Investigation of Public Perception of Brain Death Using the Internet

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BACKGROUND: Brain death is a difficult concept for the public to comprehend, resulting in a reliance on alternative resources for clarity. This study aims to understand the public's perception of brain death via analysis of information on the Internet, determine the accuracy of that information, and understand how its perception affects the physician-patient relationship.

METHODS: We conducted a prospective cross-sectional study to evaluate information available to the public about brain death. The top 10 Google websites were analyzed for language complexity and accuracy in describing brain death. The top 10 YouTube videos were examined for content and the comments qualitatively analyzed for themes.

RESULTS: Inaccuracies describing brain death inconsistent with national guidelines were prevalent amongst 4 of 10 Google websites, 6 of 10 YouTube videos, and 80% of YouTube comments. On average, Google websites were written at a 12th grade level and 90% mentioned organ donation. Videos were frequently emotional (78%); 33% included negative comments toward physicians, of which 50% mentioned organ donation. All videos included clarification comments questioning the differences between brain death, death, coma, and persistent vegetative states.

CONCLUSIONS: The study revealed a significant amount of inaccurate information about brain death, affecting the public's understanding of the concept of brain death and resulting in negative emotions specifically toward physicians, and the link between brain death and organ donation. The medical community can improve understanding through consistent, simplified language, dissociating brain death from organ donation, and recognizing the emotions tied to discussions of brain death.

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FOR EDITORIAL COMMENT, SEE PAGE 238

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The concept of “brain death” was first acknowledged in 1968, when the Ad Hoc Committee of the Harvard Medical School published a landmark report equating irreversible coma to death.¹ The medical royal colleges in the United Kingdom followed in 1979,² and in the United States, the Uniform Determination of Death Act further solidified the term in 1981.³ Although the medical field appears to have broad consensus defining brain death as the irreversible loss of all brain functions, including those of the brainstem, controversy still remains among ethicists and physicians.⁴⁻⁹ Even more uncertainty and distrust of the concept of brain death exist in the public.^{10,11}

A 2004 telephone survey of 1,351 participants revealed that only 34% of respondents believed someone who was brain dead was legally dead.¹² In addition, the mainstream media have reported misleading, often inaccurate information in highly publicized cases of brain death.¹³ These inaccuracies further erode public trust in the medical community. Unfortunately, the rapid growth of Internet use (from 50% of US adults in 2000 to 90% in 2017) has resulted in more unfiltered, often inaccurate information available to the public.¹⁴

On the Internet, Google is the largest public search engine, followed by its video-sharing website subsidiary, YouTube.^{15,16} Google receives more than 100 billion searches per month and YouTube has over a billion users, constituting almost one-third of Internet users.^{17,18} A Google search of “Can you come back from being brain dead?” produced more than 1.6 million results; however, the accuracy of the information found on these websites is unknown. Previous literature examining news articles about brain death revealed brain-dead individuals described as “alive” or on “life support” and less than 3% defined brain death.¹⁹ Approximately 80% of Internet users conduct health-related searches and seek clarification of medical terms^{20,21} frequently before consulting their own physician.²²⁻²⁵ Since the two most common sources for information on the Internet are Google and YouTube,¹⁵ we aimed to understand the public’s perception of brain death via analysis of information provided by those resources regarding brain death, to determine the accuracy of that information, and to understand how that information affects the physician-patient relationship.

Materials and Methods

Study Design

We conducted a prospective, cross-sectional study using Google and YouTube to evaluate the public’s understanding and perceptions of the term “brain death” and to assess the accuracy of that description when compared with the definition of brain death in the 2010 national guidelines.^{4,5} Search terms “brain dead” and “brain death” were selected, and the top 10 Google websites were identified. Google applies a ranking system composed of a series of algorithms to identify websites regarding a search term. These algorithms analyze the search term, match it to keywords within a website, and return websites with the best information, including how recently the content was updated, the number of times the search term appeared, and whether the website has had good user experience.²⁶ This algorithm removes spam websites—which repeat keywords continuously or pay to have a higher ranking—from the results.²⁶ In addition, we conducted the search on three separate computers outside of the hospital to prevent prior Internet browsing history from affecting search results. None of the top websites paid to have their website listed. We included only the first 10 websites because those found on the first page of a Google search account for 92% of all web traffic.²⁷ The search terms “brain dead” and “brain death” were similarly entered into YouTube, and the top 10 videos, based on number of views, were identified for study inclusion.

