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Do they have a choice? Surrogate decision-making after severe acute brain injury

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Abstract

Objective: In the early phase of severe acute brain injury (SABI), surrogate decision-makers must make treatment decisions in the face of prognostic uncertainty. Evidence-based strategies to communicate uncertainty and support decision-making are lacking. Our objective was to better understand surrogate experiences and needs during the period of active decision-making in SABI, to inform interventions to support SABI patients and families and improve clinician-surrogate communication.

Design: We interviewed surrogate decision-makers during patients' acute hospitalization for SABI, as part of a larger (n=222) prospective longitudinal cohort study of patients with SABI and their family members. Constructivist grounded theory informed data collection and analysis.

Setting: One U.S. academic medical center.

Patients: We iteratively collected and analyzed semi-structured interviews with 22 surrogates for 19 patients.

Measurements and Main Results: Through several rounds of coding, interview notes, reflexive memos, and group discussion, we developed a thematic model describing the relationship

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between surrogate perspectives on decision-making and surrogate experiences of prognostic uncertainty. Patients ranged from 20–79 years of age (mean=55 years) and had primary diagnoses of stroke (n=13; 68%), traumatic brain injury (n=5; 26%) and anoxic brain injury after cardiac arrest (n=1; 5%). Patients were predominantly male (n=12; 63%), while surrogates were predominantly female (n=13; 68%). Two distinct perspectives on decision-making emerged: one group of surrogates felt a clear sense of agency around decision-making, while the other group reported a more passive role in decision-making, such that they did not even perceive there being a decision to make. Surrogates in both groups identified prognostic uncertainty as the central challenge in SABI, but they managed it differently. Only surrogates who felt they were actively deciding described time-limited trials as helpful.

Conclusions: In this qualitative study, not all surrogate "decision-makers" viewed themselves as making decisions. Nearly all struggled with prognostic uncertainty. Our findings underline the need for longitudinal prognostic communication strategies in SABI targeted at surrogates' current perspectives on decision-making.

Keywords

Prognosis; communication; clinical decision-making; acute brain injuries; neurology

Introduction

Severe acute brain injury (SABI) encompasses brain illnesses and injuries that occur suddenly, cause decreased consciousness in the acute period, and can result in dramatic, lifelong neurologic disability.[1] Patients with SABI and their loved ones have unique palliative care needs due to several interrelated challenges. Prognosis in brain injury is complex and includes not only survival but also functional status and cognition;[2] time to recovery after SABI is prolonged, and the extent of recovery typically uncertain, especially in the first few weeks.[3,4] Additionally, patients generally cannot communicate their wishes in the acute period when initial decisions about life-sustaining therapy (LST) are made, leaving decision-making in the hands of patients' loved ones, who assume the role of surrogate decision-makers ("surrogates") while simultaneously grieving.[5] These challenges illustrate the need to integrate palliative care into the management of patients with SABI.[5–7] Doing so requires a deep understanding of the unique needs and experiences of patients' surrogates, which only a few qualitative studies to date have explored.[5,8]

As part of a larger prospective study at one academic medical center, we interviewed surrogate decision-makers for patients with SABI during the acute hospitalization.[9,10] A previous qualitative study of this cohort described the role of family presence at the bedside, comparing interviews occurring before and after COVID-19 visitation restrictions.[11] The present study explored themes that emerged during an in-depth-analysis of all of the family interviews. Our primary objective was to describe surrogate experiences of decision-making and provider-surrogate communication in SABI. As a secondary objective, we aimed to construct an explanatory framework by which to understand these experiences.

Materials and Methods

Study Design

Participants were identified from a larger single-center prospective longitudinal cohort study of patients with SABI (n=222) and their family members (n=278).[9,10] Eligible patients had been admitted to the intensive care unit with a severe acute brain injury (SABI), defined as stroke, traumatic brain injury, or hypoxic ischemic encephalopathy after cardiac arrest, and had both a Glasgow Coma Scale (GCS) score of 12 or less after hospital day 2 and a family member available. Given that the focus of this study was to better understand the experience in the intensive care unit at the time of active decision-making, we excluded patients for whom a decision had already been made to pursue comfort measures only.

