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Surrogate Satisfaction with Decision Making after Intracerebral Hemorrhage

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Abstract

Background/Objective: Surrogate decision makers for patients with intracerebral hemorrhage (ICH) are frequently asked to make difficult decisions on use of life-sustaining treatments. We explored ICH surrogate satisfaction with decision making and experience of decision regret using validated measures in a prospective multicenter study.

Methods: Cases of non-traumatic ICH were enrolled from 3 hospitals (September 2015 to December 2016) and surrogate decision makers were invited to complete a self-administered survey. The primary outcome was the 10-item decision making subscale of the Family Satisfaction in the Intensive Care Unit scale (FSICU-DM, range 0–100, higher is greater satisfaction), and the secondary outcome was the decision regret scale (range 0–100, higher is greater regret). Linear regression models were used to assess the association between satisfaction with decision making and pre-specified covariates using manual backwards selection.

Results: A total of 73 surrogates were approached for participation (in person or mail), with 48 surrogates returning a completed survey (Median surrogate age 60.5 years, 63% female, 77% White). Patients had a median age of 72.5, 54% were female, with a median admission Glasgow coma scale of 10, in-hospital mortality of 31%, and 56% with an in-hospital DNR order. Physicians commonly made treatment recommendation (>50%) regarding brain surgery or

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transitions to comfort measures, but rarely made recommendations (<20%) regarding DNR orders. Surrogate satisfaction with decision making was generally high (median FSICU-DM 85, IQR 57.5–95). Factors associated with higher satisfaction on multivariable analysis included greater use of shared decision making (P<0.0001), younger patient age (p=0.02), ICH score of 3 or higher (p=0.03), and surrogate relationship (spouse vs. other, p=0.02). Timing of DNR orders was not associated with satisfaction (P>0.25). Decision regret scores were generally low (median 12.5, IQR 0–31.3).

Conclusions: Considering the severity and abruptness of ICH, it is reassuring that surrogate satisfaction with decision making was generally high and regret was generally low. However, more work is needed to define the appropriate outcome measures and optimal methods of recruitment for studies of surrogate decision makers of ICH patients.

Keywords

Cerebral Hemorrhage; Critical Care; Resuscitation Orders; Family Satisfaction; Family Research

I. Introduction

Intracerebral hemorrhage (ICH) is known to have a high risk of early death and poor long term functional outcome, although most deaths after ICH occur after a decision is reached to limit the intensity of treatment.[1] Due to the severity of patient impairment, these life and death decisions to either continue or limit life-sustaining treatments are typically made by a surrogate decision maker.

Serving as a surrogate decision maker is challenging for many family members for multiple reasons, in particular the emotional burden which can result in post-traumatic stress or complicated grief.[2,3] Thus, there is an urgent need for further study of surrogate decision makers of patients with severe acute brain injury such as ICH. Previous studies have examined family satisfaction in the ICU,[4,5] though only a limited number of studies[3,6,7] have specifically focused on individuals with acute neurologic disease such as ICH. Given the sudden unexpected onset, high early mortality, and frequent early decisions to limit the intensity of treatment, the experience of ICH surrogates may be different than surrogates of other seriously ill patients. Thus, we conducted this study to assess the process of decision making and outcomes of decision satisfaction and decision regret among surrogate decision makers in ICH.

II. Methods

Participant Eligibility and Recruitment

ICH cases were enrolled prospectively from September 2015 to December 2016 at three hospitals across three states (one additional site did not enroll any participants). Eligible patients were hospitalized with a non-traumatic ICH, had to be over the age of 44 (to maintain consistency across sites as one site recruited from an ongoing stroke surveillance study[8] with this restriction), and required a surrogate decision maker. Surrogates needed to be over the age of 18 and able to communicate in English, with enrollment limited to one surrogate per patient.

Precise method of recruitment and consent varied slightly by study site due to differences in staff availability and institutional review board (IRB) requirements across sites. In general, surrogates were recruited in-person or by mail to complete a self-administered written survey about decision making. Surrogates recruited in-person signed an informed consent form for their own participation and also for patient medical record review. Surrogates recruited by mail were enrolled under an IRB-approved waiver of documentation of consent and waiver of consent for patient record review. In the event of known patient death, attempts at contacting the surrogate were delayed for at least 4 weeks as is standard in research for bereaved family members.[9] Surrogates received a $20 incentive for participation (pre-paid for mail recruitments).

