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# Healthcare Professionals' Understandings of the Definition and Determination of Death: A Scoping Review

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**Background.** During the 1950s, advances in critical care, and organ transplantation altered the relationship between organ failure and death. There has since been a shift away from traditional cardiocirculatory based to brain-based criteria of death, with resulting academic controversy, despite the practice being largely accepted worldwide. Our objective is to develop a comprehensive description of the current understandings of healthcare professionals regarding the meaning, definition, and determination of death. **Methods.** Online databases were used to identify papers published from 2003 to 2020. Additional sources were searched for conference proceedings and theses. Two reviewers screened papers using predefined inclusion and exclusion criteria. Complementary searches and review of reference lists complemented the final study selection. A data extraction instrument was developed to iteratively chart the results of the review. A qualitative approach was conducted to thematically analyze the data. **Results.** Seven thousand four hundred twenty-eight references were identified. In total, 75 papers met the inclusion criteria. Fourteen additional papers were added from complementary searches. Most were narratives (35%), quantitative investigations (21%), and reviews (18%). Identified themes included: (1) the historical evolution of brain death (BD), (2) persistent controversies about BD and death determination, (3) wide variability in healthcare professionals' knowledge and attitudes, (4) critical need for BD determination revision. **Conclusions.** We concluded that although BD is widely accepted, there exists variation in healthcare providers' understanding of its conceptual basis. Death determination remains a divisive issue among scholars. This review identified a need for increased opportunities for formal training on BD among healthcare providers.

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## INTRODUCTION

During the 1950s, advances in technology within critical care medicine, particularly mechanical ventilation and circulatory resuscitation, and innovations in organ transplantation together altered the relationship between organ failure and death.<sup>1-3</sup> By supporting, repairing, or replacing organ function, these technologies eliminated the necessity of the traditional "vital signs": respiratory, cardiac,

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and neurological function in sustaining life. For example, mechanical ventilation replaced respiration and supported heart function to prevent cardiac arrest, which interrupted the way death occurred. The boundaries between being alive, dying, or being dead became blurred.

In 1968, the Ad Hoc Committee of the Harvard Medical School developed a landmark document for defining and determining death, thereby declaring brain death (BD) to be a biological event, and introduced the concept of whole BD.<sup>4</sup>

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However, this shift away from the traditional circulatory determination of death to a brain-based definition and determination of death has continued to spark controversy and debate in the literature among ethicists, scholars, and clinicians.

Brain death refers to the irreversible cessation of neurological function. Circulatory death refers to the permanent loss of circulatory function, which ultimately results in loss of circulation to the brain and BD. Because of advances in organ transplantation, the concept of *permanent* and *irreversible* loss of function came to the forefront of defining death. This had significance for both donation after neurological determination of death and donation after circulatory determination of death (DCDD). In context, *permanent* refers to loss of function that will not resume spontaneously and will not be restored through intervention. Meanwhile, irreversible refers to a situation or condition that will not or cannot return or resume.5 Functions that cease permanently will almost inevitably cease irreversibly without intervention,<sup>6</sup> however, this distinction is especially important in DCDD to uphold the dead donor rule, which states that the act of donation must not cause the donor's death. Although the dead donor rule was previously held as a nearly sacrosanct rule in the transplant community, it is increasingly scrutinized by scholars with many proponents for the loosening of its definition in practice. Although death is largely a clinical diagnosis, there is significant variation in the guidelines for determination of both death by neurological and circulatory criteria.7-10

Much of the academic literature has been dedicated to the controversy surrounding the definition and determination of BD. Yet both legally and clinically, the determination of BD in critically ill patients is practiced and highly accepted by clinicians worldwide.<sup>7</sup> The laws and practice surrounding BD determination have also remained largely unchanged since inception. Little is known about the perspectives of key stakeholders, that is whether the types and extent of controversies among healthcare professionals (HCPs) are representative of those in the literature. The goal of this scoping review is to describe the current understanding(s) of HCPs regarding the meaning/definition of death and its determination, and analyze the extent, range, and nature of the evidence in this area. A separate scoping review (underway) will describe the perspectives of the public on this same topic.