Participants for this qualitative study were selected purposively using maximum variation sampling with the goal of ensuring that participants represented a range of patient characteristics that included age (range 20–79 years), disease category (stroke, traumatic brain injury, hypoxic-ischemic brain injury after cardiac arrest) and patient-family relationship (spouse or partner, adult child, parent, or other). More participants were added throughout the study period until we reached thematic saturation.[12,13] Because the aim of this study was to not only describe decision-making and communication needs in SABI, but also to construct a theory that might provide an explanatory framework by which to understand these experiences, we used a grounded theory approach, including iterative data collection and analyses.[14] Because 4 of the 5 authors were physicians, the authors adopted a constructivist approach, in which the role of subjectivity in data gathering and analysis was acknowledged and researchers' underlying assumptions were examined as part of data interpretation.[15]

All family members were interviewed once. Patients' demographic and clinical information were abstracted from medical records, and surrogates provided demographic information via standardized questionnaires.

Standard Protocol Approvals, Registrations, and Patient Consents

Participants provided written consent to participate in the larger longitudinal study ("SuPPOrT study") and provided additional verbal consent to be interviewed. The SuPPOrTT study was approved by the University of Washington Institutional Review Board, STUDY00003393, date of initial approval 12/6/2017. Procedures were followed in accordance with the ethical standards of the University of Washington Institutional Review Board and with the Helsinki Declaration of 1975.

Interview questions

Interviews were semi-structured. The interviewers included a physician (C.J.C.) and PhD-trained behavioral scientist (M.H.). An interview guide was developed through literature search to focus on palliative and supportive care needs of patients and families specific to SABI and was further refined through expert guidance including input from a multidisciplinary group of Neurology and ICU nurses and physicians as well as qualitative researchers. Open-ended questions included one about the "worst part" of the SABI experience, as well as a question prompting families to share their experience with "a treatment decision" they had already made or were going to make. (Fig. 1). Digital recordings of the interviews were transcribed verbatim and then de-identified.

Qualitative analysis

Coding was completed in two rounds. First, two investigators (A.L.G., C.J.C.) read the transcripts and employed open coding to create tentative, content-driven categories that allowed us to identify themes in the data.[14] Through discussion between the two researchers and re-readings of the complete data set, these coding categories were refined. We then used axial coding to draw connections between coding categories, developing final coding categories supported by individual quotations. This final coding scheme was applied by the two coders (A.L.G., C.J.C.) in consensus. Finally, the two investigators presented the coding scheme and themes that were supported by these codes to a larger multidisciplinary team (including R.R.V., R.A.E.). In order to support trustworthiness, this team reached consensus about the themes and used selective coding to develop a core theory around "perspectives on decision-making" in SABI. In order to address subjectivity, investigators completed interview notes and reflexive memos to assess the role of underlying assumptions in interpretation.[15] In group discussions, the two neurologist authors (A.L.G., C.J.C.) and the non-neurologist authors (R.R.V, R.A.E, J.R.C.) reviewed reflexive memos and found slightly different interpretations of the role of prognostic uncertainty based on their professional experiences; discussion of these differences and identification of common themes led to clarification of the thematic model.

Results

Patients

We interviewed 22 surrogates for 19 patients (Table 1). The mean patient age was 55 years (range 20–79), and most were male (n=12; 63%). Patient diagnoses included stroke (all types, n=13), traumatic brain injury (n=5), and cardiac arrest (n=1).

Surrogates

The mean surrogate age was 51 years (range 22–76). Most were female (n=13; 59%). Initial interviews were conducted an average of 16 days after hospital admission (range 4–50).

Findings

Organizing Perspectives—We identified the following two distinct perspectives on shared decision-making in SABI:

1) Choosing: Surrogates with this perspective (n=10 surrogates, for 9 patients) described actively deliberating over important choices about continuation or withdrawal of LST. We labeled this perspective "*Choosing*" to reflect that these surrogates had a sense of agency in these decisions. For example:

> "The worst part is worrying about her and trying to make decisions about what she would want and the likelihood of her getting back to a life that would be acceptable to her."

