A Qualitative Identification of Gaps in Understanding About Brain Death Among Trainees, Health Care Personnel and Families at an Academic Medical Center

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Abstract

Background and Purpose: Death by whole brain criteria (brain death) is a clinical diagnosis. We sought to identify aspects of brain death that were unclear to both health care personnel and patient families. **Methods:** Institutional review board approved cross-sectional survey study of attendings, medical trainees (residents and fellows), senior medical students, advanced practice providers (APPs), and critical care nursing (registered nurses [RNs]) at a tertiary referral center over 6 months (March 2018 to September 2018). Surveys were completed on paper or electronically. Participants supplied the top 3 of (1) their own personal questions regarding brain death and (2) questions received from patient families about brain death from a prepared list of questions. **Results:** Two hundred twenty-nine individuals participated in the survey, with a response rate of 46%. Participation rates in brain death declaration among attendings (92%), RNs (84%), APPs (100%), and trainees of which included fellows (92%) and residents (85%) were high. Most frequently asked questions by trainees and health care personnel were “What are brain death mimics?” and “What is the gold standard testing?”. Questions received from patient families most commonly include “What is brain death?” and “Is brain death reversible?”. All medical students had questions about brain death. Greater than 75% of attendings endorsed having questions regarding brain death. **Conclusion:** Many health care personnel are involved with brain death declaration, but there are gaps in their understanding about fundamentals regarding brain death. We identify a need for early and targeted brain death education regarding brain death and family communication for various members of the health care profession.

Keywords

brain death, medical education, coma

Introduction

Death by whole brain criteria (brain death) is the cessation of brain and brainstem function with irreversible coma following a catastrophic brain injury.¹ The incidence of brain death in the United States is estimated to be 10 000 to 13 800 per year.² The concept of brain death emerged in the 1950s after breakthroughs in intensive care resuscitation, leading to the report of the Ad Hoc Committee of Harvard Medical School,³ with an eventual national legal definition defined by the Uniform Determination of Death Act. Since 1995, the American Academy of Neurology (AAN) has published and consistently updated a clear description of recommended steps in the evaluation of brain death.⁴ The 2019 AAN position statement was recently published and reiterated no known cases where compliant application of brain death guidelines lead to inaccurate diagnosis.⁵ Brain death declaration involves clinical evaluation, including brainstem testing and apnea testing; when this clinical examination remains inconclusive, there is a possibility for ancillary testing.

Despite these well-defined and validated AAN guidelines, there is marked variability in the practice of brain death declaration at a national⁶ and international⁷ level. Surveys of major United States center protocols show deficits in removing confounding factors and using appropriate testing and brain death documentation.^{6,8} A number of explanations for this variability have been proposed: hospital infrastructure, public misinformation, and lack of exposure and comfort across medical subspecialties.^{8,9} A common theme is a lack of formal education in brain death declaration among trainees and an urgency for improved exposure and education to brain death declaration.^{2,5,10}

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The extent to which various health care professionals are being exposed to brain death education and clinical declarations is unclear. Additionally, it appears that medical student knowledge of brain death is limited, and at least one study has attempted an intervention.² It is also unknown if gaps in knowledge change with level of medical training. Yet few recent studies take a wider perspective to include querying the staff and patient interface with brain death.

The primary objective of this study was to identify aspects of brain death that were confusing for both health care personnel and patient families. We investigated specific questions as applicable to patients and staff within an academic medical center with an established brain death protocol.

Methods

We performed an institutional review board–approved cross-sectional survey of trainees and staff at University of California, San Diego (UCSD) Medical Center, an academic medical center with an established brain death protocol based on AAN guidelines.

This study was conducted over a 6-month period January to June 2018. There was no incentive to participation. Surveys were given to different cohorts in spaced clusters over 6 months. The survey included questions related to training and clinical demographics and whether they had participated in a brain death declaration (yes/no). Participants identified their own top 3 questions regarding brain death and questions asked of them by patients' families from a list of 18 provided questions. These questions were generated by a focus group of critical care attendings with specialization in neurocritical care (see Appendix A). Write-in answers were allowed, as was the option to have no questions personally, and/or no questions asked of them.

