

ORIGINAL WORK



# Taking a Chance to Recover: Families Look Back on the Decision to Pursue Tracheostomy After Severe Acute Brain Injury

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## Abstract

**Background:** Tracheostomy represents one important and value-laden treatment decision after severe acute brain injury (SABI). Whether to pursue this life-sustaining treatment typically hinges on intense conversations between family and clinicians. The aim of this study was, among a cohort of patient who had undergone tracheostomy after SABI, to explore the long-term reflections of patients and their families as they look back on this decision.

**Methods:** For this qualitative study, we reviewed the electronic medical records of patients with SABI who underwent tracheostomy. We included all patients who were admitted to our 30-bed neuro-intensive care unit with SABI and underwent tracheostomy between November 2017 and October 2019. Using purposive sampling, we invited survivors and family members to participate in telephone interviews greater than 3 months after SABI until thematic saturation was reached. Interviews were audiotaped, transcribed, and analyzed by using thematic analysis.

**Results:** Overall, 38 patients with SABI in the neuro-intensive care unit underwent tracheostomy. The mean age of patients was 49 (range 18–81), with 19 of 38 patients diagnosed with traumatic brain injury and 19 of 38 with stroke. We interviewed 20 family members of 18 of 38 patients at a mean of 16 (SD 9) months after hospitalization. The mean patient age among those with an interview was 50 (range 18–76); the mean modified Rankin Scale score (mRS) was 4.7 (SD 0.8) at hospital discharge. At the time of the interview, ten patients lived at home and two in a skilled nursing facility and had a mean mRS of 2.6 (SD 0.9), and six had died. As families reflected on the decision to proceed with a tracheostomy, two themes emerged. First, families did not remember tracheostomy as a choice because the uncertain chance of recovery rendered the certain alternative of death unacceptable or because they valued survival above all and therefore could not perceive an alternative to life-sustaining treatment. Second, families identified a fundamental need to receive supportive, consistent communication centering around compassion, clarity, and hope. When this need was met, families were able to reflect on the tracheostomy decision with peace, regardless of their loved one's eventual outcome.

**Conclusions:** After SABI, prognostic uncertainty almost transcends the concept of choice. Families who proceeded with a tracheostomy saw it as the only option at the time. High-quality communication may mitigate the stress surrounding this high-stakes decision.

**Keywords:** Tracheostomy, Stroke, Traumatic brain injuries, Intensive care units, Family, Communication, Uncertainty, Prognosis

## Introduction

Severe acute brain injury (SABI) includes all those diseases that render patients acutely neurologically devastated [1]. Taken together, stroke, traumatic brain injury,

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and hypoxic-ischemic encephalopathy after cardiac arrest account for 12 million deaths annually and are the leading cause of disability worldwide [2]. Early in the hospital course, family members are often faced with having to make life-or-death treatment decisions on behalf of their loved one, balancing the possibility of survival with severe neurological impairment vs. an early death in the setting of withdrawal of life-sustaining treatment. High-quality communication is a cornerstone of high-quality care and a prerequisite for optimal shared decision-making, and further research is needed specific to communication and decision-making after SABI [3, 4].

Tracheostomy is one such critical and value-laden decision point in the acute phase of SABI. Although necessary for patients who require prolonged airway protection or mechanical ventilation to sustain life, the decision for tracheostomy also may represent a long-term reliance on artificial life support, which some people have considered worse than death [5, 6]. This decision is especially difficult when long-term neurological prognosis is uncertain, as is often the case after SABI [7]. For example, a recent meta-analysis suggests that among patients who undergo tracheostomy after SABI, an approximately equal proportion will be independent, dependent, or dead by 6–12 months [8]. Tracheostomy use has steadily increased over the last several decades, and the wide variation in tracheostomy practices across countries, regions, and institutions suggests a lack of standard to assist these decisions [2].

The decision-making process around life-sustaining treatments, such as tracheostomy after SABI, requires sensitive conversations between families and clinicians [9, 10] because patients are unable to speak for themselves in the acute setting. Little is known about families' perspectives regarding the tracheostomy decision after SABI. A better understanding of these perspectives may assist clinicians in supporting family decision-makers more effectively during this highly stressful period. Thus, the aim of this study was to provide, among a cohort of patients who had undergone tracheostomy after SABI, a voice to the family decision-makers regarding their experiences and retrospective evaluations of the decision.