2) No Choice: The other perspective on decision-making, held by 12 surrogates for 10 patients, was that there were no choices for them to make. It was clear from the context of the interview that from the standpoint of medical professionals, these surrogates *were* facing treatment decisions, such as around artificial feeding or tracheostomy; however, these 12 surrogates did not see themselves as making decisions and instead described an automatic acceptance of LST. Surrogates in this group answered questions about medical decisions in one of three ways: 1) they were so committed to their hope for recovery that they did not even notice when they were making decisions to pursue LST; 2) prognostic uncertainty precluded them from making treatment decisions, such that LST felt like the only available choice; or 3) they so favored LST that they did not wish to even discuss goals of care or treatment options with physicians. We labeled their shared perspective *"No choice."*

The first group of *no choice* surrogates held firmly to the possibility that their family member could recover; this strong hope or faith made it difficult to recognize or consider the option to withhold or withdraw LST:

Interviewer …You have made some treatment choices?

Surrogate Not yet.

Interviewer …Did she have a feeding tube?

Surrogate Yes…. And a trach.

Interviewer …Those might have been sort of treatment choices? But it maybe didn't feel like that to you?

Surrogate Well, I don't know. [Laughter] I didn't think of it as treatment choices, but I guess it was.

Interviewer Do you understand what sort of, what other options there are? I mean…either one would do the tracheostomy…or the alternative would be to focus on comfort and letting her go…

Surrogate Letting her go has not been an issue, that has not been an item at all… Because I have hope and I have faith…I believe she's going to get well. I believe she's going to recover.

The second category of *no choice* surrogates said that uncertainty about the long-term outcomes of SABI precluded any ability to make treatment decisions in the acute setting. For example, this surrogate:

> "We know exactly what [patient] of 12 days ago wanted… [but] we have yet to meet [patient] as he is now, or may be in the near future, or extended future for

> that matter. So, we don't know who that person is yet. And how can you make an intelligent decision for somebody that you don't know?"

A third group of *no choice* surrogates said that they had not had a formal discussion with providers about aligning treatment decisions with patients' goals of care, and they were grateful for that. For example, this surrogate interviewed on day 19 of hospitalization:

Interviewer You didn't go into a different room to sit down and talk, sort of big picture, sort of, we often call it a family meeting?

Male No. I think a lot of the social workers wanted to do that kind of thing, but I didn't really want to have much part of it. All I had interest in is who can save my wife's life. And I was possibly even rude… and I apologize for that. But that's not what I need right now. I need somebody with a bag of oxygen.

What these *no choice* surrogates shared was a perception that they had not engaged in active deliberation over treatment decisions for their loved ones because they did not perceive themselves as actively making treatment decisions.

After separating the *choosing* and *no choice* surrogates, textual analysis did not identify any substantial differences between groups in their diagnosis, severity of illness or degree of uncertainty in prognosis. Demographics for the two groups are illustrated in Table 1.

Perspectives, decision making and communication—Within these two perspectives, we identified two themes that illustrated similarities and differences between the *choosing* and *no choice* surrogates' experience of decision making and communication for their family member with SABI. These were: 1) *the struggle with prognostic uncertainty* and 2) *enacting patient wishes*.

The struggle with prognostic uncertainty

Whether prompted by our question "What is the worst part of this for you?" or unprompted, surrogates in both groups readily identified prognostic uncertainty as the greatest challenge they faced in SABI, but the impact of this prognostic uncertainty varied between the two groups. Surrogates with a *choosing* perspective identified uncertainty as the source of their struggle with making treatment choices. Surrogates with a *no choice* perspective saw prognostic uncertainty as an impediment to their ability to cope with and plan for what lay ahead. Representative quotations illustrating these two perspectives are represented in Table 2.

Regardless of group, participants talked about managing uncertainty with similar strategies: 1) avoiding thinking too far into the future; 2) trying to accept a less-than-ideal neurologic outcome; and 3) taking comfort in faith. However, only those surrogates with a *choosing* perspective described a "time-limited trial" as helpful (Table 3). A time-limited trial is an agreement between clinicians and a patient or family to use certain medical therapies for a defined period of time while monitoring the patient's response; if the patient improves, the therapy usually continues, but if the patient deteriorates, the therapies are generally withdrawn.[16] In our study, the surrogates with a *choosing* perspective felt that a time-limited trial would allow for greater clarity of prognosis, which would inform their decision-making. In contrast, surrogates with a *no choice* perspective tended to view LST as necessary unless the patient improved to the point of no longer needing them and therefore didn't view time-limited trials as helpful.

