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# The Experiences and Needs of Families of Comatose Patients After Cardiac Arrest and Severe Neurotrauma: The Perspectives of National Key Stakeholders During a National Institutes of Health–Funded Workshop

**OBJECTIVES:** Severe acute brain injury (SABI) from cardiac arrest and traumatic brain injury happens suddenly and unexpectedly, carrying high potential for lifelong disability with substantial prognostic uncertainty. Comprehensive assessments of family experiences and support needs after SABI are lacking. Our objective is to elicit “on-the-ground” perspectives about the experiences and needs of families of patients with SABI.

**DESIGN:** Two-phase qualitative study of families and multidisciplinary U.S. healthcare professionals (mHCPs) with expertise in SABI: Phase 1 included semistructured interviews to generate formative findings; phase 2 entailed facilitated discussions to confirm and expand initial findings.

**SETTING:** Phase 1: academic medical center; phase 2: virtual workshop.

**SUBJECTS:** Phase 1 included seven family members and 12 mHCPs. Phase 2 included nationally recruited stakeholders (17 family members and 12 mHCPs).

**INTERVENTION:** None.

**MEASUREMENTS AND RESULTS:** We explored: 1) what are families’ needs in the first 48 hours? 2) How are these needs addressed? and 3) How can hospitals better meet these needs? Qualitative analysis included inductive and deductive approaches guided by a conceptual ecological model. Four major needs were identified: 1) challenges in coping with uncertainty in early prognostication, 2) inattention to physical needs of family, 3) deficits in compassionate and consistent communication, and 4) need for engagement with families as stakeholders in improving future practices. Participants’ recommendations included: 1) ways to communicate more clearly and consistently, 2) better assistance with navigating resources and access to places for families to care for themselves, and 3) opportunities for families to remain connected with their loved ones, social support networks, and the clinical team.

**CONCLUSIONS:** Stakeholders identified novel insights regarding families’ experiences during the hospitalization of comatose SABI patients and factors that can contribute to improved decision-making and physical/emotional outcomes. Interventions to address these unmet needs are promising targets to improve outcomes.

**KEY WORDS:** cardiac arrest; emergency medicine; family experience; neurocritical care; physician-family communication; qualitative research; traumatic brain injury

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Patients with severe acute brain injury (SABI), including comatose survivors of cardiac arrest and patients with severe traumatic brain injury (sTBI), present with a sudden and catastrophic condition (1). Family

members are charged with functioning as a proxy to represent patient values and preferences while grappling with their own emotional trauma (1, 2). As research from general critical care shows, families are propelled into the role of caregiver and surrogate decision-maker, both with extreme levels of responsibility for which they are often unprepared, creating significant emotional burden as they deal with the patient's critical illness and uncertain recovery (3–5).

Interventions to support families as surrogate decision-makers exist but have failed to mitigate long-term psychological distress (6, 7). Experts have argued that supporting families in their surrogate decision-making role alone is not enough; families require additional strategies to reduce long-term emotional effects (8). Families of patients with SABI also have unique additional stressors that limit generalizations from nonbrain injured populations. SABI is typically very sudden and unexpected, and it carries high potential for lifelong disability and substantial prognostic uncertainty during the early period of illness (9–11). Comprehensive assessments of family experiences after SABI and families' specific needs for emotional, physical, and spiritual support are lacking.

Our primary objective was to understand the experiences and needs of families of patients with SABI from the perspectives of multiple stakeholders. These findings will inform future interventions to support families after SABI, diminish psychological distress of families struggling with the surrogate role, and guide clinicians and hospitals in providing patient- and family-centered care. We focused on the early hospitalization when emotional shock, prognostic uncertainty, and acute stress prevail. We aimed to examine: 1) the information families of SABI patients needed and received, 2) how information was communicated, and 3) families' emotional, physical, and spiritual needs.