## Methods

### Study Design and Setting

For this qualitative study, we combined data collected from patient electronic medical records and semistructured interviews with families and/or patients. We screened all patients who were admitted to our 30-bed neuro-intensive care unit (neuro-ICU) during a 2-year period from November 2017 to October 2019 for inclusion (>18 years; SABI; underwent tracheostomy). Our neuro-ICU admits approximately 600 patients with

SABI every year, of whom 2.5–5% undergo tracheostomy (5–15% of patients with SABI who require mechanical ventilation). We therefore expected to identify between 30 and 60 eligible patients.

### Participant Recruitment and Data Collection

The electronic medical record was reviewed for sociodemographic and clinical characteristics (age, sex, ethnicity, diagnosis, timing of tracheostomy, number of extubation attempts, length of ICU stay, discharge disposition, and modified Rankin Scale score (mRS) at discharge). For the qualitative study, we used purposive sampling to obtain a range of patient and family characteristics, ensuring a range across conditions, age, race/ethnicity, and relationship. The unit of analysis for identifying the sample was the patient [11]. Members of the team (WL, JHG) called either patients or their surrogate decision-makers (family) by phone to invite them to participate in the study. Decision-makers were identified through the electronic medical record, as determined by the clinical team. Interviews were conducted by phone, audiotaped, and transcribed verbatim. This semistructured interview included questions about participant's recall of their experience in the hospital ("looking back"), their expectations for the future ("looking forward"), and their evaluation of their current situation ("looking at you/at [patient name]"; see interview guide in Supplementary Material). Interviews were concluded when thematic saturation was reached.

### Quantitative Analyses

Descriptive statistics by using means for continuous variables and frequencies for categorical variables were completed to analyze data from the medical record.

### Qualitative Analysis

Our research team included neurologists with specialty backgrounds in vascular neurology, neurocritical care, and palliative care. Three team members (WL, SW, CJC) reviewed all interviews independently and met weekly to analyze interviews and identify basic themes that were clustered and distilled to global themes [12]. We used an iterative framework with both an inductive (allowing the data to speak for themselves) and a deductive approach (developing initial key concepts that guided subsequent interviews) [13]. Supporting quotes from interview transcripts were generated for each theme. Clusters of interviews were reviewed after they were conducted, and interviews were reviewed multiple times; later reviews were used to employ a more directed content analysis to verify clusters and global themes [14]. Interviews continued until thematic saturation. Trustworthiness was obtained through documentation of detailed analytic memos, review of interviews, a notes and coding scheme

by other team members (JHG, RW, AS), and inclusion of verbatim excerpts within the article.

### Standard Protocol Edapprovals, Registrations, and Patient Consents

The study protocol was approved by the Institutional Review Board of the University of Washington. A waiver was obtained for written consent, and verbal informed consent was obtained from all participants in the study by phone.

## Results

### Participants

We identified 38 eligible patients (Table 1). The mean patient age was 49 (range 18–81), and a majority were male (71%) and White (67%). The distribution of brain injury included a mix of traumatic brain injury ( $n=19$ ) and stroke ( $n=19$ ), including six with ischemic stroke, eight with intracerebral hemorrhage, and five with subarachnoid hemorrhage. The mean mRS at discharge was 4.8 (SD 0.9). No patients were discharged home, and six patients died in the hospital, all of them after a decision to withdraw life-sustaining treatments (“comfort measures only”).

We conducted 18 interviews pertaining to 18 unique patients. One interview was with a patient, three were with a patient and their family member(s), and 14 were with a patient’s family member(s) only, as the patient was either unable to participate ( $n=8$ ) or had died ( $n=6$ ). Interviews were conducted at a mean of 16 (SD 9) months after hospitalization. Four patients or their families declined to participate. The group of patients who were the subject of our interviews had a mean age of 50 (range 18–76), and one third (6 of 18) were under the age of 40. The mean mRS for patients was 4.7 (SD 0.8) at the time of hospital discharge. At the time of the interview, 10 of 18 patients were living at home and two lived in a skilled nursing facility, with a mean mRS of 2.6 (SD 0.9); the remaining six had died. We collected more than 7 h of interview recordings.

### Themes

As families reflected on the decision to pursue prolonged artificial life support in the form of a tracheostomy, two key themes emerged around (1) the concept of choice and (2) the importance of communication.

### Tracheostomy Was Not a Choice

Faced with substantial prognostic uncertainty, families felt they had to take the chance on an uncertain recovery because the only alternative (certain death) seemed unacceptable. Therefore, the decision was not remembered as a choice. Without any definitive knowledge of how much

function the patient might ultimately regain, decision-makers took any chance of life over death. Tracheostomy was equated with breathing and surviving. Families felt they had to proceed with the tracheostomy to give their loved ones a chance, acknowledging that they may well have decided differently if a poor functional outcome had been more certain (Table 2).