Surveys were anonymous and distributed to critical care (ie, anesthesia, trauma, surgical, medical, and neurological critical care) and neurosciences (ie, neurology, neurosurgery) attendings, critical care advanced practice providers (APPs) and nurses (RNs), resident and fellow trainees in multiple specialties rotating through the neuroscience and critical care setting, and senior medical students in their third and fourth clinical years. Only neurosciences and critical care attendings were surveyed at our institution because only these attendings are involved in declarations of death by whole brain criteria as per our institutional protocol. Surveys could be filled out on paper (and then data manually entered into the survey platform by the project personnel) or by following a link distributed by email. The survey platform used was SurveyMonkey.com, and data were qualitatively analyzed within this platform.

Results

A total of 499 surveys were distributed, with 229 responses for a response rate of 46%. The majority of individuals completed surveys online. Of respondents, 3% (7) were APPs, 6% (13) were fellows, 13% (30) were medical students, 17% (39) were residents, 26% (60) were attendings, and 35% (80) were

critical care RN (see Figure 1). As can also be seen in Figure 1, 30% (9) of medical students, 84% (67) of RNs, 85% (33) of residents, 92% (55) of attendings, 92% of fellows (12), and 100% (7) of APPs were present for or had participated in a brain death declaration. Fifty-three percent (16) of medical students, 74% (29) of residents, 77% (46) of attendings, 84% (67) of RN, 92% (12) of fellows, and 100% (7) of APPs were asked questions by patient families.

See Table 1 for the distribution of responses for "Top 3 Questions." The top questions among providers included "What is the gold standard testing?" and "What are common brain death mimics?" across nearly all groups, excluding fellows. Questions asked of participants by families were more varied, but top questions included fundamental basics of brain death. Only 3% (1) of residents, 8% (6) of RNs, 14% (1) of APPs, and 15% (2) of fellows had no questions about brain death; 100% of medical students endorsed having questions themselves. Furthermore, 22% (13) of attendings had no questions themselves regarding the declaration of brain death (nearly one-third [4] of which were neuroscience faculty).

Discussion

Herein, we identify a gap in understanding regarding fundamental principles of brain death among relevant sectors of health care professionals, with only a minority of participants expressing a subjective mastery these principles.

A previous large cross-sectional study found that only 35% of attendings and nurses were able to accurately define brain death and they noted inconsistency in the legal and clinical ramifications of brain death declaration.¹¹ Although this Youngner et al study was performed before the first AAN guidelines and 2010 update, more recent studies demonstrate a similar lack of knowledge among various health care team members.^{2,6,12,13} Despite the AAN updates and broader aims at education since,² we too also identified continued uncertainty at a large academic medical center despite a published brain death protocol and active neurocritical care faculty.

A goal of this study was to bring attention to a vulnerable health care demographic in the declaration of brain death: medical students and nurses. Brain death is misrepresented as being the responsibility of attending-level care, often presumed to be an attending neurologist.¹² In our study, 84% of critical care nurses had participated in some way in brain death assessments and are actively asked questions by family members regarding the diagnosis. This is not surprising given the sheer amount of contact time that nursing staff often has with family members as compared with physicians.¹⁴ More surprising is that 1 in 3 clinical year medical students participated in some way in a declaration of brain death.

Although they do not perform the brain death examination per institutional policy, medical student and nursing involvement may include simple observation, preparing the family and answering questions, and/or assistance with aspects of the examination (eg, titrating infusions to stabilize the patient,

Figure 1. Cohorted characteristics of surveyed individuals. Of 229 participants, percentage of the total number of surveys represented by the cohorted group (blue), percentage of each cohort that participated in some form during the brain death declaration (orange), percentage of each cohort that had any personal questions regarding brain death declaration (gray), and percentage of each cohort that were asked brain death–related question by families (yellow).