## **MATERIALS AND METHODS**

We conducted a two-phase qualitative study of families of comatose patients hospitalized after cardiac arrest or sTBI and healthcare professionals who care for this patient population. Phase 1 was a single-site study using individual semistructured interviews to generate formative findings. Phase 2 was a virtual workshop bringing together a national purposive sample of stakeholders to further explore and expand on findings from

phase 1. This combination of both phases with multiple data sources was designed to facilitate triangulation and to increase trustworthiness of the data. Participants included family members of survivors and nonsurvivors, and healthcare professionals, including emergency medicine and critical care physicians, researchers, paramedics, critical care nurses, chaplains, and social workers. The study team was assembled to include four cochairs with expertise in neuroprognostication, surrogate decision-making, and emergency research, supplemented by two methodologic experts in medical ethics and qualitative research. Five qualitative researchers from Westat, a health, statistical, and social science research organization headquartered in Rockville, MD, drafted interview and workshop discussion guides, conducted interviews, facilitated workshop discussions, and analyzed data. The Westat research team was composed of four research staff experienced in mixed methods research under the supervision of a Project Director with doctoral training in Developmental Psychology. Study procedures were supported by an administrative supplement to the "Strategies to Innovate EmERgENcy Care Clinical Trials Network," a clinical trials network focused upon improving the outcomes of patients with neurologic, cardiac, respiratory, and hematologic emergencies by identifying effective treatments given in the earliest stages of care. All study procedures were reviewed and deemed exempt for further review by the Westat Institutional Review Board (Date of approval: February 25, 2019).

### **Phase 1: Family, Clinician, and Ancillary Staff Member Interviews**

**Setting and Study Population.** We conducted one-on-one semistructured interviews with participants from a single academic medical center intentionally sampled for its experience with postcardiac arrest and sTBI care. Participants included family members of patients with cardiac arrest and sTBI, clinicians, and ancillary staff. We purposively sampled each group to ensure diversity by race/ethnicity, gender, and specialty. Given the highly sensitive nature of the research and challenges of recruiting, we asked clinicians to identify family members with whom they had existing clinical relationships.

**Data Collection, Management, and Analysis.** The research team developed interview guides with

open-ended questions (**Supplementary Digital Content 1**, <http://links.lww.com/CCX/A939>) focusing on our three major study questions. Hour-long interviews were conducted with healthcare professional participants in July-August 2020 and with family member participants in August-October 2020. All interviews were conducted telephonically and were led by a Westat qualitative researcher. A second Westat staff member took notes and served as an observer during each interview. Interviews were audio-recorded, professionally transcribed, and imported into NVivo11 (QSR International Pty Ltd. 2017). Westat developed a codebook using both a deductive and inductive analysis approach. The initial codebook was structured around a framework that focused on families' experiences within five domains based on an ecological model adapted from National Institute on Minority Health and Health Disparities (12) (**Fig. 1**). The core concept of ecological models is that health behaviors have multiple levels of influences (social, psychological, environmental, public policies, etc.) and are often used as frameworks for understanding these interacting factors of health behaviors (13). The codebook was then refined inductively through iterative review of the data and sharing of emerging thematic content among the coders. Discrepancies were resolved by consensus.

## Phase 2: Virtual Workshop

We conducted a virtual workshop on November 19, 2020, to confirm the initial findings from families and

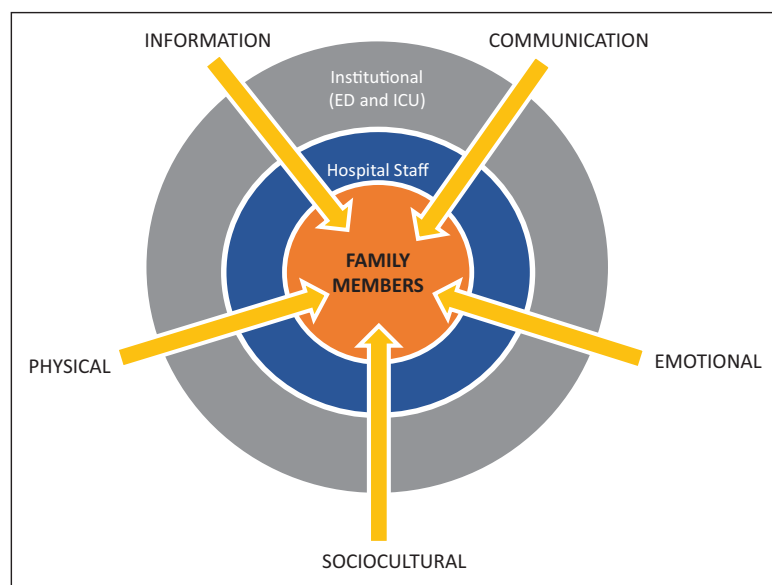
providers with multiple stakeholders, capture missing themes, and expand upon themes identified during phase 1.

