Adapting to a New Normal After Severe Acute Brain Injury: An Observational Cohort Using a Sequential Explanatory Design

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OBJECTIVES: Treatment decisions following severe acute brain injury need to consider patients' goals-of-care and long-term outcomes. Using family members as respondents, we aimed to assess patients' goals-of-care in the ICU and explore the impact of adaptation on survivors who did not reach the level of recovery initially considered acceptable.

DESIGN: Prospective, observational, mixed-methods cohort study.

SETTING: Comprehensive stroke and level 1 trauma center in Pacific Northwest United States.

PARTICIPANTS: Family members of patients with severe acute brain injury in an ICU for greater than 2 days and Glasgow Coma Scale score less than 12.

MEASUREMENTS AND MAIN RESULTS: At enrollment, we asked what level of physical and cognitive recovery the patient would find acceptable. At 6 months, we assessed level of recovery through family surveys and chart review. Families of patients whose outcome was below that considered acceptable were invited for semistructured interviews, examined with content analysis.

RESULTS: For 184 patients, most family members set patients' minimally acceptable cognitive recovery at "able to think and communicate" or better (82%) and physical recovery at independence or better (66%). Among 170 patients with known 6-month outcome, 40% had died in hospital. Of 102 survivors, 33% were able to think and communicate, 13% were independent, and 10% died after discharge. Among survivors whose family member had set minimally acceptable cognitive function at "able to think and communicate," 64% survived below that level; for those with minimally acceptable physical function at independence, 80% survived below that. Qualitative analysis revealed two key themes: families struggled to adapt to a new, yet uncertain, normal and asked for support and guidance with ongoing treatment decisions.

CONCLUSIONS AND RELEVANCE: Six months after severe acute brain injury, most patients survived to a state their families initially thought would not be acceptable. Survivors and their families need more support and guidance as they adapt to a new normal and struggle with persistent uncertainty.

KEY WORDS: family members; goals-of-care; neuropalliative care; prognosis uncertainty; severe acute brain injury; shared decision-making

Severe acute brain injury (SABI) includes ischemic stroke, intraparenchymal hemorrhage, subarachnoid hemorrhage, traumatic brain injury, and hypoxic-ischemic encephalopathy after cardiac arrest. Despite

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improvements in management, SABI continues to account for the death of 10 million people every year and causes more serious long-term disabilities than any other disease (1, 2). Increasingly, clinicians are recognizing the need for early integration of palliative care and focusing on improving communication, decision-making, and quality of life for patients with SABI and their family members (3, 4).

Patients with SABI lack decisional capacity, and written advance directives (ADs) are often missing, not applicable, or only partially followed in real-life situation (5–7). Physicians and family members need to make treatment decisions on the patient's behalf, using substituted judgment to determine the patient's preferences (8–10). This task is complicated by two different types of uncertainty: the clinical uncertainty of how much the patient might recover, and the affective uncertainty of how the patient and their family may emotionally adapt to future disability (11, 12). This decision-making process aimed at providing patient-centered, goal-concordant care (10) is also challenged by different expectations, beliefs, and understanding among physicians and family members (13, 14).

More than one in three patients with SABI die in the hospital (15), most of them after a decision to withdraw life-sustaining treatment (LST) (16, 17). Decisions around the use of LST in the ICU are associated with substantial long-term psychologic distress among family members (18, 19). Sources of distress include not wanting to feel responsible for a loved one's death or harm to the patient and a desire to pursue any chance of recovery (20, 21). Others have described a fear for the patient to miss the opportunity to die quickly if LST is not withdrawn early-on (22).

Patient-centered treatment decisions about LST rely on predicting how patients might feel about their condition in the future, namely affective forecasting (23, 24). This prediction can be questioned later on in retrospect because people underestimated their ability to adapt to a future health state (25). Therefore, the goals of this study were to: 1) investigate family members' assessment of patient's goals-of-care acutely after SABI, 2) among patients who survived to a level initially considered below that minimally acceptable to them, explore the process of adaptation among patients and families, and 3) develop a conceptual model describing the role of adaptation and goal-concordant care for long-term outcome after SABI.