Enacting patients' wishes:

In contrast to the difficulties families described with prognostic uncertainty, respondents did not appear to struggle much with identifying their loved ones' wishes. Regardless of group, some surrogates reported knowing the patient's wishes while others did not. Among those who knew, regardless of group, some surrogates reported the patient as wanting to limit treatment if quality of life would be poor, while others described the patient as wanting all available treatments in hope of achieving recovery. Despite these shared perceptions across perspectives, the two groups offered different reflections on the implications of patients' wishes. Surrogates in the *choosing* group attempted to apply patients' wishes to medical decisions via substituted judgment. In the *no choice* group, surrogates seemed to consider patients' wishes as irrelevant because prognostic uncertainty was so profound (Table 4).

A model incorporating a "choosing" and "no choice" perspective—From the above data, we developed a thematic model (Supplemental Figure 1) in which surrogate decision-makers in SABI adopted two differing perspectives on decision-making. Some surrogates were actively deliberating around treatment decisions, while others were not. The difference in these perceived roles seemed to associate with a difference in how surrogates viewed and managed prognostic uncertainty, which was identified by both groups as a central challenge in SABI. Only those who felt as though they had actively deliberated their decision also felt that a "time-limited trial" of intensive medical care would have been helpful to clarify prognosis before making decisions.

Discussion

In this qualitative study during the acute phase of SABI, we found two distinct ways that family members experienced their role as surrogate decision-makers. Our findings have important implications for how clinicians communicate with surrogate decision-makers in SABI.

First, our results suggest that there may be a benefit to clinicians in assessing surrogates' perspectives on decision-making – determining, for each surrogate, whether they view themselves as making decisions. Our findings build upon general critical care literature that has identified differences in the degree to which surrogates want to be involved in decision-making[17,18] and the degree to which clinicians involve them,[19] as well as population-level research in SABI that has identified surrogate predictors of LST selection.[20] Collectively, this literature argues that different groups of surrogates need different approaches to goals-of-care discussions.[21] Our findings suggest that these approaches need to account not only for surrogates' *preferred degree of control* over decision-making, but also whether surrogates even perceive there being a decision to make. Those surrogates who, for varied reasons, do not perceive themselves as making decisions may not benefit in the same way from strategies like time-limited trials,[16] decision-aids,[22,23] or from repeated discussions of prognosis and treatment options, at least during the acute phase of care in the ICU. Instead, our data suggests that *no choice* surrogates might need prognostic communication to focus less on decision-making and more on the acknowledgement of uncertainty and its contribution to the surrogate's coping, as well as on assurance of a longitudinal relationship.

Second, the exploration of a patient's goals of care may also be more pertinent when surrogates are trying to make goal-concordant treatment decisions than it is for those surrogates who are focusing on hope and for whom prognostic uncertainty thwarts the integration of the patient's goals. Many surrogates in our study readily described their knowledge or lack of knowledge of loved ones' wishes for medical care, regardless of their perspectives on decision-making. A struggle with uncertainty *about their loved one's wishes* was uncommon, whereas the struggle with prognostic uncertainty was common. Surrogates' confidence in their assessment of patient wishes in our study may be surprising given previous reports on high rates of discordance between surrogate and patient assessments of wishes under hypothetical scenarios involving severely cognitively disabled states.[24] Our finding that surrogates felt confident in their assessments of wishes, while challenging to interpret in a small qualitative study, suggests that for surrogates, the central struggle may be less about not knowing what the patient would want, and more about not knowing what the patient can eventually achieve.

Neither of these observations suggest abandoning current or future discussions about prognosis and goals of care for patients represented by "no choice" surrogates. Rather, our findings suggest that the framing of a time-limited trial may need to be modified for these surrogates in the acute setting of SABI. In the acute setting, our findings suggest that prognostication and decision-making be decoupled in family meetings for these surrogates, so that a clear prognostic range is delivered with acknowledgment of prognostic uncertainty (such as through the use of a best-case/worst-case/most-likely scenario framework[25]) without pressuring the surrogates to make decisions. In the post-acute setting or after a pertinent event (for example, a decline, complication or substantial improvement), it may be helpful for clinicians to hold another conversation re-evaluating not only prognosis and goals of care but also the surrogate's decision-making perspective, since that perspective may have changed. For example, surrogates with a *choosing* perspective during the critical phase of SABI may later develop a *no choice* perspective if a patient makes a promising recovery. Similarly, surrogates with a *no choice* perspective during the critical phase of SABI might later consider choosing withdrawing or withholding LST depending on the patient's condition. At each stage, our analysis indicates that surrogates need to hear the prognosis not only to facilitate decision-making, but also to help them reach acceptance, grieve, and make plans.[26]