Chart Abstraction and Survey Measures

The medical record was reviewed for key patient characteristics and hospitalization details such as co-morbidities, ICH characteristics, and use of life-sustaining treatments. Glasgow coma scale (GCS) score was assessed at the time of hospital admission consistent with the timing in the original ICH score development.[10] A written self-administered survey for surrogate decision makers contained a combination of validated measures, as well as original items assessing the scope of decisions and physician recommendations based on prior qualitative work.[11] The written survey was pilot tested in 10 surrogates to check clarity and acceptability of the questions, with minor updates to the survey items made based on the pilot. Due to changes in survey content, pilot survey data are not presented.

The pre-specified primary outcome for the survey study was the 10-item decision making subscale of the Family Satisfaction in the Intensive Care Unit scale (FSICU-DM, range 0–100, higher indicates greater satisfaction).[12] The FSICU-DM assesses domains such as physician and staff communication, consistency and completeness of information, and support in decision making. The pre-specified secondary outcome was a modified version of the decision regret scale (DRS).[13] The DRS includes items assessing whether the individual feels they made the right decision, a wise decision, regret the choice, and would do the same thing again. Minor modifications to the wording of the original DRS were made to adapt use for surrogates of ICH patients. First, the item “The choice did me a lot of harm” was removed (rescaling the total score to 0–100) over concerns that this item could be considered insensitive if the patient had died and also potential confusion whether the patient or surrogate is the appropriate reference for this item. Second, the original DRS starts with a prompt asking the respondent to focus on a single specific decision: “Please think about the decision you made about _____” However, in prior qualitative semi-structured interviews with over 50 ICH surrogates preparatory to this survey,[11] we learned that many surrogates discussed a variety of possible treatment decisions with the medical team. Furthermore, some surrogates did not seem to consider some of these conversations with the medical team to be a “decision” in the same way that the health care team did. Therefore, the DRS items were preceded by several questions about “conversations” that they had with the healthcare team on 3 common decisions from our prior qualitative work: Brain surgery, do-not-resuscitate (DNR) orders, and transitions to comfort care. Several questions followed each item, such as who participated in these conversations, and whether or not the doctor made a recommendation for the treatment. Then surrogates were asked “Which of these decisions

… did you consider to be the hardest decision ?" with response options of "Performing brain surgery"; "Deciding about a do-not-resuscitate (DNR) order"; "Changing treatment goals to comfort care, palliative care, or hospice"; "We did not discuss any of these"; or "I did not find any of these decisions particularly hard". Surrogates were then asked to reflect on the hardest decision when answering the DRS. The FSICU-DM and the DRS were both scaled to a range from 0–100 with higher numbers indicating greater decision satisfaction or regret.

Shared decision making was assessed with the CollaboRATE scale,[14] which consists of three items asking how much effort was made to understand the patient's health issues, to listen to the things that matter most, and to include what matters most in choosing what to do next. Responses were collected on a 10-point scale with anchors of "0 - No effort was made" and "9 - Every effort was made" and a total score calculated by taking the average of the three items (range 0–9, higher scores indicate greater shared decision making). Religious affiliation and religious importance were also assessed with standard measures.[15]

Statistical Analysis

Study data were collected and managed using REDCap[16] electronic data capture tools hosted at the University of Michigan, and analysis was performed using SAS software, Version 9.4 (SAS Institute, Inc., Cary, NC). Descriptive statistics summarizing characteristics of patients and surrogates were calculated with median and interquartile range (IQR) for continuous variables, or frequencies and percentages for categorical variables. Due to delays in early stages of the project and slower than expected recruitment, the study was ended after receiving 48 completed surveys.

Linear regression models were used to assess the association between FSICU-DM and other covariates. The list of potential covariates was selected based on known or possible associations with family member satisfaction, as well as completeness and distribution of the responses. Candidate variables considered for inclusion in the multivariable model were patient and surrogate age (continuous and mean-centered) and sex, patient vital status at the time of survey (alive vs. dead), severe ICH (ICH score of >=3 vs <3),[10] shared decision making (collaboRATE, continuous and mean centered), patient pre-stroke advance directive (yes vs. no); relationship of patient and surrogate (spouse vs. other); whether the patient lived with the surrogate before the stroke (yes vs. no); DNR orders (categorized as early: day 0 or 1; late: day 2 or later; or none).[17] Unadjusted linear regression models were estimated for each of the candidate covariates. A multivariable linear regression model was estimated with manual backward selection, starting with potentially modifiable factors (e.g. collaboRATE scale, DNR timing, and presence of advance directives) as well as other characteristics selected based on either prior literature or unadjusted association with satisfaction (patient age/sex, patient vital status at time of survey, surrogate relationship, and severe ICH). The final multivariable model included collaboRATE, DNR timing, patient age, severe ICH, and surrogate relationship. A similar regression analysis of decision regret was originally planned, but deferred due to the smaller than expected final sample size and proportion of respondents who were unable to identify a single decision to use in the stem of the DRS. Therefore, the DRS is presented descriptively by classification of hardest decision.