MATERIALS AND METHODS

Study Design and Participants

The SuPPOrTT study is a prospective, observational, single-center cohort study following patients with SABI and their families admitted to the ICU of a large county hospital staffed by University physicians in the Pacific Northwest United States. We defined SABI as a disease category comprising ischemic stroke, intraparenchymal hemorrhage, subarachnoid hemorrhage, hypoxic-ischemic encephalopathy after cardiac arrest, and traumatic brain injury. The study included patients greater than or equal to 18 years old who had been hospitalized in the ICU for greater than or equal to 2 days after SABI, with a Glasgow Coma Scale less than or equal to 12 at enrollment and with an available family member, who was able to participate in English. Patients were ineligible for the study if a decision to withdraw LST had already been made. Using a mixed-methods sequential explanatory design (26), we first collected and analyzed quantitative data for eligible patients and their family members from the electronic health record (EHR) and family surveys at enrollment in the hospital and 6 months later. We then conducted in-depth qualitative interviews with the subgroup of families whose patients at 6 months had not reached the level of recovery initially considered minimally acceptable.

Procedure

After receiving permission from the medical team, family members were contacted in person at the bedside and invited to participate. Informed consent was obtained from the family member to use the information they provided and from the patient's legal next-of-kin (if different from the family member) to retrieve the patient's sociodemographic and clinical data from the EHR including age, gender, race/ethnicity, primary diagnosis, and presence of premorbid ADs. Sociodemographic data of family members were collected via self-report and included their relationship to the patient, their age, gender, and race/ethnicity. To assess patient's presumed goals-of-care, we developed a questionnaire pertinent to a range of SABI outcomes. We enlisted 12 national experts and professionals in neurology ($n = 4$), critical care ($n = 3$), nursing ($n = 3$), and palliative care ($n = 2$) who assessed it for face-validity (27).

In a private room separated from the patient bedside, the participating family member was asked to answer the following question: "Looking at 6 months or so from now, how much better from now does your loved one need to get so that he/she would feel that 'all of this medical care was worth going through'?" Response options are specified in **Figure 1**. None of the responses were shared with the clinical team.

Six months after enrollment, survivors' levels of cognitive and physical recovery were assessed through 1) a patient and a family survey, 2) review of the EHR for follow-up clinical visits, and 3) questioning of the family member directly if the research team needed clarification. The ability to complete the survey (with or without assistance) was considered equivalent to the cognitive level of recovery described in the questionnaire as "able to think and communicate." To assess patient's physical level of recovery, we used the modified Rankin Scale (mRS) (28) and the Two-Simple-Questions tool (29) in the 6-month survey or physician assessments in the EHR. Patients were considered functionally independent if they had a mRS of 3 or better, and the family member responded with "no" to the following question: "In the last 2 weeks, did your family member require help from another person for their everyday activities?".

For the qualitative interviews, we screened all patients enrolled after December 2018 and selected those who had not recovered to the physical or cognitive level their family member had initially considered acceptable to them at the follow-up survey. We then invited their family members to participate in an in-person, telephone, or video-call interview depending on their preference within 12 months of the follow-up survey. We used purposive sampling to ensure a range of patient and family member characteristics including age, race, sex, relationship type, and diagnosis. Semistructured interviews were conducted by a palliative care physician and qualitative postdoctoral researcher (R.R.V.) and a neurologist (C.J.C.) according to an interview guide (**supplemental data**, Supplemental Digital Content 1, http://links.lww.com/CCM/G219). The interview guide consisted of open-ended questions that focused on the trajectory of recovery since the patient left the ICU, the family member's expectations for recovery, how patient and family member were dealing with their current situation, and its impact on goals-of-care and future treatment decisions. Interviews were audio-recorded and transcribed verbatim. Qualitative interviews were conducted until we reached a point at which no new themes were emerging from the data ("thematic saturation") (30).