Finally, regardless of decision-making, the interviews made it clear that prognostic uncertainty was hard to tolerate and that surrogates adopted a range of strategies to manage it. Surrogates in both groups found comfort in faith, affirming the need for medical providers to explore spiritual needs and offer spiritual support to families of patients with SABI.[6,27,28] Surrogates in both groups also described a mindset of acceptance helpful, as well as a strategy of taking one day at a time; these coping strategies may point to approaches for future wellness interventions targeted at this population. Clinician communication strategies may also influence how surrogates conceptualize and develop a sense of agency in the face of prognostic uncertainty. One generally recommended method to communicate prognostic uncertainty is to bracket the range of possible outcomes (such as offering best-case and worst-case scenarios), offer the most likely outcome, and discuss the role of uncertainty.[25–27,29,30] Surrogates' sense of agency may also be influenced by whether physicians offer treatment recommendations that account for medical facts, professional experience, prognostic uncertainty and patients' known beliefs and values. Although many physicians are reluctant to make treatment recommendations to patients,[19,31,32] the American College of Critical Care Medicine and American Thoracic Society recommend that physicians offer to do so.[33] Optimal strategies for communicating prognosis specific to SABI have not been established and are urgently needed.

Our study has important strengths and limitations. Strengths of this study are that we sampled surrogates for patients with a breadth of SABI conditions, interviewed them in real time and utilized a rigorous qualitative methodology. Limitations of this study include the small sample size and largely white male patient population; a larger number and a more diverse set of participants would be needed to identify sociodemographic, cultural, or clinical factors that may contribute to decision-making perspective. Second, we only spoke to family members of patients with SABI who were receiving LST at the time of the interview. While this decision was made to focus on surrogates who were actively making decisions around LST, surrogates who had already chosen to withdraw LST might have provided additional perspectives. Third, surrogates in this study were interviewed at different times during the hospitalization, which might have influenced their perspectives and introduced recall bias. Finally, while our qualitative analysis suggested that prognostic uncertainty was the main driver of some surrogates' inability to make treatment decisions, other unidentified factors may have been at play, such as degree of prognostic uncertainty, clinician communication, or surrogate coping strategies. One possibility raised in a recent qualitative study of families who had consented for tracheostomy after SABI is that a perceived lack of choice might be a coping mechanism to avoid negative emotion around a difficult decision.[34]