Data Collection

In May 2017 we collected the following data from the top 10 Google websites: source, website address, intended audience (public vs professional), accuracy of website information (comparing the website definition of brain death with the 2010 guidelines⁴), and mention of organ donation. As the websites are directed at the public, we assessed language complexity and readability using the Microsoft

Word “grammar summary statistics.” These include (1) the percentage of passive sentences, (2) the Flesch Reading Ease score,²⁸ and (3) the Flesch-Kincaid Reading Grade Level score.²⁹ A higher percentage of passive sentences indicates more formal language. The Flesch Reading Ease and Flesch-Kincaid Reading Grade Level scores calculate educational level necessary to understand a piece of text and its ease of reading. Reading ease is scored between 0 and 100; “plain English” ranges from 60 to 70. Higher scores indicate the text is easier to read.

We searched the top 10 YouTube videos in March 2017 and 3 months later in June 2017 because YouTube frequently updates “view count” per video to reflect the video’s popularity.³⁰ For each video, we collected the following: source, number of views, release date, production quality (amateur vs professional), accuracy of information regarding brain death, video length, overall tone, and number of comments. Professional videos included videos by news production teams with minimal movement during filming and professional staging; whereas, amateur videos had shaking cameras or lower resolution quality. Exclusion criteria for selecting YouTube videos included non-English descriptions, music videos, and full-length movie parodies based on the music band “Brain Death,” resulting in exclusion of 14 videos.

YouTube Video Coding

We applied qualitative analysis to code the content of YouTube comments into similar themes based on the intention and meaning of each comment.^{31,32} Because of the large number of comments for Video 1 (8,845), we selected the median number of comments (95) to code. Only one comment per YouTube username was included. Emotional comments were coded as empathetic, neutral, or derogatory. We also classified the content of the comments as information seeking, neither providing nor seeking information, or providing information. We used investigator triangulation to

qualitatively analyze the comments.³³ A random sample of 20% of the comments was selected by a third researcher to determine interrater reliability between coders. The Cohen's kappa was 0.97 ($P < .001$).

This study was deemed exempt by the Children's National Health System's Institutional Review Board Electronic Application Review System, approval number Pro00008797.

Results

Google Results

The search terms "brain death" and "brain dead" returned 27.9 million results. Of the top Google websites, 4 of 10 (40%) presented inaccurate descriptions of brain death when compared with the national guidelines definition (Table 1). For example, the National Center for Biotechnology Information's website states "when we pronounce individuals dead by neurological criteria, they are not really dead."³⁴

Almost all of the websites (nine of 10; 90%) mentioned organ donation. For example, Wikipedia states, "patients classified as brain-dead can have their organs surgically removed for organ donation," which is followed by an entire section on organ donation with a link to the organ donation Wikipedia website. The majority of websites (seven of 10) were written for the public, and three were written for a professional audience. On average, 23.2% of the sentences were passive and written at a 12th grade level. The average reading ease score was 46, equivalent to an undergraduate college student level of

comprehension. Two websites (20%) reference the highly publicized Jahi McMath brain death case. This 2013 case involved a 13-year-old girl who underwent tonsillectomy and adenoidectomy, with subsequent cardiac arrest secondary to uncontrolled bleeding in the postoperative period, who was declared brain dead in California. Despite a certificate of death issued at that time, her family petitioned to have her body moved to New Jersey, where she remains as of November 2017 with tracheostomy in place and on mechanical support.^{35,36}

YouTube Results

The top 10 "brain death" and "brain dead" videos were viewed nearly 5.5 million times and were produced between 2011 and 2016 (Table 2). The top video received nearly 3 million views and lasted 3 min. The length of videos ranged from 00:38 s to 18:51 min, and averaged 3:43 min. Most videos were professional (80%), either news broadcasts or produced for educational purposes, and presented a case report (70%).

TABLE 1] Google Website Demographics

Website ^a	Accurate	Mentions Organ Donation	Audience	Passive Sentences (%)	Reading Ease ^b	Grade Level
Wikipedia: Brain Death	Yes	Yes	Public	25	28.2	16.3
<i>Indian Journal of Critical Care Medicine: The Diagnosis of Brain Death</i>	Yes	Yes	Professional	21	26.2	13.2
<i>Journal of the South Carolina Medical Association: Brain Death, Cardiac Death, and the Dead Donor Rule</i>	No	Yes	Professional	15	43.1	12
American Academy of Neurology: Determining Brain Death in Adults	Yes	Yes	Public	27	52.4	8.9
WebMD: What "Brain-Dead" Means	Yes	Yes	Public	13	63.7	8.9
Finger Lakes Donor Recovery Network: Understanding Brain Death and Organ Donation	Yes	Yes	Public	18	65.9	7.8
Huffington Post: How Long Will a Brain-Dead Person's Body Keep Working?	No	Yes	Public	34	42.8	12.4
FindLaw: Brain Death vs Persistent Vegetative State	Yes	Yes	Professional	25	41.6	12.7
CNN: Why Brain Dead Means Really Dead	No	No	Public	10	51.7	10.6
Bob Enyart Live: "Brain Dead" Means "Not Dead"; Don't Trust That Diagnosis	No	Yes	Public	13	51.8	11.5

^aAccessed May 24, 2017.