Analysis

Quantitative data were descriptive, collected through Research electronic data capture (REDCap) and analyzed with Stata V.14 (Stata Statistical Software: Release 14; StataCorp LP, College Station, TX). For the interviews, we used qualitative content analysis as this technique lends itself well to being combined with quantitative data (31–33). With an analytic team of three researchers (R.R.V., K.M.D., C.J.C.), we used systematic coding to identify themes and subthemes; themes were reviewed to confirm consensus, and all interviews were organized under themes. Interviews were concluded when thematic saturation was reached. We used an iterative approach to the analysis that allowed us to develop initial key concepts to guide subsequent interviews and analysis (deductive approach), while allowing for unique themes that emerged naturally from the data (inductive approach) (33). Based on these qualitative analyses, we developed a conceptual model connecting the themes and their relationship with patient and family member outcomes. Trustworthiness of qualitative analyses was established through construction of a network of themes and subthemes ("thematic network") (34), weekly review of the coding scheme by threes investigators (R.R.V., K.M.D., C.J.C.), and review of the table of themes by a multidisciplinary team of qualitative experts (including R.A.E., R.J.J.).

The protocol was approved by the institutional review board of the University of Washington (STUDY 00003393).

RESULTS

Of 196 patients with SABI and their family members enrolled between January 2018 and March 2020, 184 family members (94%) completed all goals-of-care questions at enrollment and were included in this study (flow-chart in **Appendix**, Supplemental Digital Content 2, http://links.lww.com/CCM/G220). Patients had a mean age of 63 years; 66% were White, 44% female, 58% had a stroke. Family members had a mean

