination of care	77	44	70.1	81.8	0.20
Competence of nurses	76	45	81.6	93.3	0.10
Competence of physicians	74	43	79.7	88.4	0.31
Amount of health care received in ICU	79	45	55.7	60.0	0.71
<i>Care of family members by ICU staff</i>					
Interest in needs	74	44	74.3	77.3	0.83
Emotional support	74	41	64.9	68.3	0.84
Concern and caring of family members by members by ICU staff (courtesy, respect, compassion)	76	41	76.3	92.7	0.04
Frequency of communication with ICU nurses	77	45	70.1	73.3	0.84
<i>Facility</i>					
Atmosphere in the ICU	77	45	72.7	64.4	0.41
Atmosphere in the waiting room	74	41	47.3	58.5	0.33

**Table 4**

Selected family characteristics that correlate with complete satisfaction with concern and caring towards family members by Neuro ICU staff

<b>Variable</b>	<b>Odds ratio</b>	<b>95% Confidence interval</b>	<b><i>p</i></b>
Living with patient prior to admission	3.70	1.18–11.62	0.03
Four to six “core” family members visiting patient in hospital	13.64	1.70–109.11	0.01
Not living with patient prior to admission	0.27	0.086–0.85	0.03
Zero formal family meetings during patient’s ICU admission	0.28	0.094–0.85	0.03

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**Table 5**

## Family satisfaction with decision making

Variable	Number of responses to item (n)		Complete satisfaction (%)		p
	Neuro ICU (total = 79)	MICU (total = 45)	Neuro ICU	MICU	
Frequency of communication by ICU doctors	73	45	46.6	57.8	0.26
Ease of getting information	79	45	70.9	64.4	0.55
Understanding of information	79	45	74.7	71.1	0.68
Honesty of information	79	45	74.7	80.0	0.66
Completeness of information	79	45	64.6	71.1	0.55
Consistency of information	75	45	64.0	62.2	0.85
Inclusion in decision making	78	42	52.6	52.4	1.00
Support during decision making	75	43	44.0	51.2	0.57
Control over the care	76	43	54.0	65.1	0.25
Time to address concerns and questions when making decisions	71	43	98.6	93.0	0.15

**Table 6**

Selected family characteristics that correlate with satisfaction ratings of aspects of ICU decision making

<b>Variable</b>	<b>Odds ratio</b>	<b>95% Confidence interval</b>	<b><i>p</i></b>
<i>Parent of patient</i>			
Very satisfied with inclusion in decision making	5.19	1.09–24.80	0.04
Very satisfied with support during decision making	3.91	1.002–15.28	0.05
<i>High school level of education</i>			
Completely satisfied with frequency of ICU physician communication	4.07	1.24–13.34	0.02
<i>More than 3 formal family meetings during ICU admission</i>			
Completely satisfied with frequency of ICU physician communication	2.67	1.002–7.10	0.05
<i>Zero formal family meetings during ICU admission</i>			
Feeling complete control over care that family members received	0.43	0.20–0.90	0.03