**Setting and Study Population.** The coauthors identified 30 invitees from across the United States: 18 family members and 12 healthcare professionals. We created a purposeful sample of U.S. healthcare professionals based on their known expertise in the care of patients with SABI, and their engagement in research focused on families of SABI patients. We chose family member participants to maximize representation by gender, race, and patient's disease and survival status among family participants. Family members were identified by study coauthors, healthcare professionals who were recruited as participants, and a national organization with a survivor/caregiver network (Sudden Cardiac Arrest Foundation, Wexford, PA, [www.sca-aware.org](http://www.sca-aware.org)). We used snowball sampling to further identify family participants from these initial individuals. We offered technological support and compensated them \$500 for their time.

**Workshop Agenda.** The workshop was conducted virtually using Zoom for Government. Four trained qualitative researchers from Westat facilitated discussions according to a predetermined agenda (**Supplementary Digital Content 2**, <http://links.lww.com/CCX/A939>).

### Presentations and Reflection Sessions

After a presentation of the phase 1 findings, attendees were divided into four groups (two groups of families and two groups of healthcare professionals) to reflect, each guided by a Westat facilitator and



**Figure 1.** Analytical framework. We applied a framework, grouping family members' experiences into five domains based on an ecological model adapted from the National Institute on Minority Health and Health Disparities where there are multiple and bidirectional interactions among the domains and levels of influence (12). The five domains included: information (verbal or written information about the patient's status or care and navigating the hospital), communication (how this information is conveyed to the family member), emotional (range of emotional needs), sociocultural (how cultural, religious, and social beliefs affect family members' experiences), and physical (how the hospital physical environment can be better suited for family members). ED = emergency department.

workshop cochair. A discussion guide was used to substantiate findings and identify gaps of the phase 1 findings (**Supplementary Digital Content 3**, <http://links.lww.com/CCX/A939>).

#### *Breakout Sessions*

Two rounds of breakout sessions were conducted. During the first session, the two family groups discussed their perceptions on logistical needs in the first 48 hours, and two healthcare professional groups focused on “provider training” and “care as a team” approaches. The second breakout session included four mixed groups of families and healthcare professionals to solicit diverse perspectives on “communication of uncertainty” in the first 48 hours.

**Data Management and Analysis.** All workshop sessions were recorded and professionally transcribed. Additional data sources included Padlet responses (Padlet by Wallwisher, San Francisco, CA), chat messages, notes and observations from research staff, and postworkshop e-mails. Westat analyzed these data using the analytic framework from phase 1 while focusing on our main research questions. The analysts looked for any disconfirming findings, expanded understandings, and confirmation from the previous findings.

**Triangulation of Findings From Phase 1.** Data were analyzed to produce summative themes related to family members’ needs and categorized according to domains within the research framework. We also assembled strategies used by hospital staff and institutions or recommended by families to address these needs. We considered findings transferable if they were generated in phase 1 and supported in phase 2. We added new themes or subthemes that emerged from the workshop to the overarching analytic framework.

## **RESULTS**

In phase 1, 19 participants were interviewed (seven family members and 12 healthcare professionals). In phase 2, of 30 individuals invited, 29 participated in the workshop (17 family members and 12 healthcare professionals). **Table 1** displays the participant characteristics.

We categorized findings by domains according to the analytical framework (Fig. 1). Although the intent was to examine the first 48 hours of the patient’s admission, many family members discussed needs beyond

this time period. Representative quotes for all domains are shown in **Table 2**. Complete domains from both phases are shown in **Supplementary Digital Contents 4–8** (<http://links.lww.com/CCX/A939>).

### **Domain 1: Information Needs**

Family members reported a need for information about their loved one’s (LO’s) disease progression and possible outcomes, especially if the injury or condition may be fatal or seriously impact quality of life. Family members also expressed a need for information about their LO’s care plans and test results and expressed frustration when updates were not received in a timely manner. They expressed logistical concerns related to contacting the care team. To support informed decision-making, families commented on the importance of receiving clear information about options, including therapies and treatments. Families discussed that they clarified their understanding through trusted and knowledgeable resources (friends, family, or established physician relationships). Many participants discussed their reliance on personal contacts in the medical field to help them make decisions. Searching the internet was described as “overwhelming” for families. Finally, families discussed their need for hospital staff to share information about what to expect in transitions from the emergency department (ED) to ICU, as well as to different postdischarge care settings.