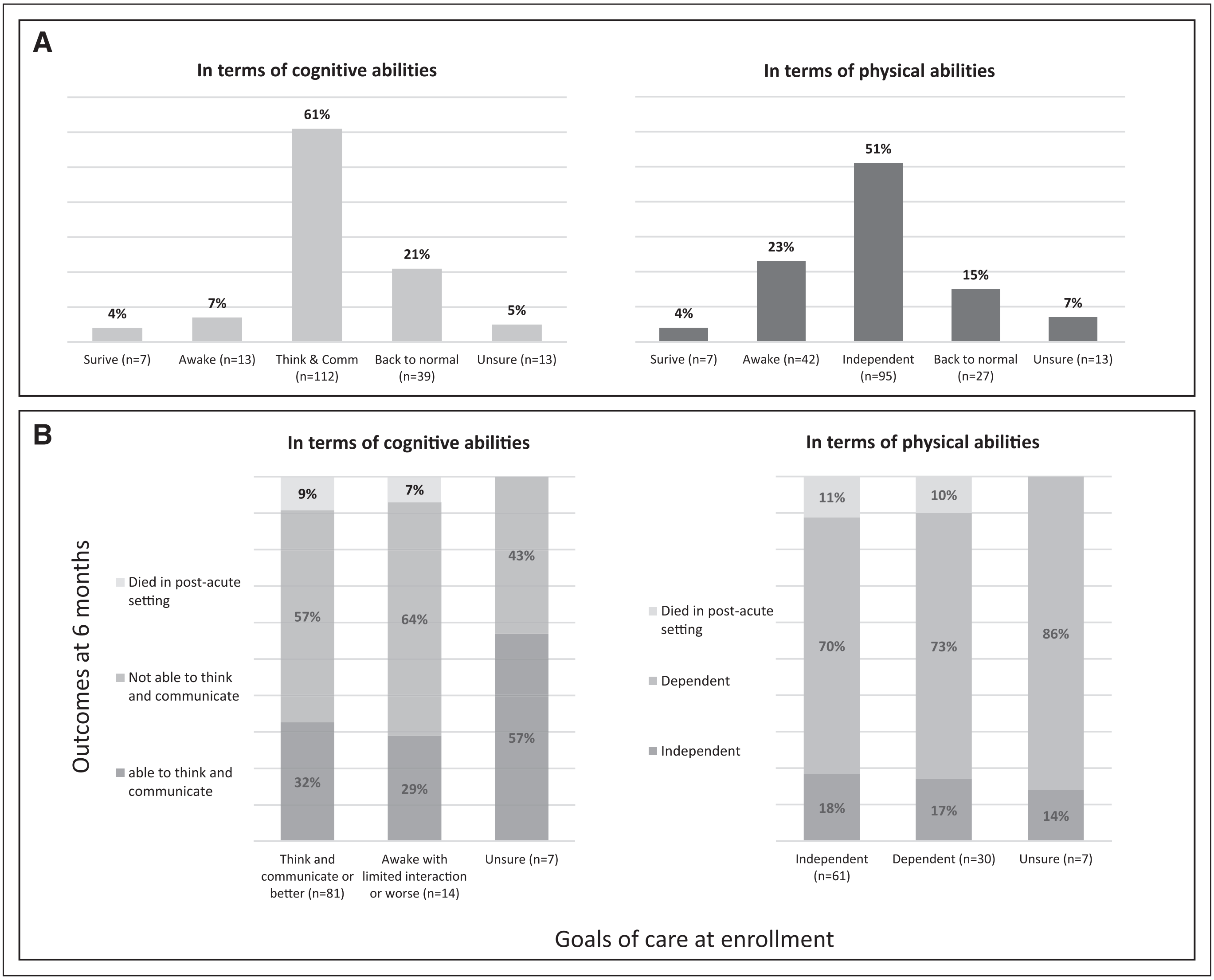

Figure 1. A, Patients' presumed goals-of-care at enrollment: "Looking at 6 months or so from now, how much better does your loved one need to get that they would say that 'all of this medical care was worth going through'?", $n = 184$. For cognitive goals-of-care, family members were presented with the following options (abbreviated in the figure): 1) As long as he/she survives, even if he/she remains unconscious (unable to interact with the environment or people). 2) As long as he/she is awake even if with limited interaction (e.g., able to look around but not recognize, or able to smile but not understand or speak). 3) As long as he/she can think and communicate (Comm), even if it is not the way he/she used to be. 4) Only if he/she can return to their previous, normal cognitive abilities. For physical goals-of-care, family members were presented with the following options: 1) As long as he/she survives, even if he/she remains unconscious. 2) As long as he/she is awake even if bedridden and/or dependent on others for toileting and feeding. 3) As long as he/she can walk, toilet and feed him/herself independently (without needing help). 4) Only if they can return to previous, normal physical abilities. **B**, Actual outcomes 6 mo after severe acute brain injury among patients who survived the hospital stay in relation to their goals-of-care as initially presumed by their families, $n = 102$ and 98.

age of 56 years; 63% were White, 63% female, and most were either the patient's spouse (34%) or child (35%) (**Table 1**). Of the 184 patients, 17 (9%) had premorbid ADs documented in the EHR. Of those, three had assigned a durable power of attorney only, two had a living will that was not found, nine declined LST if their condition was terminal, incurable or irreversible, and three declined LST altogether.

Goals-of-Care

Goals-of-care for these 184 patients as reported by family members are represented in Figure 1. With regard to cognitive recovery, 61% of families set their loved one's goals as "able to think and communicate," whereas 21% felt their loved one would only want to survive if they recovered to their "previous, normal"

TABLE 1.
Sample Characteristics of Participants, $n = 184$

Variable by Participant Category	Patient, $n = 184$	Variable by Participant Category	Family, $n = 184$
Age, yr		Age, yr	
Median	63	Median	56
Range	19–98	Range	19–96
Gender, *n* (%)		Gender, *n* (%)	
Female	63 (44)	Female	116 (63)
Diagnosis, *n* (%)		Relationship, *n* (%)	
Traumatic brain injury	59 (32)	Spouse	62 (34)
Ischemic stroke	35 (19)	Child	64 (35)
Intraparenchymal hemorrhage	31 (17)	Parent	28 (15)
Subarachnoid hemorrhage	41 (22)	Sibling	17 (9)
Hypoxic-ischemic encephalopathy after cardiac arrest	18 (10)	Other	13 (7)
Race, ethnicity, *n* (%)		Race/ethnicity, *n* (%)	
Non-Hispanic White	126 (68)	Non-Hispanic White	117 (63)
Hispanic White	12 (7)	Hispanic White	18 (10)
Black, African American	20 (11)	Black, African American	21 (11)
Asian	19 (10)	Asian	16 (9)
Others[a]	7 (4)	Others[a]	12 (7)
Premorbid advanced directives, *n* (%)	9 (17)		

[a] Others race and ethnicity included Native American, Alaskan Native and Pacific Islander, and unknown.

cognitive abilities. One in 10 felt their loved one would accept being “awake with limited interactions” (7%) or “unconscious” (4%). Regarding physical recovery, 51% of families set their loved one’s goals at independence with walking, toileting, and feeding, whereas 15% felt their loved one would only want to survive if they recovered to their “previous, normal” physical abilities. One in four felt their loved one would accept being “awake, even if dependent on others” (23%) or “unconscious” (4%). For both categories, the same 7% of families were unsure of the patient’s goals-of-care.

