

INVESTIGATION OF PUBLIC PERCEPTION OF BRAIN DEATH USING THE INTERNET

Amy H. Jones, MD
Pediatric Critical Care Fellow
Children's National Medical Center
amyhopejones@gmail.com

Zoelle B. Dizon, BA
Tessie W. October, MD, MPH

Aims: Brain death is a difficult concept for the public to comprehend, resulting in a reliance on alternative resources for clarity. The Internet is the most likely source patients and families use to gather health-related information. This study aims to understand the public's perception of brain death via analysis of information on the Internet, determine accuracy of that information, and understand how its perception affects the physician-patient relationship.

Significance: Inaccuracies and misinformation erode public trust in physicians and lead to confusion regarding the differences between brain death, coma, and persistent vegetative states, which in turn harms the physician-patient relationship.

Methods: We conducted a cross-sectional study using Google, the most popular search engine, and YouTube, the most popular video-sharing website, to evaluate the public's perception of the terms "brain dead" and "brain death". The top ten Google websites were analyzed for language complexity and accuracy in describing brain death. The top ten YouTube videos were examined for content and the comments qualitatively analyzed for themes.

Key Findings: Inaccuracies describing brain death inconsistent with national guidelines were prevalent amongst 4/10 Google websites, 6/10 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 towards physicians, of which 50% mentioned organ donation. All videos (100%) included clarification comments questioning the differences between brain death, death, coma, and persistent vegetative states.

Implications: This study revealed a lack of public understanding of brain death, a predominance of negative emotions, specifically towards 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.