Healthcare professionals in both phases of the research discussed the physicians’ responsibility to communicate uncertainty honestly to families without declaring premature conclusions, which can have deleterious effects on patient outcomes (i.e., a self-fulfilling prophecy). They noted variation across physicians in communicating uncertainty.

### **Domain 2: Communication Needs**

Families emphasized the need for healthcare professionals to be clear, consistent, and compassionate in their communication, particularly when delivering bad news. They often recalled feeling overcome with emotion and distracted and appreciated when healthcare professionals’ communication facilitated information processing. Families identified practices such as repeating information, pausing for families to ask questions, and avoiding medical terminology or clarifying

**TABLE 1.**  
**Baseline Characteristics of Participants**

<b>Phase</b>	<b>Case Study<sup>a</sup></b>	<b>Workshop<sup>b</sup></b>
<b>Family Members</b>	<b>(n = 7)</b>	<b>(n = 17)</b>
Relationship		
Parent	4	8
Spouse	3	9
Gender		
Female	4	14
Male	3	3
Experience		
Traumatic brain injury	4	9
Survivor	2	7
Nonsurvivor	2	2
Cardiac arrest	3	8
Survivor	2	7
Nonsurvivor	1	1
Race/ethnicity <sup>c</sup>		
Non-Hispanic White		15
Black or African American		2
Education		
Graduate school education		9
4-yr college graduate		5
High school, general educational development test, < 4 yr college education		3
Health literacy		
How comfortable are you filling out medical forms alone?		
Extremely		9
Quite a bit		7
Somewhat		1
<b>Healthcare Professionals</b>	<b>(n = 12)</b>	<b>(n = 12)</b>
Role		
Physician	4	8
Nurse or paramedic	4	3
Chaplain, social worker, or organ donation coordinator	4	1
Gender		
Female	6	5
Male	6	7
Years in profession		
10–24 yr	6	
> 25 yr	6	

<sup>a</sup>Phase 1: qualitative study conducted at a single U.S. academic hospital and level 1 trauma center.

<sup>b</sup>Phase 2: virtual workshop held on November 19, 2020, over video conference.

<sup>c</sup>In accordance with the Institutional Review Board protocol, we did not systematically collect information on race/ethnicity to prevent inadvertent identification of individuals due to the small sample sizes in phase 1 participant groups and in the healthcare professionals in phase 2.