Table 1. (A) Main 3 Questions Among Surveyed Groups and (B) Questions Asked by Patients.^a

A		Percentage	N			Percentage	N
RN n = 80	Before brain death testing what criteria must be met?	42	34	Resident n = 39	What is the gold standard testing?	33	13
	What are the common brain death mimics?	40	32		What are common brain death mimics	33	13
	What is the gold standard testing?	35	28		Before brain death testing, what criteria need to be met?	33	13
APP n = 7	What are common brain death mimics?	57	4	Fellow n = 13	Before brain death testing what criteria must be met?	30	4
	What is gold standard testing?	57	4		Can a diagnosis of brain death be challenged?	30	4
	Before brain death testing, what criteria must be met?	57	4		Where can I find the UCSD policy?	30	4
Attending n = 60	What are common brain death mimics?	28	17	Medical student n = 30	What is the gold standard?	53	16
	What is the gold standard testing?	27	16		What are common brain death mimics?	50	15
	Where can I find UCSD's policy?	27	16		Before brain death testing, what criteria need to be met?	37	11
B		Percentage				N	
All groups n = 229	What is brain death?	41				91	
	Is brain death reversible?	38				88	
	What logistically happens during brain death declaration?	22				50	

Abbreviations: APP, advanced practice provider; UCSD, University of California, San Diego.

^aThe top portion of table represents the 3 most commonly asked personal questions regarding brain death as cohorted across surveyed staff. The bottom table shows the aggregate top 3 questions by families among all surveyed groups.

preparing ice water, drawing arterial blood gas during apnea testing). We acknowledge that self-endorsed “participation” on the questionnaire is ambiguous, and this was done purposefully since personal ownership in the brain death declaration experience goes beyond the technicalities and performance of the examination; there is a measured subjective experience to participating that can have a lasting impact on an individual. Notably, nurses and medical students had the highest percentage of personal questions regarding brain death but also get asked questions by the family. This incongruity supports need for medical school education on the topic and also emphasizes the need to expand this educational directive toward nursing curriculum. The most common questions we noted that were asked by families could be used as a future template for targeted teaching, as is underway at our institution.

A unique aspect of this study is the particular attention to nursing personnel. The majority of nurses in our study had participated in some way in brain death declaration and were being asked questions by families that require a strong understanding of intricacies in brain death protocol and diagnosis. Few studies have looked at the perspective of nurses, even though nurses play an integral role in recognizing signs of death, daily family communication, and unique care in transition to organ donation.¹⁵ Given that nurses are privy to and often involved in initial questions by family, nurses carry a burden of needing to be tactful, empathetic, and accurate. Ultimately, targeted teaching of brain death declaration to nurses has wider implications of potentially improving the organ donation process.¹⁵

Lastly, our data support the growing recognition that there is poor public understanding about brain death, which also impact goals of care.¹³ The questions asked by families are at a basic level, thus there should be an emphasis on bidirectional conversation and education to the level the family requires. The majority of hospital protocols are ill-equipped for handling family disagreement in brain death declaration, which can have negative emotional, social, and financial consequences.^{16,17} Public and family mistrust in brain death may benefit from protocolized responses.¹⁶ We feel these responses should include review of basic knowledge that the family has regarding the diagnosis. Imparting knowledge—and asking *why*—is one easily executed solution to address barriers to brain death acceptance⁹; given the nuanced nature of societal, religious, and personal belief, this should be further investigated.

Limitations to this study include possible regional bias and the fact that this study reflects an academic center in southern California. Furthermore, this sampling is from 2 large centers within our medical system. Thus, it is unclear if these results hold in community settings. Additionally, any survey-based study has the potential for sampling and response bias. It is possible some participant responses may represent the same brain death declaration, especially among nurses and medical student care teams that rotate frequently, though the focus of this study was on the individual provider’s experience. We furthermore did not survey health care providers regarding

their prior education in brain death and we do not know at what point during the brain death declaration process families posed questions. It may be of interest in the future to also explore where families received their knowledge of brain death, as a reflection of the health care team’s ability to educate families.