Outcomes

Six-month outcomes were available for 170 (92%) of the 184 patients at a mean of 5.3 months from enrollment through the family survey questionnaire (79%) or the EHR (21%). Among those 170 patients, 40% had died in hospital, the majority (93%; $n = 63$) after a decision to withdraw LST. Among the patients who survived the hospital stay and whose cognitive level of recovery was available to us at 6 months ($n = 102$), 33% ($n = 34$) were able to think and communicate, whereas 57% ($n = 58$) were unable, and 10% ($n = 10$) had died in the postacute setting. When we looked at the subgroup of hospital survivors whose family member had initially set cognitive goals-of-care at “able to think and communicate” or better ($n = 81$), 26 (32%) achieved this goal, whereas 46 (57%) survived at a level below that, and nine (11%) died in the postacute setting. Among the patients who survived the hospital stay and whose physical level of recovery was available to us at 6 months (*n* = 98), 13 (13%) patients had a mRS of 0–2, 28 (29%) had a mRS of 3, and 47 (48%) had a mRS of 4–5. Ten (10%) had died in the postacute setting. Of the subgroup of hospital survivors whose family member had initially set physical goals-of-care at functional independence or better (*n* = 61), 11 (18%) achieved this goal, whereas 43 (70%) remained dependent, and seven (11%) died in the postacute setting (**Fig. 1*B***).

Qualitative Interviews

Among the cohort of 6-month survivors who had recovered below their presumed goals-of-care at 6 months, we identified 39 eligible patients and interviewed 17 family members at a mean of 12.2 months after enrollment until thematic saturation was reached. Participants ranged from 35 to 73 years old, and most (*n* = 13) were women. The majority of family members (*n* = 12) were non-Hispanic White, followed by Black (*n* = 2) and Asian, Hispanic White, and American Indian (*n* = 1, respectively). We interviewed eight spouses, four children, four parents, and one sibling of patients. The distribution of these characteristics among participants was similar to that across all family participants (Table 1). For three participants, the patient had died by the time the family member was interviewed. We conducted six interviews in person, two through videoconference, eight on the phone, and one through chat by e-mail due to hearing impairment of the participant for a total of over 600 minutes recording time.

Themes

In this sample of family members whose loved one had survived SABI to a state the family member initially reported the patient would not have found acceptable, two major themes arose in the postacute setting.

Theme 1: A New, Yet Uncertain, Normal. As families learned to accept a new normal, they identified a need to grieve the person their loved one was previously and the relationship they shared. Uncertainty fuels hope for further recovery but also leaves little room to grieve and stands in the way of preparing for the possibility that this situation may be their new reality. Families described a need for more support specific to brain injury to help them adapt and recover long after they have left the hospital (**Table 2**).

Theme 2: Guidance for Ongoing Decisions. Families reflected on the challenges of their role as decision-makers for their loved one. Looking back on decisions already made, they noted prognostic uncertainty as the driver for continuing LST in the hospital to give their loved one every possible chance to recover. Even at a mean of 12 months of survival, uncertainty still fostered hope for many families and a desire to continue LST. As surrogate decision-makers, they tried to imagine what their loved one would want. Some of them faced the hard question of letting their loved one go, often by withdrawal of artificial nutrition. Across all of these circumstances, their need for professional long-term support and guidance, in order to reassess the patient's goals-of-care, was evident (**Table 3**).

Based on these two key themes, we developed a conceptual model (**Fig. 2**) describing how adaptation and treatment decisions shape long-term outcomes for patients and families after SABI, including receipt of goal-concordant care. Uncertainty plays a central role for both adaptation and decision-making: the ability to adapt to a new normal is hindered by persistent uncertainty of what the new normal will be, and this same uncertainty fosters decisions to continue LST, enabling adaptation. Both implicitly and explicitly, these two themes suggest an urgent need for ongoing support and guidance to improve quality of care and long-term outcomes for these patients and their families.