*We felt we had to give her the chance of making a recovery...I don't think we had morally any other choice.*

*No. 15 (husband)*

Other families saw the tracheostomy as one of the necessary procedures following a SABI. For these families, prognosis played a less explicit role, but they, too, saw no alternative.

*At the time they were doing the tracheostomy, there was no thought of...life-versus-death decisions. It was “This needs to happen. Just do it.” Because there was no thought of death.*

*No. 13 (father)*

### Clinician Communication Requires Compassion, Hope, and Clarity

The process of decision-making in favor of a tracheostomy was tied closely with the quality of clinician–family communication. To navigate the idea of a tracheostomy after SABI and to trust the eventual decision, families relied on supportive communication from the health care team, specifically compassion, hope, and clarity. When this need was met, families were able to reflect on the tracheostomy decision with peace, regardless of their loved ones’ eventual outcomes (Table 2).

Compassion led to a feeling of being supported. Families focused on the emotion behind the communication they received. To demonstrate compassion meant to convey an understanding that the patient is loved by their family and not simply a part of the clinician’s job. Compassion was exemplified when providers communicated with kindness and patience. For example, families cited not feeling rushed into a decision until they understood all the presented information.

*If I had felt rushed...maybe I wouldn't feel that way, but I feel like that really has helped ease the traumatic memories...*

*No. 6 (daughter)*

Hope, including a validation of their own hope, allowed families to cope with the stressful circumstances and was critical to maintaining trust and rapport with clinicians.

**Table 1 Patient characteristics**

	Interviewed (n = 18)	All (N = 38)
Age, mean (SD) (years)	50.3 (19.7)	49.2 (20.1)
Female sex, n (%)	4 (22)	11 (29)
Race/ethnicity, n (%)		
Asian American and Pacific Islander	4 (22)	9 (18)
Black	2 (11)	6 (16)
Hispanic	0 (0)	0 (0)
American Indian and Alaskan native	0 (0)	1 (3)
White	12 (67)	24 (63)
Other	0 (0)	0 (0)
Advance directives present on admission, n (%)	0 (0)	0 (0)
Diagnosis, n (%)		
Ischemic stroke	4(22)	6 (16)
Intraparenchymal hemorrhage	3(17)	8 (21)
Subarachnoid hemorrhage	3 (17)	5 (13)
Traumatic brain Injury	8 (44)	19 (50)
Number of failed extubation trials prior to tracheotomy, n (%)		
None	7 (39)	20 (53)
One	2(11)	4 (11)
Two	9 (50)	14 (37)
Three or more	0 (0)	0 (0)
Palliative care consultation prior to tracheotomy, n (%)	2 (11)	7 (18)
Ethics consultation prior to tracheotomy, n (%)	0 (0)	0 (0)
PEG tube during hospitalization, n (%)	18 (100)	38 (100)
Days ventilated before tracheotomy, mean (SD)	13 (6.1)	15 (6.5)
Months between interview and hospital discharge, mean (SD)	16 (9)	–
Length of initial ICU stay, days, mean (SD)	27 (9)	33 (15.1)
Length of hospital stay, mean (SD) (days)	55 (30)	62 (38.8)
Alive at time of interview, n (%)	12 (67)	–
Disposition at time of hospital discharge, n (%)		
Home	0 (0)	0 (0)
Inpatient rehabilitation facility	7 (39)	8 (21)
Skilled nursing or long-term acute care facility	8 (44)	23 (61)
Death	3 (17)	6 (16)
Other	0 (0)	1 (3)
Residence at time of interview, n (%)		
Home	10 (56)	–
Inpatient rehabilitation facility	0 (0)	–
Skilled nursing or long-term acute care facility	2 (11)	–
Death	6 (33)	–
Other	0 (0)	–
Decision-maker relationship to patient, n (%)		
Spouse/partner	5 (28)	–
Parent	6 (33)	–
Adult child	2 (11)	–
Sibling	4 (22)	–
Other	1 (6)	–