Finally, this was a highly selected population of participants, with the majority either having expertise in neurology or critical care (ie, anesthesia, trauma, surgical, medical, and neurological critical care). Although some might see this as a limitation of the study, we chose this participant population because these are the professionals who are most often involved with the care of a patient who progresses to brain death—and theoretically should be most aware of and abreast of issues surrounding a diagnosis of brain death—or in the declaration of brain death. Even so, our results indicate that these individuals with subspecialty training still have basic questions about a—quite frankly—life or death topic. A survey of a community setting where there are fewer subspecialists may show an even lower level of comfort with brain death. Of note, the majority of brain death examinations in the community are done by practitioners outside of neurosciences specialties.¹² This is concerning given multiple studies demonstrating a discomfort with the declaration of brain death among generalists.^{6,12} However, knowledge of brain death—and the ability to appropriately educate families and answer questions—is a universal medical professional responsibility and is not solely knowledge restricted to specialists, arguing again in favor of targeted medical student and general resident trainee-level education on the topic.

It was outside the scope of this project to evaluate brain death knowledge, comfort level, or competency examination as in other studies.^{2,12} Future directions will be toward creating educational interventions and reevaluating posteducation subjective comfort with and objective knowledge of brain death. The Neurocritical Care Society recently released the “Brain Death Kit,”¹⁸ a series of webinar, proposed checklists, frequently asked questions, and core guidelines material which may be integrated into a targeted curriculum.

Brain death fundamentals remain elusive to many individuals involved in the care of patients undergoing clinical assessment for brain death as well as family members of loved ones who progress to brain death. We identify a compelling need for timely and targeted education about brain death and family communication at all levels of medical training including clinical medical students, and also for nurses and APPs. Our institution is currently in the process of implementing targeted education. We hope that other institutions will consider refocusing their education plan about brain death to include these health care professionals as well, since education is critical for the use of appropriate terminology and avoidance of misinformation about such an important topic.

Appendix A

Study Survey

Copy of survey utilized during study which included questions on level of training, top 3 questions individuals had and top 3 questions participants were asked by families.

Understanding Brain Death

What's your level of training?

☐ MD/DO

Level: ☐ Attending ☐ Fellow
☐ Trainee, PGY-_____

Specialty: _____

☐ Medical Student, MS-_____

☐ RN

☐ NP/PA

Have you ever taken care of a patient who underwent brain death examination or was declared dead by brain death criteria? YES No

What are the top three questions you personally have regarding brain death?

- ☐ I don't have any questions.
- ☐ What is brain death?
- ☐ How is brain death different from cardiac death?
- ☐ Is brain death reversible?
- ☐ What are common brain death "mimics"?
- ☐ What causes brain death?
- ☐ What is the gold standard testing?
- ☐ Before brain death testing, what criteria need to be met?
- ☐ When can you declare brain death, who declares it, and how?
- ☐ How do you perform apnea testing?
- ☐ Does an apnea test always need to be performed?
- ☐ What happens if the clinical exam is inconclusive or apnea test cannot be completed?
- ☐ What ancillary tests exist?
- ☐ What if my patient is becoming hemodynamically unstable, but brain death hasn't formally been diagnosed yet?
- ☐ How do I find another attending to perform the second brain death exam?
- ☐ Can a diagnosis of brain death be challenged?
- ☐ Where can I find the UCSD policy?
- ☐ What logistically happens after brain death is declared?
- ☐ Other: _____

What are the top three questions you have been asked by families regarding brain death?

- ☐ I have not been asked any questions.
 - ☐ What is brain death?
 - ☐ How is brain death different from cardiac death?
 - ☐ Is brain death reversible?
 - ☐ What causes brain death?
 - ☐ What are common brain death "mimics"?
 - ☐ What is the gold standard testing?
 - ☐ Before brain death testing, what criteria need to be met?
 - ☐ When can you declare brain death, who declares it, and how?
 - ☐ How do you perform apnea testing?
 - ☐ What happens if the clinical exam is inconclusive or apnea test cannot be completed?
 - ☐ What ancillary tests exist, and what are their limitations?
 - ☐ Can brain death be challenged?
 - ☐ Where can I find the UCSD policy?
 - ☐ What logistically happens after brain death is declared?
 - ☐ Other: _____
-

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