IRB Approval and Consent

This study was approved by the IRB of the University of Michigan and the enrolling hospital systems. All participants either provided written informed consent or were enrolled under an IRB-approved waiver of consent or waiver of documentation of consent.

III. Results

A total of 130 patients were identified as eligible from September 2015 through December 2016. Of these, 57 were missed for enrollment (most commonly due to not having a surrogate at the bedside when study staff was able to approach), 10 were approached in-person and refused participation, and 63 were given a survey either in-person or by mail. In the end, 48/130 (37%) of the total population and 48/63 (76%) of those approached for enrollment returned a completed survey and were included in the study. Descriptive characteristics of the study population of surrogate decision makers can be found in Table 1, and patients in Table 2. Patients and surrogates were mostly women and predominantly white, and surrogates were most commonly the spouse followed by the child of the patient. Patients had fairly severe ICH (median GCS of 10, intraventricular hemorrhage in half) with an in-hospital mortality of 31% and 60% of patients alive at the time the surrogate completed the survey.

Surrogates' descriptions of the decisions are shown in Table 3. Most surrogates (87%) reported discussing at least one of the three primary decisions of brain surgery, DNR orders, or comfort measures only with the doctors (40% discussed only one; 35% discussed two, and 13% discussed all three). Brain surgery and DNR orders were each reported as discussed by more than half of surrogates, while transition to comfort measures was discussed in less than half. Surrogates reported that physician recommendations were common (>50%) regarding decisions involving brain surgery or transitions to comfort measures, but rare (<20%) for DNR orders. Regarding the "hardest" decision, the most common response (27%) was that none of the 3 primary decisions were hard, followed by DNR orders (23%).

Details of responses to the individual items assessing surrogate satisfaction and regret are shown in the Supplemental Appendix. Surrogate satisfaction with decision making was generally high (median FSICU-DM 85, IQR 57.5–95). Regression analysis assessing factors associated with surrogate satisfaction with decision making is shown in Table 4. On unadjusted analysis, shared decision making (collboRATE), patient age, and sex were associated with satisfaction with decision making. The final multivariable model identified that higher satisfaction was associated with greater use of shared decision making, younger patient age, severe ICH, and surrogate relationship of spouse (vs. any other). Timing of DNR orders was not associated with satisfaction.

Levels of decision regret were found to be generally low (median DRS 12.5, IQR 0–31.3). While there was no statistically significant difference in decision regret depending on which decisions was the hardest (p=0.12, Kruskal-Wallis), regret was generally numerically lower among individuals who indicated that the hardest decision was transition to comfort

measures (median DRS 0, range 0–25, n=8) when compared with DNR orders (median DRS 25, range 0–43.75, n=11) or brain surgery (median DRS 25, range 0–62.6, N=7).

IV. Discussion

Overall, we found that surrogate decision makers of ICH patients reported relatively high levels of decision satisfaction and low levels of decision regret. We also found that decision satisfaction was generally higher for younger patients, more severe ICH cases, or if the surrogate was the spouse. The association of greater satisfaction with younger patients or more severe ICH could be explained if physicians take more time in counseling families with younger patients and more severe ICH cases. We also found that physician recommendations were relatively common for decisions on brain surgery or transitions to comfort measures only, but rare for decisions on DNR status. Currently, there are few, if any, standard protocols or scripts to guide physicians in how to have these difficult conversations. Surrogates are therefore potentially vulnerable to either undue physician influence on decision making (if unwanted recommendations are provided), or alternatively needing to seek additional guidance (if physicians leave the decisions to the surrogate).