ICU intensive care unit, PEG xxx

**Table 2 Themes and interview excerpts**

Themes	Interview excerpts
Tracheostomy was not a choice	"We felt we had to give her the chance of making a recovery... don't think we had morally any other choice, OK? It's a horrible decision to try to make in a short period of time." No. 15 (husband)
	"We've got to keep her alive because... we were in that window of not knowing. The window of possibly she will come out of the coma, possibly she won't come out of the coma... we were in a window of she might survive, she might not survive." No. 14 (sister)
	"... we had no idea at that time what [patient]... was going to be. And so we personally thought [patient] would want every chance in the world to recover. And we somehow believed that we had to give him that opportunity." No. 7 (mother)
	"When we were there, we were really conscious of the fact—especially the first two months—that he needed something to prevent him from choking his own saliva. So therefore the question of that tracheostomy was—how to say? [laughter] It was not a matter of question even. We didn't have to decide. This had to be done!" No. 7 (father)
	"If I was in the position where, I mean the brain's just flat-lining. There's no brain activity at all, you know? Or there's nothing, and they're telling me, 'He's brain dead.' Well, you know, I might not do the tracheostomy. But if they're telling me, 'Well, there's brain activity,' and it's a young kid, I don't know why anybody would give up. The brain's an amazing thing... I'm probably not doing the tracheotomy if my 90 year old mother has a stroke." No. 13 (father)
Clinician communication requires compassion, hope, and clarity	"At the time they were doing the tracheostomy, there was no thought of... life-versus-death decisions. It was 'This needs to happen. Just do it.' Because there was no thought of death." No. 13 (father)
	"It's like if somebody was at the Boston Marathon and his leg was blown off and to ask the family, 'Can we put a tourniquet on his [leg]...' It's kind of a no-brainer." No. 20 (sister)
	"We felt so supported and we felt that everybody was trying to explain things as clearly as possible, and compassionately. And to me, those are the two pieces: to clearly give the information, to give it in several ways or to go over it several times, and just the compassion piece." No. 7 (mother)
	"I feel like really understanding that this is not just your job, but it's somebody's loved one and it needs to be dealt with really gingerly and with a lot of patience and kindness is really important... if I had felt rushed and I did things on a whim, maybe I wouldn't feel that way, but I feel like that really has helped ease the traumatic memories of Dad, knowing that at the time everything was presented before me, I asked so many questions, I took my time. I never let myself feel rushed into any decision. Even though sometimes we were talking daily about an important decision that we had ahead of us, like the tracheostomy." No. 6 (daughter)
	"One doctor would call me and we would have this great conversation, and he would explain it perfectly to me. And then the next time, it was a different doctor who maybe wasn't quite as thorough... sometimes there was a little bit of confusion because of the switch." No. 6 (daughter)
	"I can't stand doctors that talk down to you. They need to come to your level and explain things if you don't understand them. And not talk over you, not talk around you, like you're not in the room. They didn't break it down, and I didn't realize, 'OK this is not recoverable, and she's not going to come back from that.'" No. 14 (sister)
	"I think after that conversation I didn't trust them. As a matter of fact, I wouldn't even [let the doctor] come in the room. Every time he set foot in the room, I just, 'Nope. Out. Turn around. I can't listen to negativity.'" No. 17 (mother)
	"It was like all of us sort of felt like we had been kicked in the gut rather than lifted up... most of us felt like the [neuro-ICU] is kind of gloom-and-a-doom. There were a couple of people [who] experienced hope, but we didn't. And that was sort of the general consensus, is that the whole industry kind of needs to change the way they feel." No. 17 (mother)

ICU intensive care unit

Families associated hope with feeling lifted and rejected providers who appeared negative.

*Every time [the doctor] set foot in the room, I just, "Nope. Out. Turn around. I can't listen to negativity." No. 17 (mother)*

Finally, families needed clear messaging from the health care team. Clarity in communication meant the ability of clinicians to break down complicated medical information into understandable terms as well as to provide a consistent and unified message. Some families recalled with frustration their failure to understand explanations that allowed them to comprehend the situation.

*They need to come to your level and explain things if you don't understand them.... They didn't break it down, and I didn't realize, "OK this is not recoverable, and she's not going to come back from that." No. 14 (sister)*

## Discussion

This study provides another angle to the acute shared decision-making process of tracheostomy in patients with SABI and gives a voice to family decision-makers. Our interviews suggest that prognostic uncertainty limits the families' perception of having a choice in the decision-making process, and that compassionate



communication allows families to reflect on the process with peace.