DISCUSSION

SABI renders patients acutely neurologically devastated, yet some face the possibility of a meaningful recovery. As clinicians and families undergo shared-decision-making in the acute setting of SABI, achieving goal-concordant care is challenging. In this prospective study that enrolled 184 patients with SABI and their families and followed them for a median of 5.3 months, less than one third of survivors achieved the level of recovery presumed by their family member to be consistent with their goals-of-care. In the subgroup of 17 family members who underwent a qualitative interview at a median of 12.2 months, some were adapting to a new normal, whereas others were facing the difficult possibility of letting their loved one go. Both groups struggled with uncertainty and, either implicitly or explicitly, asked for more support and guidance.

TABLE 2.

Adapting to a New, Yet Uncertain, Normal

Subthemes	Quotes
Acceptance	"I try to stay focused as much as possible on the present moment and deal with things as they are rather than spending a lot of time thinking about how life could be or how I wish things had been different. 6-Spouse"
Grieving the relationship they had with the pre-SABI individual	"[…] people around me don't fully understand, because they'll be like, "Well you should be happy because she's still here", and I was like it's not that I'm not, it's just that it's night and day in who she is. And so being able to grieve that without looking like I'm saying, "she should have just not come out of the coma" or something." (4-Child)
Loss of their prior life	"It's like I no longer have my partner. I have someone who looks like her and, you know, occasionally you'll kind of see flashes, but suddenly it's a lot like living with a stranger." (6-Spouse) "My life has changed profoundly as...I was the director of […], and I've had to give up the directorship." (15-Parent)
Ongoing uncertainty fosters hope but also complicates adaptation	"And we still haven't given up hope. It's nine months. And we were told that a year's time will show the improvement." (5-Parent) "It's been hard to make any kind of plan. But the neurologist said anything from …no recovery to being able to stand and transfer. So, it's been hard to know where we're actually going to end up and what we're going to need." (2-Spouse)
New sense of responsibility to protect the patient's best interest	"I really feel sorry for the patients who do not have someone to be with them every day and to… walk that journey with them, because they need an advocate." (1-Spouse) "Now he needs me more than ever because I'm his voice. He doesn't have that voice anymore. He doesn't have anybody to say I want to live or I want to not." (12-Parent)
SABI-specific support	"I would probably benefit from some kind of family head trauma support, just because, you know, my life has changed profoundly…" (15-Parent) "When he had cancer, he had a group of people and they followed him through the whole thing and that's what was important. He had support all the way through and to me that was amazing. [Interviewer: 'What about neurology after his brain injury'?] I didn't hear anything." (13-Spouse)

SABI = severe acute brain injury.

Theme I of the qualitative interviews with example quotes.

Our findings also suggest that, from the perspective of their family members, only 11% of patients would accept LST if they were left unable to think and communicate, whereas physical dependence was deemed acceptable to a larger degree. Still, many families decided to continue LST, possibly in the setting of a time-limited trial to see whether the patient improved over time. Our in-depth interviews with 17 family members suggest that the process of adaptation after a life-changing event is made more challenging when the future is uncertain and a decision endpoint not in sight.

Although the concept of time-limited trials has been well described (35), this concept may not be well implemented for patients with SABI in the post-acute setting. Prognostic uncertainty should lessen over time and offer the opportunity to reconsider goals and treatment decisions with more accuracy regarding the potential recovery in the future and possibly more accuracy regarding the patient's values. Our findings suggest that continuity of care with a specially trained healthcare provider who can provide anticipatory guidance around SABI and assist in reassessing