**TABLE 2.**  
**Representative Quotes by Analysis Domain**

Domain	Representative Participant Quotes
Information	<p>“I do remember feeling like frustrated or a little just – like the fear of the unknown. Like first they were talking about like on day one they were talking about like being in a coma, and like nobody ever said to me like your [loved one is] in a coma or – I mean, I could see that she wasn't awake, but I don't know, just to hear those words was hard, and then the next day they're talking about a TBI. ... but like nobody ever said to me she has a traumatic brain injury. And I'll tell you, that hit me the hardest.” (family member [FM], Phase 1)</p> <p>“I think things should be forthright and the person like me who is waiting for this stuff, especially if they have a major test like that, a CT scan, MRI, when you have those kinds of things, you should be informed on what's going on with them.” (FM, Phase 1)</p> <p>“So much scary info online, so need to direct us to trustworthy sites/sources vs. looking up info on our own...” (FM, Phase 2–Padlet)</p> <p>“I don't think everyone does it well, but I can tell you what we try to teach and preach, which is just–In a way embracing uncertainty... So it can be uncomfortable. But I think we do a disservice to our patients when we don't acknowledge uncertainty.” (Professional, Phase 2)</p>
Communication needs	<p>“They'd answer and explain things in, you know, terminology that we could all understand, and never made us feel rushed. We could ask whatever questions we wanted. They gave us their business cards. So, I think they were a source of comfort and you know, just trying to answer our questions and reassure us about things.” (FM, Phase 1)</p> <p>“We did not have a social worker greet us. We did not have a single point of contact...never met the neurologist, and I hope I don't offend anybody by saying this, but I felt like they were on two different planets, the cardiologist and the neurologist.” (FM, Phase 2)</p> <p>“One of the principal problems in all of this is that modern medicine is shift work, and you don't have the same provider from start to finish. And that's true at the nursing level, just as much as that is true at the physician level with very rare exceptions. And that becomes a problem.” (Professional, Phase 2)</p>
Emotional needs	<p>“Just the thought of not knowing, and not know if he's dying, is he going to be okay. You know, I didn't know. So, I just prayed about it, and I didn't know what else to do.” (FM, Phase 1)</p> <p>“But I think I'd be disingenuous if I said we just have absolutely no idea, because that's not really discussing and preparing the family for the situation in which – what you're facing...having done this for a very long time, I'm coming from a place where I've been disappointed at the level of certainty that physicians have had when they're wrong over time. And that's been the biggest concern that I've seen over my 25-year career as a neuro intensivist, is that physicians have overestimated their ability to precisely prognosticate poor outcomes early after injury.” (Professional, Phase 2)</p>
Sociocultural needs	<p>“And when I tell you I was treated so nasty, and when I tell you that my son was treated so nasty, (cries) and when I tell you I tried to stay respectful, I didn't say anything out of line to nobody and I just let it pass. And I'm not the one to let nothing pass when somebody's being disrespectful. And you know, I'm glad I'm here to tell my side of the story. I don't know if it's my background, I don't know what it is, but like I said, I have a bunch of professional kids in my family – when we came in there, we were quiet, we kept everything clean. I had to ask for mop buckets for my son's room. I had to ask for – for a sheet, because we had to wash my son up. We had to wipe his butt. We had to suction out his neck and clean his nose out. When I tell you that I was disrespected on every level, I'm honest. I was. But that's okay, though. That's okay. We prevailed. (FM, Phase 2)</p> <p>“Thank you, guys, so much, was so glad to share that, never got to share. kind of suppressed it, was glad to let out because I know there's others that will no doubt go thru” (FM, Phase 2– Chat).</p> <p>“[It is] important [for healthcare professionals] to establish relationships and understand patient values” (Professional, Phase 2– Padlet).</p>
Physical needs	<p>“I was met at the door by a clergyman who took me into a little room which kind of scared me, because I knew that that meant things were really bad, but it was a space that I could just be isolated from other places. And he stayed with me the whole time. And then there's a whole compassionate care team at the hospital, and the first thing they did (laughs) was give me this blanket that was knitted by Women In Prayer, which I cherish, and I've taken to the hospital any time [name] had to go back.” (FM, Phase 2)</p> <p>“So I do think that people get very lost in hospitals. [They] can be very confused about where they're going to go, and unfortunately while providers, physicians, nurses are prioritizing the patient's health, families are often literally lost, and don't know what to do.” (Professional, Phase 2)</p>

frequently used terms, such as “TBI” and “coma,” as helpful.

Families recalled confusion over roles and responsibilities of healthcare team members, leaving them unsure of what type of information to request from individuals at the bedside or whom to ask to speak to.

Families emphasized the importance of receiving consistent information from healthcare professionals, particularly when consultants were involved. Some families experienced consulting clinicians communicating in “siloes,” indicating a perceived lack of coordination with the primary team. A holistic team functioning collectively, in communication with one another, provides more consistent information to families. Healthcare professionals confirmed the importance of communicating with compassion to families and emphasized the importance of spending time with families to build trust. One healthcare professional reflected on the challenges of shift work and the potential for the impression of “disjointed” care teams.

### Domain 3: Emotional Needs

Families experienced a range of feelings (shock, distress, confusion, and despair) as they attempted to cope with their LOs’ critical illness. The unexpected life-threatening event, uncertainty regarding their LO’s outcome, and reliance on the healthcare team for compassionate support contributed to their emotional responses. It was important to families that the healthcare team genuinely cared for their LOs. They valued the care team frequently “checking-in” with updates, being respectful and attentive, addressing questions, and conveying empathy and compassion. Social support from friends and family, as well as services offered at the hospital, helped families deal with their emotional overload.

Regarding prognostication, most families generally desired explicit information on what to anticipate, but some expressed difficulty hearing about a possible poor prognosis. A few stated that they wished to hear the range of possible outcomes, given the reality of prognostic uncertainty and a desire to prepare for the worst, whereas others preferred this information to remain hopeful. Several indicated that they were unaware that death or poor quality of life were potential outcomes. Conversely, physicians were more likely to express concern about providing inaccurate

information. Physicians also discussed the challenge of overconfident colleagues when conveying prognosis.

### Domain 4: Sociocultural Needs

During both study phases, families and healthcare professionals emphasized the need for equitable treatment and socioculturally appropriate communication to ensure that families feel respected and are treated without bias. Participants noted that these vital factors contribute to effective and positive communication and encourage rapport building between the families and the care team. During the workshop in particular, one family described negative experiences, such as discriminatory care due to the family’s race. For instance, some families felt disregarded, overlooked, and even disrespected by some hospital staff whom they perceived as racist. These families expressed hope that sharing their experiences could improve how other families are cared for and stressed the importance of providing families an opportunity to reflect on their experiences.