Conclusions

In conclusion, our study suggests that eliciting surrogates' perceived decision-making role may help inform a clinicians' approach to communicating prognosis, discussing patients' wishes, and providing targeted support to surrogates for patients with SABI. In our study, surrogates' decision-making perspective emerged inductively from analysis of interview data. Research is needed to develop tools that may identify and incorporate surrogates' perspectives on decision-making; evaluate effective, replicable strategies for communicating prognosis and providing support to surrogates with different perspectives on decision-making in SABI, particularly to those who do not perceive themselves as making a "choice"; and better understand how surrogates' decision-making perspectives might change over time.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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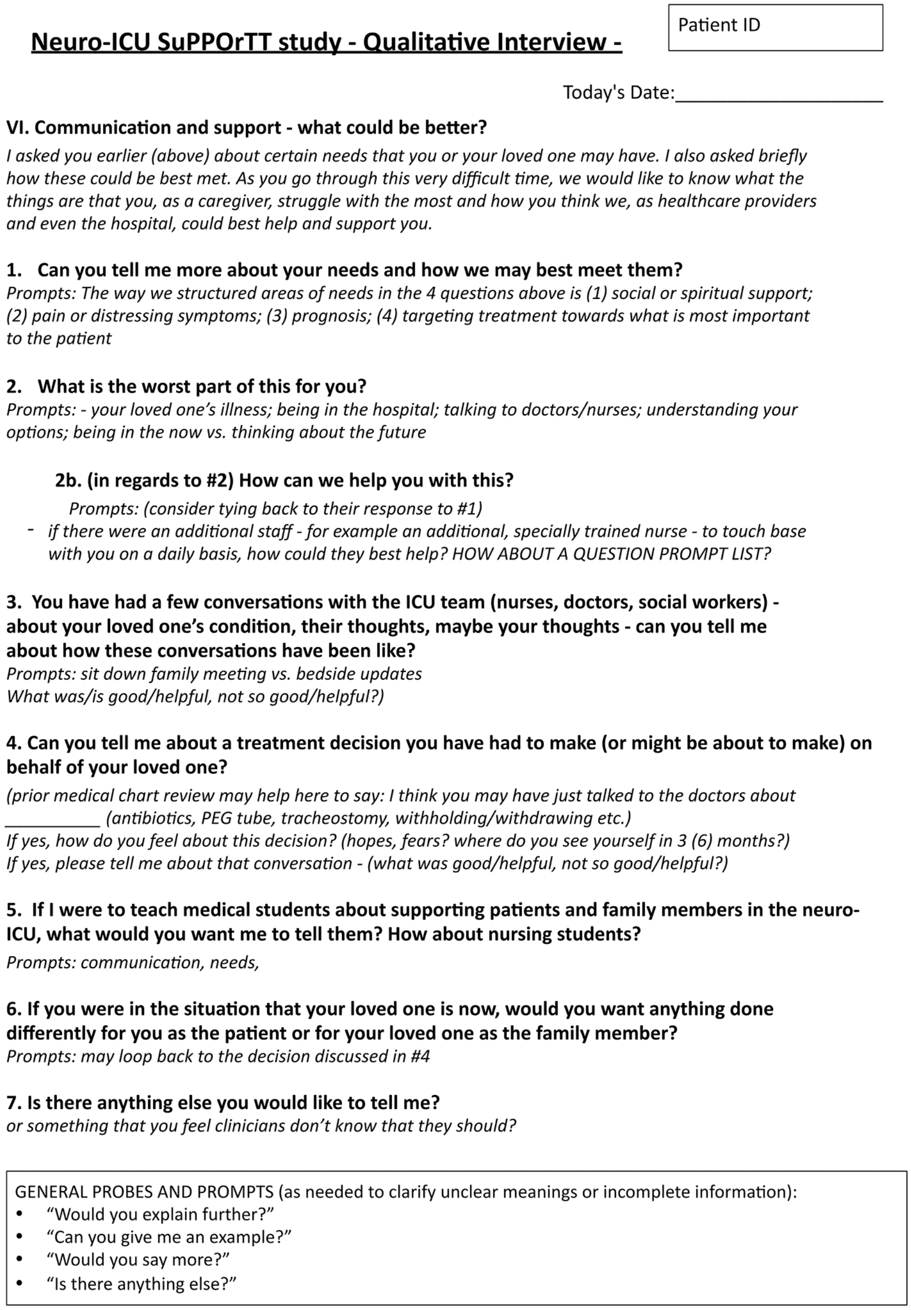
Key Points

- **Question:** The objective of this qualitative study was to describe surrogates' experiences of decision-making after severe acute brain injury (SABI), where surrogates face unique challenges related to prognostic uncertainty and patients' inability to communicate.
- **Findings:** Some surrogates described actively deliberating around major treatment decisions, while others, for varied reasons, did not perceive there being a decision to make. Surrogates in both groups identified prognostic uncertainty as the central challenge in SABI, but the two groups viewed and managed uncertainty differently.
- **Meaning:** Our findings suggest possible strategies for communicating about prognostic uncertainty in SABI depending on surrogates' current perspective on medical decision-making.



Neuro-ICU SuPPOrTT study - Qualitative Interview -

Patient ID

Today's Date:____________________

VI. Communication and support - what could be better?

I asked you earlier (above) about certain needs that you or your loved one may have. I also asked briefly how these could be best met. As you go through this very difficult time, we would like to know what the things are that you, as a caregiver, struggle with the most and how you think we, as healthcare providers and even the hospital, could best help and support you.

1. Can you tell me more about your needs and how we may best meet them?
Prompts: The way we structured areas of needs in the 4 questions above is (1) social or spiritual support; (2) pain or distressing symptoms; (3) prognosis; (4) targeting treatment towards what is most important to the patient

2. What is the worst part of this for you?
Prompts: - your loved one's illness; being in the hospital; talking to doctors/nurses; understanding your options; being in the now vs. thinking about the future

2b. (in regards to #2) How can we help you with this?
Prompts: (consider tying back to their response to #1)
- *if there were an additional staff - for example an additional, specially trained nurse - to touch base with you on a daily basis, how could they best help? HOW ABOUT A QUESTION PROMPT LIST?*

3. You have had a few conversations with the ICU team (nurses, doctors, social workers) - about your loved one's condition, their thoughts, maybe your thoughts - can you tell me about how these conversations have been like?
Prompts: sit down family meeting vs. bedside updates
What was/is good/helpful, not so good/helpful?)