Prognostic uncertainty is a well-established theme in neuropalliative care, especially after SABI, in which possible future outcomes can range anywhere between death and meaningful recovery, complicating the acute decision-making process [8, 15, 16]. If the chance for improvement existed, decision-makers in our study saw no appropriate alternative but to pursue this life-sustaining measure. In hindsight, families saw their consent to tracheostomy as a chance for recovery and a prioritization of survival over death. It is possible that this perceived lack of choice represents a coping mechanism to avoid feeling badly about making a difficult decision; families are more likely to develop negative feelings when they were the ones who made the decision rather than the decision being made externally [17]. Clinicians may be able to mitigate this effect by actively engaging in a process of “shared deliberation” with patients and families [18]. Shared deliberation describes the interaction between patients, families, and clinicians as they deliberate the patient’s prognosis, values, and treatment options and mutually discover patient preferences. This process may move the perceived locus of control to the “shared mind” that emerges from the interactions between the key stakeholders.

The more intuitive, though no less important, finding from our interviews was the need for effective communication, which has also been described previously after SABI and especially regarding prognosis [19, 20]. Poor communication during decision-making processes in the ICU, especially when around the end of life, can lead to worse psychological outcomes for families and patients [21]. When prognostic uncertainty deprives families of any feeling of control [21], families ask for hope [22]. In this study, families felt supported when clinicians allowed for hope. With this explicit need for hope came also the need for clarity. The successful delivery of this balance between hope and realism influenced the families’ long-term subjective experiences of their tracheostomy decisions. These findings highlight the recommendation to communicate uncertainty by describing possible best case/worst case scenarios [23] or by hoping for the best while at the same time preparing for the worst [24].

The decision to pursue a tracheostomy is typically considered when a patient has been ventilator dependent for at least several days and is predicted to require artificial life support for a prolonged period of time [25, 26]. Clinicians sometimes view this time as a window of opportunity to discuss the patient’s values and treatment preferences around the use of artificial life support. If early prognostic uncertainty precludes choice for families, like for those in our study, then providers may

instead be able to use the foregone conclusion of a tracheostomy as a checkpoint to advance goals-of-care discussion by introducing the concept of a time-limited trial [27] and exploring a minimally acceptable level of recovery that can be reassessed at a time point when the prognosis may be clearer.

This study has several important limitations. First, it was conducted at a single hospital in the United States with predominantly White and male patients. Additional work is needed to better understand the influence of race, ethnicity, and socioeconomic status in the medico-cultural and medico-legal context of tracheostomy and in the larger realm of medical care [28, 29]. Similarly, the impact of participant health literacy and the level of education or religious practice in the decision-making process need to be explored further. Second, given the inconsistent documentation of family meetings in the electronic medical record, let alone documentation of prognosis assessment or communication, we were unable to measure the amount or quality of information received by family members before tracheostomy. The general practice in our unit is to have a family meeting within the first 48 h and at least one additional meeting by the end of the first week on the basis of family needs; with a mean time to tracheostomy in this cohort of 2 weeks, we will assume that at least one formal family meeting had occurred. Third, decision-makers were interviewed at different times from discharge because of variable patient responses by telephone, which might have influenced perspectives as a function of time and introduced recall bias. Fourth, we did not interview clinicians, nursing staff, or other health care personnel involved in these cases, which might have provided additional perspectives and interpretations of the tracheostomy decision. Finally, we did not interview decision-makers who declined tracheostomy for their loved ones and chose death over prolonged artificial life support, which might have highlighted additional facets and distinct relevant factors in this complex decision.

## Conclusions

As families look back at the decision to pursue tracheostomy for their loved ones after SABI, this study identifies two well-established themes in neuropalliative care, namely prognostic uncertainty and communication, and how they limit the perception of choice and influence the longitudinal outlook of proceeding with a tracheostomy. Future studies are needed to explore the perspectives of families who declined tracheostomy as well as the perspectives of the clinicians involved in these decisions. Our study adds to a growing number of studies that provide important information for us to develop tools that

## will improve and standardize decision-making and family–clinician communication after SABI.

### Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1007/s12028-021-01335-9>.

### Author contributions

WL and CJC had full access to all of the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. The final manuscript was approved by all authors. Concept and design: JHG, CJC. Acquisition, analysis, or interpretation of data: All authors. Drafting of the manuscript: WL, SW, CJC. Critical revision of the manuscript for important intellectual content: All authors. Obtained funding: CJC. Supervision: SW, CJC.

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### Conflict of interest

The authors of this study have no conflicts of interest to disclose.

### Ethical approval/informed consent

The study was reviewed and approved by the University of Washington Institutional Review Board (ID #00003459).

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