### Domain 5: Physical Needs

Families described needs related to physical, tangible, or logistical issues, including the location and hours of the cafeteria, visitor parking locations, and lodging. Several families desired a comfortable private space within the hospital. The physical needs changed over the first 48 hours, especially for those who had to travel emergently to be at their LO’s bedside. Families described being so focused on the status of their LO that many arrived at the hospital without remembering to bring personal belongings and other travel items for a stay of unknown duration. They wanted visitation rules that allowed families to be with their LO around-the-clock and to be allowed to assist in cleaning and bathing the patient as a way to connect with their LO.

### Cross-Cutting Themes

Consistent themes related to family experience emerged from both phases and cut across all domains: 1) a desire for information about illness and prognosis for recovery and the challenges of uncertainty, 2) identifying gaps in provision of logistical information and support, 3) importance of communicating compassion, sharing uncertainty, and responding to emotional and

physical needs, and 4) a desire to participate in the discussion and development of practices to improve support for future families in similar situations.

### Key Recommendations for Hospitals and Staff

Workshop participants identified a number of strategies to address the various needs of family members during the first 48 hours (Table 3). Three areas of focus identified by families included: 1) clear, compassionate, and timely information about the patient's status, expectations, and care, 2) to feel respected and part of their LO's care team, and 3) various types of support after their LO is discharged from the hospital or dies. Recommendations for actions hospital staff and institutions can do to alleviate these major concerns were discussed by the group and detailed in Table 3.

## DISCUSSION

In this qualitative study, we elicited real-world, "on-the-ground" perspectives of families, multidisciplinary clinical providers, advocates, and experienced researchers. This approach bringing multiple stakeholders together presents novel insights regarding emergency and critical care in SABI. Our findings address the call to better understand families' experiences in SABI and to illuminate factors that contribute quality of decision-making and long-term patient and family physical and emotional outcomes (9, 14, 15). Our findings underscore the need to include families in discussions on how to improve care for SABI patients and emphasize the need for institutional support to the entire family unit.

Our study confirms and extends prior findings from sTBI (9) but also provides recommendations formulated by key stakeholders to enhance the care of families in their times of crisis. Implementation of these recommendations could improve family experience and also help healthcare providers, who experience the stress of caring for critically ill patients and families on the worst day of their lives.

By design, our study contrasted the perceptions and needs of families with the experience of healthcare providers. Families repeatedly emphasized the need for direct, timely, and consistent information from clinicians that is presented empathically. Although the need to "communicate uncertainty with directness" was mentioned by families, it did not rise to the top

of their needs. However, especially among physicians, the topic of communicating uncertainty around neuroprognostication was a repeated focus of discussion. The source of this discordance may stem from physicians' reluctance to disclose uncertainty and their perception that discussing prognostic uncertainty with families is "harmful" (10, 16–19). Concomitantly, physicians raised concern that families do not understand uncertainty. Previous research on family perspectives about uncertainty is mixed. One study indicates a lack of awareness among families of prognostic uncertainty (20), whereas other studies in both general critical care and sTBI have found that families are quite aware of prognostic uncertainty, finding it "unavoidable" and "inherently present" (10, 16). Our findings suggest that physicians should focus on clear and honest communication, including directly acknowledging and stating that uncertainty exists.

One notable observation in our study was the willingness of families to collaborate and use their experiences to improve care for others. Such patient and family partnerships have had positive impact on clinical care and prioritization of research questions, while being highly valued by the patients, families, and many participating clinicians (9, 14, 21). Similarly, in our study, stakeholders illuminated blind spots within systems of care, for example, the need for care teams to communicate with each other to provide uniform information to families. The clinicians participating in our study endorsed the value of families' experiences and embraced the opportunity to improve patient- and family-centered care.

Our study has notable strengths and limitations. We conducted an in-depth phase within a single setting first, followed by a phase with a broad geographic representation. Cardiac arrest and sTBI are common and emblematic diseases among SABI; therefore, our findings are likely transferable to other catastrophic neurologic emergencies. Additionally, the workshop afforded a unique opportunity to bring families and healthcare providers into a shared discussion and to engage in dialogue raising awareness of the need to improve support for families.