The association of higher satisfaction with the use of shared decision making may represent an opportunity to improve satisfaction by enhancing the use of shared decision making in the ICU. In general, shared decision making has been promoted as a way to incorporate patient and family preferences into the customized treatment plan for an individual.[18] While greater use of shared decision making is generally a laudable goal, several challenges arise when applying shared decision-making principles to surrogate decisions on life-sustaining treatment in acute neurological injury. The challenges include helping surrogates work though potential conflicts between their own goals and values and those of the patient, as well as how to approach surrogates who may not want to share in these emotionally difficult decisions.[2,4,19] Thus, more work is needed on how to further develop the application of principles of shared decision making in acute neurologic injury to optimize outcomes among patients and family.

We did not find any impact of timing of DNR orders on surrogate satisfaction with decision making. Deferral of DNR orders for the first 48 hours has been recommended by national ICH guidelines.[20] However, the reasoning behind this recommendation was concerns over inappropriate early pessimistic prognostication and potential for a self-fulfilling prophecy, rather than concerns about surrogate outcomes. Still, it is somewhat reassuring that neither early initiation nor delay in DNR orders had any adverse effects on surrogate satisfaction.

Other studies have reported factors associated with family satisfaction in the ICU,[4,5,21,22] in general, or the neuro ICU more specifically.[6,7] Our work adds to the growing literature with more data specifically focused on ICH cases. These reports have also generally reported satisfaction to be high,[6,21,22] which may raise some concerns about the ability of this scale to assess the response to any improvement measures.[22] Similar to our findings, these prior reports have suggested that use of shared decision making is positively associated with FS-ICU scores.[4,5] Specific communication strategies such as honesty, accuracy, active listening, and respect have been shown to have a positive influence on family satisfaction.[5] In contrast,

incomplete information or difficulty interpreting information was associated with lower scores on the FS-ICU. We were unable to assess specific communication strategies in the current analysis, though a prior qualitative study conducted at these same sites identified the importance of receiving consistent information from the healthcare team to surrogates.[11]

We also examined decision regret, though we encountered a challenge in administering the DRS in this population where multiple overlapping decisions are made. Based on the low number of surrogates who were able to identify a single decision for the DRS, we did not conduct a multivariable analysis of predictors of regret. Typically, the DRS is limited to a single decision, though we wanted this study to be flexible enough to capture a broad range of decision making in ICH surrogates. Another group has recently reported a pilot study of decision regret among ICU surrogates.[23] However, in contrast to our design asking surrogates to identify the "hardest" decision, they asked surrogates to identify the "most important" decision. We were not able to incorporate a comparison of these two strategies of "hardest" vs "most important" for selection of the appropriate anchor for the DRS. We do note that 27% of surrogates in our study did not find any of the three primary decisions to be hard, which suggests that our strategy of asking surrogates to identify the hardest decision on a self-administered questionnaire may not be optimal.

Furthermore, surrogates in this study reported overall fairly low levels of decision regret, particularly among individuals reporting on decisions to transition to comfort measures. We did remove one item ("The choice did me a lot of harm") from the DRS due to concerns about sensitivity if the patient died, which may have artificially lowered the regret scores. Additionally, our surveys were generally conducted fairly early in the course of illness (median 12 days from ICH onset), which may have been too early for regret to have developed. Other studies of decision regret in critical illness[23,24] have reported similarly low levels of regret and also investigated regret fairly soon in the illness course. Low levels of regret in this setting could also be explained by cognitive dissonance theory, where individuals rationalize their choice by altering attitudes after making a decision that cannot be reversed.[25,26] Given the overall low levels of regret in this and other studies,[23,24] combined with challenges in anchoring the DRS to a single decision, the DRS may not be the optimal measure for use in surrogates of seriously ill high-mortality ICU patients, though more work in this area is needed to assess how regret may change over time and how patient outcome may influence regret. We have an ongoing study examining decision regret in stroke surrogate decision makers that will longitudinally assess regret at 3, 6, and 12 months and hopefully provide more insight into this issue.