4. Can you tell me about a treatment decision you have had to make (or might be about to make) on behalf of your loved one?
(prior medical chart review may help here to say: I think you may have just talked to the doctors about ___________ (antibiotics, PEG tube, tracheostomy, withholding/withdrawing etc.)
If yes, how do you feel about this decision? (hopes, fears? where do you see yourself in 3 (6) months?)
If yes, please tell me about that conversation - (what was good/helpful, not so good/helpful?)

5. If I were to teach medical students about supporting patients and family members in the neuro-ICU, what would you want me to tell them? How about nursing students?
Prompts: communication, needs,

6. If you were in the situation that your loved one is now, would you want anything done differently for you as the patient or for your loved one as the family member?
Prompts: may loop back to the decision discussed in #4

7. Is there anything else you would like to tell me?
or something that you feel clinicians don't know that they should?

GENERAL PROBES AND PROMPTS (as needed to clarify unclear meanings or incomplete information):
- "Would you explain further?"
- "Can you give me an example?"
- "Would you say more?"
- "Is there anything else?"

Figure 1: Interview Guide

Interview guide utilized to elicit experiences and communication needs of surrogate decision-makers in severe acute brain injury.

Table 1:

Participant characteristics according to surrogate perspective on decision-making

Participant characteristics	**Total (n=19)**	**Choosing (n=9)**	**No choice (n=10)**
Patients	***Mean (range)***	***Mean (range)***	***Mean (range)***
Patient Age (Years)	55 (20–79)	59 (26–74)	52 (20–79)
Length of stay at first interview (Days)	16 (4–50)	20 (4–50)	13 (4–28)
GCS on day of interview	9.0 (4–12)	8.6 (5–12)	8.9 (4–12)
Total hospital length of stay (Days)	35 (8–96)	44 (17–96)	26 (8–46)
	n (%)	**n (%)**	**n (%)**
Patient Gender (Female)	7 (37)	3 (33)	4 (40)
Patient Race/ethnicity (White, non-Hispanic)	15 (79)	8 (89)	7 (70)
Diagnosis subgroup			
Stroke	13 (68)	7 (78)	6 (60)
Traumatic brain injury	5 (26)	2 (22)	3 (30)
Cardiac arrest	1 (5)	0 (0)	1 (10)
Advance Care Planning documentation at time of admission (Yes)	4 (21)	2 (22)	2 (20)
Alive at discharge	15 (79)	7 (78)	8 (80)
Surrogates	**Total (n=22)**	**Choosing (n=10)**	**No choice (n=12)**
	Mean (range)	***Mean (range)***	***Mean (range)***
Surrogate Age (Years)	51 (22–76)	50 (31–72)	55 (22–76)
	n (%)	**n (%)**	**n (%)**
Surrogate Gender (Female)	13 (59)	6 (60)	7 (58)
relationship to patient			
Spouse/Partner	9 (41)	5 (50)	4 (33)
Adult child	7 (32)	3 (30)	4 (33)
Parent	5 (23)	1 (10)	4 (33)
Other	1 (5)	1 (10)	0 (0)

Table 2: “

Worst part” of the experience of severe acute brain injury, with representative quotations

“Choosing” perspective ***(Prognostic uncertainty makes choosing harder)***	**“No Choice” perspective** ***(Prognostic uncertainty makes it hard to cope and plan)***
“The worst part for everybody… is…the fear of having her be in a state that was not acceptable to her and still being alive for a long time.” “The toughest part is…the unknowns… So it was really me and my daughters trying to think about what Mama said and what are her wishes. And at that point we were pretty scared, because we had no idea what the outcomes might be.” “Nobody can tell me how bad he will be… I cannot deliver that kind of [decision to limit treatment] because nobody’s clear.”	“We’re not worried about her recovering process. It’s about how does my dad continue his working life, knowing that my mom may never be able to do what she was able to do before. And right now, that…is the biggest stress: Is how do I take my life as I’ve known it, what do I do moving forward?” “Being uncertain about, you know, the future… Like I was filling out FMLA paperwork, I’m like I have no idea what to put on this form for how long I’m going to need it.” “[The doctor] always ends everything, ‘But we just don’t know.’ So it’s like, you know, we’re pretty intelligent. We get the fact that…it’s a long road. But we don’t understand what this long road is…I know it’s not a concrete science… But it’s just, it’s kind of the back and forth, back and forth.”