Despite extensive efforts to enroll participants diverse in gender, race, and roles, the family participants were predominantly highly educated, non-Hispanic White women. Our challenging experience recruiting minority participants is not unique (9, 22). One



**TABLE 3.**  
**Recommendations for Hospital Staff and Institutions**

Family Need	Recommendations
<p>Clear, compassionate, and timely information about the patient's status, expectations, and care plan</p>	<p><b>Hospital Staff Can</b></p> <ul style="list-style-type: none"> <li>Provide regular updates about patient status, including test results, treatment options, and prognosis</li> <li>Provide guidance or where to go or whom to approach with questions</li> <li>Give assistance to make informed decisions (e.g., use lay terms, guidance with internet searches, explanation for technical details, encourage a second opinion, and end-of-life discussions)</li> <li>Communicate honestly and clearly about expectations or uncertainty</li> <li>Be compassionate and deliver difficult news with empathy</li> </ul> <p><b>Institutions Can</b></p> <ul style="list-style-type: none"> <li>Provide resources to ensure family members are oriented upon arrival with coordinated communication and basic information about the hospital and cardiac arrest/sTBI</li> <li>Offer private space for family members to use as "home base" where providers can meet with family</li> <li>Designate a "point person" or a "nurse mediator" to serve as the family's coordinator for the duration of the stay and delineate the roles of other members of the healthcare team.</li> <li>Palliative care training for physicians with best practices for the conduct of family meetings</li> <li>Establish communication competencies for providers and offer trainings on multiple topics, including empathetic communication, recognizing family distress, and providing comfort</li> </ul>
<p>To feel respected and part of their loved one's care team</p>	<p><b>Hospital Staff Can</b></p> <ul style="list-style-type: none"> <li>Spend time with family members to build trust, assess communication needs, and build rapport</li> <li>Pay attention to how family members respond when engaging with them and recognize different styles, values, beliefs, and communication needs</li> <li>Deliver news in a human and empathetic way, with sincerity and authenticity</li> <li>Give guidance for how best to interact with their loved one and encourage involvement in their loved one's care and care team discussions</li> <li>Encourage additional family and community members to provide support for the patient and family</li> </ul> <p><b>Institutions Can</b></p> <ul style="list-style-type: none"> <li>Promote family- and patient-centered care</li> <li>Implement quality improvement strategies, such as recording family meetings to provide feedback on providers' communication and promote a culture of continuous learning in communication</li> <li>Provide training and mentoring for providers to understand how sociocultural background affects trust, communication, and healthcare decisions; and how racial inequities affect health</li> </ul>
<p>Various types of support after their loved one is discharged from the hospital or dies</p>	<p><b>Hospital Staff Can</b></p> <ul style="list-style-type: none"> <li>Explain how hospital staff can support transitions (e.g., roles and responsibilities of social workers) and how to access information about resources and support options after discharge</li> <li>Provide information to ease the transition post-emergency department/ICU, including accessing disability benefits, what to expect in behavioral or personality changes, whom to call with questions, and rehabilitation</li> <li>Assist families of nonsurvivors with arrangements, such as funeral planning and autopsy</li> </ul> <p><b>Institutions Can</b></p> <ul style="list-style-type: none"> <li>Develop a continuity of care procedure for postdischarge support and share opportunities with family</li> <li>Assess how staff can support transitions</li> <li>Consider opportunities for families and the care team to reunite to share gratitude and experience</li> </ul>

participating Black family's experience with racism and unacceptable treatment during their family member's hospitalization provides context for how such negative interactions can erode minority families' trust in the healthcare system and willingness to engage in medical research. Tailored and innovative approaches are needed to explore more fully how racism influences family members' experiences. Additionally, we experienced challenges in enrolling families of nonsurvivors during the hospitalization, presumably due to the aversion of reexperiencing the traumas associated with the event or resentment with the outcome.

Future research should explore the relationship between families' information and decision-making needs, health outcomes, and cost. Finally, researchers need to develop and study efficacy of interventions to support family members' informational and decision-making needs through means such as family support tools (23) or decision aids that facilitate shared decision-making (24–26).

## CONCLUSIONS

In this two-phase study, we identified and confirmed major needs of families of patients with SABI after cardiac arrest and sTBI. Key stakeholders' perspectives informed recommendations on how to better support families during the acute phase of hospitalization. Our study underscores the need to include families in discussions on how to optimally tailor care for patients with SABI.

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