The primary limitations in this study were challenges in recruitment that led to a small sample size and possible non-response bias. Recruitment and retention are common challenges in palliative care studies, with reasons for non-participation including patients feeling too sick, family disinterest, and perception of burden posed by being involved in the study.[27] Although we did not systematically collect data on reasons for refusal, anecdotally many of the non-participants appeared overwhelmed with the sudden, serious illness of a loved one. Therefore, it is possible that our sample was biased toward less severe patients or surrogates who were less overwhelmed, or more satisfied with their care, and therefore may have excluded those individuals in most need of help who may have had lower satisfaction

or higher levels of regret. Given the high early mortality and frequent early limitations in treatment intensity in ICH,[17,28] we intentionally sought to enroll individuals early in the hospital course. More work needs to be done to optimize the recruitment of family members into ICU research,[29] particularly among race-ethnic minority groups and those who may be overwhelmed with the shock of sudden illness of a loved one or struggling to balance their new role as a caregiver. Recall bias could be a concern, particularly for surveys completed later, though we attempted to time the surveys as soon as possible after the ICU stay. Additionally, the cross-sectional design of the study based on surrogate report is a limitation and we cannot be certain, for example, if the high satisfaction was due to use of shared decision making or if these factors were merely associated. Finally, other important surrogate factors such as education, anxiety, depression, or symptoms of post-traumatic stress[3] were not assessed in this study.

V. Conclusion

We found that satisfaction in decision making among surrogates of ICH patients was generally high and decision regret was generally low, which is encouraging given the challenges in caring for this acutely ill population. However, more work is needed to define the appropriate outcome measures and optimal methods of recruitment for studies of surrogate decision makers of ICH patients.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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References

1. Zurasky JA, Aiyagari V, Zazulia AR, Shackelford A, Diringer MN. Early mortality following spontaneous intracerebral hemorrhage. Neurology 2005;64:725–7. [PubMed: 15728302]
2. Wendler D, Rid A. Systematic review: the effect on surrogates of making treatment decisions for others. Ann Intern Med 2011;154:336–46. [PubMed: 21357911]
3. Trevick SA, Lord AS. Post-traumatic Stress Disorder and Complicated Grief are Common in Caregivers of Neuro-ICU Patients. Neurocrit Care 2017;26:436–43. [PubMed: 28054288]
4. Hinkle LJ, Bosslet GT, Torke AM. Factors associated with family satisfaction with end-of-life care in the ICU: a systematic review. Chest 2015;147:82–93. [PubMed: 25103451]
5. Salins N, Deodhar J, Muckaden MA. Intensive Care Unit death and factors influencing family satisfaction of Intensive Care Unit care. Indian J Crit Care Med 2016;20:97–103. [PubMed: 27076710]

6. Huang KB, Weber U, Johnson J, et al. Primary Care Physician Involvement in Shared Decision Making for Critically Ill Patients and Family Satisfaction with Care. J Am Board Fam Med 2018;31:64–72. [PubMed: 29330241]
7. Hwang DY, Yagoda D, Perrey HM, et al. Assessment of satisfaction with care among family members of survivors in a neuroscience intensive care unit. J Neurosci Nurs 2014;46:106–16. [PubMed: 24556658]
8. Zahuranec DB, Lisabeth LD, Sanchez BN, et al. Intracerebral hemorrhage mortality is not changing despite declining incidence. Neurology 2014;82:2180–6. [PubMed: 24838789]
9. Casarett D, Shreve S, Luhrs C, et al. Measuring Families' Perceptions of Care Across a Health Care System: Preliminary Experience with the Family Assessment of Treatment at End of Life Short Form (FATE-S). Journal of Pain and Symptom Management 2010;40:801–9. [PubMed: 20813493]
10. Hemphill JC 3rd, Bonovich DC, Besmertis L, Manley GT, Johnston SC. The ICH score: a simple, reliable grading scale for intracerebral hemorrhage. Stroke 2001;32:891–7. [PubMed: 11283388]
11. Zahuranec DB, Anspach RR, Roney ME, et al. Surrogate Decision Makers' Perspectives on Family Members' Prognosis after Intracerebral Hemorrhage. J Palliat Med 2018;21:956–62. [PubMed: 29608394]
12. 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;35:271–9. [PubMed: 17133189]
13. Brehaut JC, O'Connor AM, Wood TJ, et al. Validation of a decision regret scale. Med Decis Making 2003;23:281–92. [PubMed: 12926578]
14. Barr PJ, Thompson R, Walsh T, Grande SW, Ozanne EM, Elwyn G. The psychometric properties of CollaboRATE: a fast and frugal patient-reported measure of the shared decision-making process. J Med Internet Res 2014;16:e2.
15. Strawbridge WJ, Shema SJ, Cohen RD, Roberts RE, Kaplan GA. Religiosity buffers effects of some stressors on depression but exacerbates others. J Gerontol B Psychol Sci Soc Sci 1998;53:S118–26. [PubMed: 9602836]
16. Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)--a metadata-driven methodology and workflow process for providing translational research informatics support. J Biomed Inform 2009;42:377–81. [PubMed: 18929686]
17. Hemphill JC 3rd, Newman J, Zhao S, Johnston SC. Hospital usage of early do-not-resuscitate orders and outcome after intracerebral hemorrhage. Stroke 2004;35:1130–4. [PubMed: 15044768]
18. Cai X, Robinson J, Muehlschlegel S, et al. Patient Preferences and Surrogate Decision Making in Neuroscience Intensive Care Units. Neurocrit Care 2015;23:131–41. [PubMed: 25990137]
19. Braun UK, Naik AD, McCullough LB. Reconceptualizing the experience of surrogate decision making: reports vs genuine decisions. Ann Fam Med 2009;7:249–53. [PubMed: 19433843]
20. Hemphill JC 3rd, Greenberg SM, Anderson CS, et al. Guidelines for the Management of Spontaneous Intracerebral Hemorrhage: A Guideline for Healthcare Professionals From the American Heart Association/American Stroke Association. Stroke 2015;46:2032–60. [PubMed: 26022637]
21. Ferrando P, Gould DW, Walmsley E, et al. Family satisfaction with critical care in the UK: a multicentre cohort study. BMJ Open 2019;9:e028956.
22. Harrison DA, Ferrando-Vivas P, Wright SE, McColl E, Heyland DK, Rowan KM. Psychometric assessment of the Family Satisfaction in the Intensive Care Unit questionnaire in the United Kingdom. Journal of Critical Care 2017;38:346–50. [PubMed: 27914907]
23. Miller JJ, Morris P, Files DC, Gower E, Young M. Decision conflict and regret among surrogate decision makers in the medical intensive care unit. Journal of Critical Care 2016;32:79–84. [PubMed: 26810482]
24. Hickman RL Jr., Daly BJ, Lee E. Decisional conflict and regret: consequences of surrogate decision making for the chronically critically ill. Appl Nurs Res 2012;25:271–5. [PubMed: 21658906]
25. Brehm JW. Postdecision changes in the desirability of alternatives. J Abnorm Psychol 1956;52:384–9. [PubMed: 13318848]