TABLE 3.
Need for Support and Guidance With Ongoing Decisions

Subthemes	Quotes
Uncertainty drives early decisions for continuing life-sustaining treatment	"If there was any single chance in the world that he could you know - I was hoping for that hail Mary. I was hoping and hanging on to that one in a million chance." (14-Spouse) "[Looking back,] I would still want to have her treatment and see, you know, how far it could go. And it's not like somebody can tell you in advance, 'If you do A, B and C, we can guarantee such-and-such an outcome.'" (6-Spouse)
With hindsight, families question early decisions but do not regret them due to uncertainty at the time	"'Did we make the right choice?"' We have had to go with the idea that we made the right choice at that time for what we knew." (3-Child) "I could look in his beautiful green eyes forever, you know? And I feel selfish sometimes that we made this choice to keep him alive." (5-Parent) "I mean his choices led him to this life but I helped determine his consequence and that's a huge burden on my heart and in my life…. I can't regret it either because I've learned from it." (14-Spouse)
Families try to imagine the patient's perspective on living on	"She was on a feeding tube for the whole time, but… at that point, we had to put ourselves in her shoes." (7-Sibling) "And so part of me feels really bad because I wonder if, you know, pre-coma Mom would even want to still be here with her lowered capacity." (4-Child)
Thinking about letting their loved one go	"But, we're looking at after a year's time, you know, where does he go from here if he doesn't get better, do we let him go?" (5-Parent) "The decision to pull the feeding tube was the most difficult of anything, because her body was in good shape, you know? And how do you say goodbye or make that decision to someone whose, heart is beating strong and everything, but unfortunately, the brain just wasn't connected to it anymore." (7-Sibling)
Families call for specialized guidance	"That'd be really nice to be able to have someone say, 'These are your options for the future, and maybe this is when instead of waiting for that other shoe to drop.'" (6-Spouse) "They [the nursing home] didn't have an actual neurologist on staff or that would visit on a regular basis, so I just wanted to talk to somebody who was familiar with severe head trauma and knowing what was ahead, you know?" (7-Sibling)

Theme II of the qualitative interviews with example quotes.

prognosis and goals-of-care throughout the trajectory may be helpful.

The optimal method for assessing goals-of-care, or treatment concordance with goals, for patients with SABI has not been determined. Even previously expressed goals-of-care through AD may be either not applicable (7, 36) or may underestimate an individual's ability to adjust to new health states (37), which can lead to overuse or underuse of LST (38, 39). In our cohort, premorbid ADs were rarely available and mostly not relevant to the context of SABI as they were limited to a terminal condition. The rate of AD in our cohort was lower than the 37% reported in a recent meta-analysis of mostly older U.S. adults (40) and may be attributable to the acute context of SABI. The combination of not knowing one's future values before suffering SABI and the prognostic uncertainty in the acute setting of SABI challenges the concept of advance care planning for this disease in particular. If family members, then, are left with these tragic