### **MATERIALS AND METHODS**

This review was undertaken in accordance with the Joanna Briggs Institute methodology for scoping reviews<sup>11</sup> and the PRISMA-ScR checklist.<sup>12</sup> As a scoping rather than a systematic review, study inclusion was not limited by quality or methodology, and all aspects of HCPs' understanding of death definition and determination were included.

#### **Literature Search**

We used a 2-step process for this review. The first step was to identify similar systematic or scoping reviews on the topic of BD meaning, definition, and determination. We searched online databases Ovid MEDLINE and PsychINFO to identify a known set of studies relevant to the topic. The topic was refined based on identification of research gaps in the systematic review literature. Two independent reviewers (S.S. and L.H.) screened titles and abstracts in duplicate.

We used key search terms identified from the systematic reviews to refine the search strategy for a second search of online databases and gray literature sources (see Appendix S1, SDC, http://links.lww.com/TXD/A410 for the search strategy). An information specialist (R.F.) searched Ovid MEDLINE, Ovid PsycINFO, and CINAHL using controlled vocabulary and text words for concepts: death, organ donation, determination, and attitudes. R.F. also searched Conference Proceedings Citation Indices, ProQuest Dissertations & Theses Global, and Google Scholar for any additional results. Search results were limited to studies published post-2003 in English or French. The search was updated July 2021. Duplicates were removed.

We included studies that explicitly discussed healthcare provider attitudes around BD or circulatory death. We defined "healthcare providers" to include medical and nursing students, physicians, and nurses involved in caring for either adult or pediatric populations. Our search yielded many articles that described people's understanding of death/ determination of death within the context of organ donation. We excluded those focused primarily on organ donation and transplantation, definitions of a "good death," which referred to papers focused on experiences of around palliation and end of life care.

#### Screening

Two independent reviewers (S.S. and K.Z.) screened titles and abstracts using predefined inclusion and exclusion criteria. Articles were divided by 2 stakeholder groups, healthcare providers, and the public. The focus of this scoping review is on the healthcare workers subset of the search. Both reviewers extracted data for specific content variables and performed the descriptive examination. The full text of selected citations was then retrieved and assessed in detail against the criteria by the 2 independent reviewers. Any disagreements were resolved through discussion.

#### **Data Extraction and Synthesis**

A data extraction instrument was developed to iteratively chart the results of the review. Extracted fields included authors, year of publication, country of origin, type of text, language, aims/purpose, study population, methodology, and key findings. S.S. and K.Z. extracted data and undertook thematic analysis of included studies. Additional papers identified from review of the reference lists of included papers and hand searches of the literature were included for data extraction. All data were extracted in duplicate (S.S. and K.Z.).

## RESULTS

Of a total of 4935 search results, 64 met the inclusion criteria initially. The updated search done July 2021 captured 1042 additional abstracts, of which a further 11 were included. Fourteen papers were added from hand searches, resulting in 89 total papers included for data extraction (see Figure 1 for the PRISMA diagram). Appendix S2 (SDC, http://links.lww.com/TXD/A410) provides a complete list of all included studies, their characteristics, and main findings. Table 1 provides a listing of the characteristics of included papers. The most common study type was narratives (35%), followed by quantitative studies (21%) and reviews (18%), and most studies originated from North America (64%) and Europe (18%). The papers meeting inclusion criteria pieced together the historical evolution of the death definition, from the traditional circulatory criteria, to the nuanced concepts