26. Jarcho JM, Berkman ET, Lieberman MD. The neural basis of rationalization: cognitive dissonance reduction during decision-making. Soc Cogn Affect Neurosci 2011;6:460–7. [PubMed: 20621961]

27. LeBlanc TW, Lodato JE, Currow DC, Abernethy AP. Overcoming recruitment challenges in palliative care clinical trials. J Oncol Pract 2013;9:277–82. [PubMed: 24130254]

28. Zahuranec DB, Brown DL, Lisabeth LD, et al. Early care limitations independently predict mortality after intracerebral hemorrhage. Neurology 2007;68:1651–7. [PubMed: 17502545]

29. Dotolo D, Nielsen EL, Curtis JR, Engelberg RA. Strategies for Enhancing Family Participation in Research in the ICU: Findings From a Qualitative Study. J Pain Symptom Manage 2017;54:226–30 e1. [PubMed: 28438584]

Table 1:

Surrogate decision maker characteristics

Characteristic	Surrogate % or Median (IQR)
Age	60.5 (52,73)
Female	63%
Race-Ethnicity	
White	77%
Black	4%
Hispanic	8%
Other	6%
Missing/Refused	4%
Surrogate is Patient's	
Spouse	44%
Child	46%
Parent/Other	10%
Religious affiliation	
Roman Catholic	33%
Other Christian	42%
Jewish	2%
Muslim	2%
None	15%
Missing	3%
Religious importance[1]	69%
Days from admission to survey	12 (3.5, 66)
Survey completed on or after day of hospital discharge	56%
Survey completed on or after day of intensive care unit discharge[2]	73%
Patient alive at time of survey	60%
Surrogate lived with patient	50%
Surrogate reported that the patient had an advanced directive	60%

[1]Based on response to question "How important are your religious or spiritual beliefs as a source of meaning to your life?" The percentage indicates the proportion who responded, "Fairly important" or "Very important".