^bReading Ease: increased scores indicate a piece of text is easier to read; a score of 60 to 70 is considered "plain English."

TABLE 2] YouTube Video Demographics

Title ^a	Source	No. of Views	Production	Tone	Accurate	Length (min)	No. of comments
Brain Dead Teen, Only Capable of Rolling Eyes and Texting, to Be Euthanized	The Onion	2,993,802	Professional	Humor	No	3:09	8,845
Thrown in Pool by Instructor Leaves Young Girl Brain Dead	AppleDaily	827,182	Professional	Case report	Yes	1:04	150
Whitney Houston's Daughter Bobbi Kristina Reportedly Brain Dead	GistOnItNow	697,370	Professional	Case report	No	2:50	82
Jahi McMath Moving Arm Twice by Request #Jahi	Family	477,953	Amateur	Case report	No	0:38	0 ^b
Brain Death—Rare Complex Spinal Reflex—Lazarus Sign	Neurosurgeon	229,218	Amateur	Case report	Yes	0:43	105
Student Wakes Up From Coma	ABC News	192,177	Professional	Case report	No	2:01	39
Is a Brain Dead Person Actually Dead?	DNews	190,751	Professional	Educational	Yes	3:26	226
3-Year-Old Boy Declared Brain Dead After Cops Say Mother's Boyfriend Abused Him	Inside Edition	178,564	Professional	Case report	No	1:12	164
Brain Dead Girl's Body Moved, But How?	CNN	97,023	Professional	Case report	No	3:19	84
Clinical Brain Death Testing	College of Intensive Care Medicine of Australia and New Zealand	77,065	Professional	Educational	Yes	18:51	27

^aAccessed March 20, 2017.^bComments disabled for this video.

The most popular video, posted by “The Onion,” was designed as satire, involving a “brain dead” teenager distracted by technology, who walks, talks, and is without any neurologic deficits. Videos were reaccessed 3 months later, and only one new video emerged on the top 10 list; it was entitled “Can Stem Cells Bring ‘Dead’ Back to Life?” This video discussed a “novel technology to bring brain dead

patient back to life,” was produced in May 2016, with 191,513 views.

Sixty percent of videos contained inaccurate information regarding brain death. There were two main forms of inaccuracies identified: (1) use of “brain dead,” “coma,” and “persistent vegetative state” as interchangeable terms and (2) an inaccurate description of brain death,

such as in “The Onion” video where a teen classified as brain dead has full mental and physical capacities.

YouTube Comments

We coded 707 comments, of which 178 were coded as “neutral” because the comment was unrelated to the video content, for example, “my son has same name.” Excluding neutral comments, four major themes emerged among the remaining 529 comments: negative emotional response, positive emotional response, brain death clarification, and spirituality (Table 3). Negative emotion, the most common theme, was further subdivided into three targets of negative emotion: toward the poster/video, physicians, or organ donation. There were no positive comments toward doctors or regarding organ donation.

The majority of comments (74%) neither provided nor sought information, 18% provided information, and 8% were coded as information seeking. Of those providing information, 80% were inaccurate in describing brain death, for example “I know personally 2 people who did wake up...surely one of them was brain dead” and “Brain death is not actual death.” All videos included comments requesting brain death clarification, of which 84% requested clarification between “brain death” and death, coma, and persistent vegetative states.

Twenty-one percent of these comments were from “The Onion” satire video, suggesting the viewer frequently believed this was really a case of brain death, for example, “Seriously?! A second opinion from a different doctor could’ve saved her life!” The art of satire often consists of exaggerating, typically through humor, an emotionally or politically charged topic. The fact that many people are unable to distinguish satire from reality in “The Onion” video is worrisome and may be due in part to the grave nature of the topic of brain death.

Discussion

In this study we examined public exposure to the terms “brain death” and “brain dead” using the two most commonly accessed resources on the Internet and found not only a profound lack of understanding of the term, but also a predominance of negative emotions, specifically toward the term “brain death” and the medical field. CNN produced the ninth most popular video, “Brain Dead Girl’s Body Moved, But How?,” which discusses the Jahi McMath case and resulted in extremely negative emotions in the YouTube comments. The phrases used, such as “dead body” and “parents’ ghoulish behavior,” were perceived as emotionally insensitive and resulted in anger directed toward the news anchors and the medical community as a whole.