Table 3:

Methods of managing uncertainty in severe acute brain injury and representative quotations

Method of managing uncertainty	"Choosing" perspective	"No choice" perspective
Take one day at a time	"Early on, I mean, my brain was going everywhere, analyzing every different possible scenario, and I finally just calmed down and like, I just need to take it hour by hour and not try to look too far into the future, till we know that there is going to be a future or what that future might be."	"If you start doing uncertainty, then you're going to start analyzing to death and you're going to run your nerves…okay? Just cross the bridge when you get there."
Accept an imperfect outcome	"We know that the probability of him ever being 100% is ridiculous. But will he someday be 50%? I mean, even if I get 50% on that left side, I'm going to be a happy camper, you know?"	"All we can do his hope for the best. And then the best could be a whole new definition of what the best was. Our definition of okay is going to have to change a little bit."
Take comfort in faith	"Yes. And I guess the underlying part of that is that we're both Christians, and we know what our future is going to hold. So, holding onto that faith—and that's what's keeping me strong."	"I don't stress because I have faith in God and the doctors."
Time-limited trial	*(The concept of TLT helps with choosing)* "The game plan was to just see if he could regain the things that I mentioned within the next two to three months. But if we did not see an improvement and there was a decline or no improvement, then we was going to go with, you know, just making him comfortable in the rest of the time he has." "Let's just see what we can do for the next two weeks. Hope and pray for the best, but expect that with the damage that was done…that it probably is not going to work."	*(TLT does not seem to be a concept)* *Interviewer*: "You felt like [the doctors have] got to do [the tracheostomy] anyway for her comfort… And this 'how long do we want to be in this uncertainty and see where she will go eventually' was not really part of this decision for you?" *Surrogate*: "No." "She has a feeding tube…she still needs speech therapy to determine if her swallowing and cognitive abilities are such that she can eat with her mouth… And then if it seems like she can eat enough to sustain her, then they'll remove it.."

Table 4:

Patient's wishes in severe acute brain injury with representative quotations

Comments about patient wishes	**"Choosing" perspective**	**"No choice" perspective**
Knowledge of patient wishes	"If there's hope at all, then we want them to do every single thing that we can do. And that's what [patient] would want." "She didn't want to be… a vegetable… not being able to communicate, not being able to move… She wanted to be able to speak, read, hopefully use her hands. Some… comprehensible way of communicating her needs."	"We both said if it came to the point where we had a heart attack or a stroke and had to be put on life support systems, that…we did not want that prolonged." Q: "How comfortable are you speaking for him about treatment choices? " M: "I think I'm reasonably comfortable. I think I understand him pretty well."
Role of patient wishes	*(Knowing what the patient would want guides my decisions)* "He has always told all of us, 'If I don't have a quality of life, I do not want to live.' So, you know, that's in the back of your mind… … So is he going to be able to, you know, drive? Probably not, you know. Is he going to be able to … do the things that he loves? Maybe eventually. At least we gave him a chance to do that or to, you know?" "He did not want to be in a vegetative state. Meaning he did not want to be unconscious; he did not want to be in a coma, or, you know, things of that nature. …. So, knowing that—like I said, I'm trying to be his spokesperson and give him the best quality of life of the time that he does have."	*(The patient's wishes don't apply to this situation)* *Surrogate*: "You think you have had these what you view as intelligent, impacting conversations with each other and you know what you want to do, and even though it would be hard, we have made a promise to each other to carry out each other's wishes. And then suddenly I'm put in a situation where…he's unconscious, and he's not responsive to me. And from what the care providers have told me, there is really no way to know about the prognosis with the brain. Sometimes you recover with limitations, sometimes you recover completely, and sometimes it never gets any better." *Interviewer:* "You talked about everything, but not, but this situation doesn't fit into what you have talked about?" *Surrogate*: "No, it does not fit… that's the frustration." "We had that kind of conversation [about wishes] before that accident happens…[But the current] situation is not clear… Nobody can tell me how bad he will be."