[2]Estimated by comparing the intensive care unit length of stay to the number of days between admission and survey completion

Table 2:

Patient characteristics

Characteristic	Patient % or Median (IQR)
Age	72.5 (63.5, 81.5)
Female	54%
Race-ethnicity	
White	83%
Black	4%
Hispanic	4%
Other	4%
Missing/Refused	4%
Prior ICH	8%
Hypertension	85%
Atrial Fibrillation	19%
Dementia	17%
Diabetes	21%
Intraventricular hemorrhage	52%
Admission Glasgow Coma Scale	10 (6.5, 14)
ICH volume (in cc)[1]	25 (13, 39)
ICH Score[1]	
0	13%
1	13%
2	40%
3	30%
4	6%
Hospital length of stay (days)	10 (6, 17.5)
Discharge Disposition	
Home	4%
Rehab or Nursing Facility	46%
Hospice (facility or home)	19%
Deceased	31%
DNR orders and timing	
Early DNR (Day 0 or 1)	33%
Late DNR (Day 2 or later)	23%
No	44%
Tracheostomy	16%
Feeding Tube	35%
Any brain surgery (e.g. hematoma evacuation, or ventricular drain)	35%

[1]Exact ICH volume missing in one case, though it was estimated as <30cc in the radiology report and thus an ICH score was still calculated for this patient.

Table 3:

Surrogate report on treatment decisions discussed with doctors

Treatment	N(%)
Doctor discussed possibility of brain surgery	27/48 (56%)
Doctor recommendations about brain surgery[1]	
Recommended brain surgery	9/27 (33%)
Recommended against brain surgery	7/27 (26%)
No recommendation	7/27 (26%)
Not sure	3/27 (11%)
Doctor discussed DNR orders	26/48 (54%)
Doctors recommendation about DNR orders	
Recommended DNR	2/26 (8%)
Recommended against DNR	2/26 (8%)
No recommendation	17/26 (65%)
Not sure	5/26 (19%)
Doctor discussed making comfort care the main goal[2]	18 (38%)
Doctor recommendation for comfort care	
Recommended comfort care	12/18 (67%)
Recommended against comfort care	0/18 (0%)
No recommendation	4/18 (22%)
Not sure	2/18 (11%)
Hardest Decision	
Brain surgery	7/48 (15%)
DNR order	11/48 (23%)
Comfort measures only	8/48 (17%)
None of these were hard	13/48 (27%)
Did not discuss any of these	6/48 (13%)
Missing	3/48 (6%)

[1]The section on brain surgery included introductory text defining brain surgery as, "…any procedures to either remove the blood or blood clot, or to place a small tube in the brain to relieve pressure or drain fluid (*sometimes called a ventriculostomy or shunt).*"

[2]Given the variety of terms use by patients and families, the section on comfort care was preceded by introductory text, "For some people, the goals of treatment focus on keeping them comfortable rather than keeping them alive longer. This is sometimes called comfort care, palliative care, or hospice."

Table 4:

Factors associated with surrogate satisfaction with decision making

	Unadjusted beta (SE)	P	Adjusted beta[1] (SE)	P
Shared decision making (collaboRATE scale)	7.3 (0.78)	<0.0001	7.1 (0.78)	<0.0001
DNR Timing Early vs none Late vs none	0.19 (7.9) −16.7 (8.9)	0.98 0.07	5.8 (5.1) −3.0 (5.1)	0.26 0.57
Patient Age (per 10 years)	−6.0 (2.7)	0.03	−4.1(1.7)	0.02
Severe ICH (ICH score 3 or higher)	11.9 (7.2)	0.11	10.5 (4.6)	0.03
Surrogate is Spouse (vs. any other relationship)	−6.8 (7.2)	0.35	10.9 (4.6)	0.02
Patient Female (vs. male)[2]	18.3 (6.6)	0.008		
Patient Alive at time of Survey	10.1 (7.1)	0.16		
Surrogate Age (per 10 year)	−1.6 (2.4)	0.51		
Surrogate Female (vs. Male)	−0.60 (7.43)	0.93		
Surrogate reported that patient had Advance Directive	−1.57 (7.3)	0.83		
Did surrogate Live with patient prior to stroke	−3.4 (7.1)	0.64		

[1]For the adjusted model, Intercept=65.3 and adjusted R-squared=0.73. Continuous variables (age and collaboRATE score were centered at the mean value). Note that N=45 for the adjusted model due to missing data for FSICUDM in 1 case and collaboRATE score in 2 cases. Beta >0 indicates a positive association with FSICUDM, and a beta <0 indicates a negative association with FSICUDM.

[2]Although patient sex was associated with satisfaction on unadjusted analysis, it was no longer associated after adjustment for other factors and was dropped from the final model.