TABLE 3] Similar Themes Across YouTube Video Comments

Theme	Definition	N = 529 Comments [No. (%)]	Sample Quote
Negative emotion		242 (46)	
Toward poster/video	An angry/negative response directed at video subject or poster	187 (77)	“These people have no respect, their language is not only disrespectful but disgusting”
Toward physicians	An angry/negative response directed at physicians or health care	34 (14)	“These disgusting doctors, they won’t even give people a chance to fight for their life. After only one week and ready to pull the plug and harvest his organs. Damn shame. I’m glad the young man woke up.”
Toward organ donation	A response negatively referencing organs or organ donation	21 (9)	“Doctors are like vultures on ppl in coma .For their organs ..”
Positive emotion	An empathetic response directed at video subject or poster	158 (30)	“Oh my god heartbroken”
Brain death clarification	Asks a question or comment regarding brain death	83 (15)	“Was he actually dead though? The beep machine was on & he still had all the tubes etc strapped onto him?”
Spirituality	A religious-based response from the commenter	46 (9)	“From the point of view of MEDICINE???? NOT from the point of view of GOD!!!!”

This resentment erodes the therapeutic relationship we hope to form with families and complicates their grieving process.³⁷ It is also a call to the medical community to recognize the emotional weight of the term “brain death” and acknowledge it cannot be treated solely with medical explanations. During this stressful time, families and their communities need their medical team to acknowledge their loss and respond with empathy.³⁸

One major source of distrust revealed in reviewing YouTube comments is the association between brain death and organ donation. Ninety percent of Google websites mention organ donation, and on YouTube, comments regarding organ donation were universally discussed in a negative light, with several accusing physicians of falsely declaring someone dead to acquire their organs. The linkage of brain death and organ donation on the Internet may add to the negative emotions surrounding this topic and skew public perception of a physician’s intent in declaring a patient brain dead. In most medical centers, attempts are made to separate brain death from organ procurement, yet on the Internet, these terms are coupled. As many of the top Google websites are produced by medical organizations, future medical websites should consider the impact of connecting these terms if the public is the audience we seek to educate.

Severing the bond between brain death and organ donation is one way to improve the delivery of information to the public. The larger challenge the medical community faces is to ensure the accuracy of this information. Unfortunately, we found an abundance of false information on Google (40%) and YouTube (60%). The terms “brain death,” “persistent vegetative state,” and “coma” were used almost interchangeably. In addition to inaccuracies, information on the websites is also difficult to understand. On average, a 12th grade level is required to understand the text despite the National Assessment of Adult Literacy report recommendation that text be written between the 7th and 8th grade levels.³⁹ Acknowledging that most people begin seeking health-related information on the Internet, material published online should be written at a reading level appropriate for the target audience.

Because of the emotional complexity and the perceived ambiguity in describing brain death, it is unlikely the public denial of brain death will diminish. In fact,

disagreements with the medical community are likely to increase as people rely on the Internet more heavily.^{40–42} The Internet has transformed the way news is disseminated to the public, and the publicized case of Jahi McMath is an example of how media exposure brought the topic of brain death to the forefront.^{43,44} Ms McMath was mentioned in two of the top Google websites and was the subject of two of the most viewed YouTube videos. Despite declaration of brain death, the McMath family has been steadfast in believing their daughter is alive and have a widespread Internet following. The national attention this case continues to receive emphasizes the distrust in the medical community by many families and highlights the need for explicit explanation of brain death.

Limitations

To our knowledge, this is the first study to evaluate the public understanding of brain death, using the Internet. Although there are strengths in this article, there are several limitations to consider. We chose to evaluate only the top 10 Google websites and YouTube videos associated with brain death. Public opinion viewing more data may result in different results, although Internet data suggests most users do not search beyond the first page. In addition, views regarding brain death on YouTube are not representative of the population as a whole since younger audiences are more likely to use YouTube, and only a select number of YouTube users post comments on videos. We are not able to capture the views of YouTube users who do not post comments. Posting of comments is voluntary, creating selection bias among those who post. This study also does not reflect the views of individuals without access to the Internet.

Conclusions

The public most commonly seek information regarding brain death from Wikipedia, and on YouTube, a satire produced by “The Onion” was most commonly viewed. These resources and the other top 10 Google websites and YouTube videos unfortunately often provide inaccurate information to the public. Knowing our patients and families are exposed to unreliable information, the medical community should use the Internet to educate our patients using language that is readable, accurate, and clear when describing brain death.

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