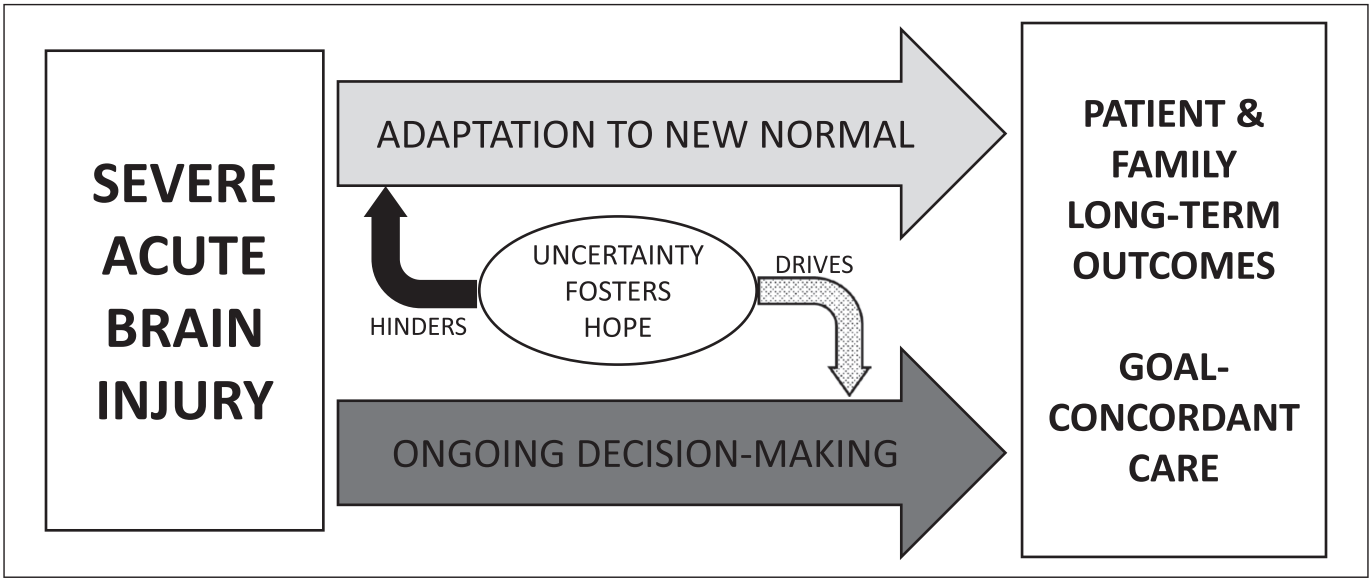

Figure 2. Conceptual model of the two key themes identified in this study as they relate to long-term outcome after severe acute brain injury (SABI). On the trajectory of recovery leading from SABI toward a post-SABI outcome, patients and families struggle to adapt to a new normal (*light gray arrow*) and face challenging short and long-term treatment decisions (*dark gray arrow*). Uncertainty fosters hope and over time also hinders adaptation (*black arrow*) and drives decision-making (*white dotted arrow*).

choices, we must better understand how they later review and cope with them. Emotional reactions to tragic choices depend on a sense of responsibility for having made the choice (41). In our qualitative interviews, it appears that families' clear acknowledgement of uncertainty may help them escape or externalize that responsibility, possibly explaining the absence of regret reported.

This study has several important limitations. First, data were collected at a single, academic county hospital, which may limit the generalizability of the results. However, this is the only comprehensive stroke and level 1 trauma center for a five-state region, which may mitigate this concern. Second, our patient population is diverse by SABI etiology (including both traumatic and nontraumatic causes), age, and family relationship with the patient. Although this diversity is a strength for the qualitative component, heterogeneity inpatient population may make some quantitative associations less evident. Third, most of the patients were non-Hispanic White, and we do not have data regarding economic disparities or comorbidities, all of which limit generalizability of our findings. Fourth, by definition, patients were neurologically impaired at enrollment and therefore could not provide information about their own goals-of-care. Fifth, the goals-of-care survey was administered at a mean of 4.8 days after ICU admission, and family member's perspective on goals-of-care may change over time. Sixth, recovery was assessed at 6 months, but some recovery may occur after that, especially after traumatic brain injury (42). Finally, there may be a selection bias for those willing to participate in qualitative interviews.

CONCLUSIONS

Our findings offer important insights into opportunities to support and guide patients and family members affected by SABI. In addition to our ongoing quest to improve prognostic accuracy, further research is needed to understand 1) barriers and facilitators of adaptation, especially in terms of potential interventions that could help patients and families adapt; 2) how to communicate and elicit values with an acknowledgement that these may change, and how to integrate the potential for adaptation into prognosis communication; and 3) how to optimally guide patients and families toward patient-centered decisions even in the face of uncertainty. Finally, our findings suggest an urgent need to support family members through the full duration of time-limited trials after SABI.

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Drs. Rutz Voumard, Curtis, Jox, and Creutzfeldt designed the study and wrote the protocol. Drs. Rutz Voumard, Kiker, Dugger and Creutzfeldt were responsible for data acquisition and management. Drs. Rutz Voumard, Dugger, Engelberg and Creutzfeldt did the data analysis and interpretation. Drs. Kiker, Borasio, Jox, and Curtis did a critical review of the data analysis. Drs. Rutz Voumard and Creutzfeldt wrote the draft of the article. All authors contributed to writing, review and approved the final version of the protocol.

The acronym SuPPOrTT stands for the four questions we asked clinicians and family members: 1) Do the patient or family require social, spiritual, or emotional Support? 2) Does the patient have Pain or other distressing symptoms? 3) Does the family have concerns about Prognosis or treatment Options? and 4) Do we need (re-)address goals-of-care or Target Treatment to patient-centered goals?

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All coauthors had full access to all the data in the study and had final responsibility for the decision to submit the publication.

Requests for access to the data reported in this article will be considered by the corresponding author.

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