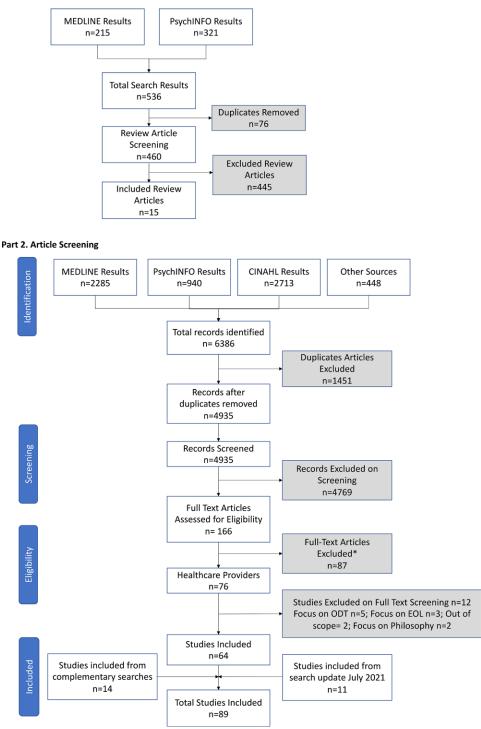


FIGURE 1. PRISMA flow diagram for included studies.

of BD and circulatory death, to the more recent initiative to achieve uniformity in the BD definition.

# **A Brief History of Brain Death**

To understand the current state of BD, it is imperative to understand the historical context, which gave rise to contemporary definitional issues. The precise history of defining BD and death determination dates back centuries and is beyond the scope of the current review. Our historical starting point begins in the 1950s with the innovations such as mechanical ventilation, and the practice of transplantation thereby altering the relationship between organ failure and death<sup>1-3</sup> (Figure 2). The climate of the BD controversy necessitated the publication of the landmark document, Report of the Ad Hoc Committee of the Harvard Medical School to produce a brain-based definition of death,<sup>4</sup> followed in 1976 by the Conference of Medical Royal Colleges,<sup>13</sup> which defined brainstem death. BD gained worldwide acceptance, but there

### TABLE 1.

Characteristics of included papers (n = 89)

Descriptor		N (%)
Source	Initial search	64 (72)
	Complimentary searches	14 (16)
	Updated search	11 (12)
Type of paper	Narrative/opinion	32 (35)
	Quantitative	19 (21)
	Review	16 (18)
	Policy papers	6 (7)
	Book chapter	5 (6)
	Panel report	5 (6)
	Qualitative	4 (4)
	Mixed-methods	1 (1)
	Case report	1 (1)
Country of publication <sup>a</sup>	United States	45 (51)
	Europe	16 (18)
	Canada	12 (13)
	Asia	6 (7)
	Oceania	3 (3)
	South America	3 (3)
	Other	4 (4)
Language	English	89 (100)
Publication Date	Pre-2013	33 (37)
	2013–2021	56 (63)

Country where the study was conducted or when not available, the country of the lead author.

lacked consensus on diagnostic criteria. To rectify growing controversy, the Uniform Determination of Death Act was legislated in 1981 in the United States,<sup>14</sup> which specified 2 criteria for determining death: cardiorespiratory and neurological. For most of the 1980s and 1990s the BD controversy focused on the biological concept of death versus the medical standards of death, and much of the scholarly literature was consumed by answering 2 questions: Are brain-dead donors dead? Are DCDD donors dead?

Ongoing efforts to clarify and establish BD guidelines included the 1995 American Academy of Neurology Guidelines,<sup>15</sup> the 1999 Canadian Neurocrit Care Group guidelines,<sup>16</sup> the 2006 Canadian neurological determination of death and DCDD Guidelines,<sup>17</sup> and the 2013 Australia and New Zealand Intensive Care Society statement.<sup>18</sup> The 2008 Report of the President's Council of Bioethics<sup>19</sup> controversially suggested that BD was death caused by the loss of the organism's ability to "perform its self-preserving work." In 2010, the American Academy of Neurology Practice Parameters<sup>20</sup> stated that the variability in BD policy was a known national problem inadequately addressed solely with updates from professional society guidelines.

Brain death scholars note that recent legal challenges to BD, like the Jahi McMath case, have served to renew and reinvigorate BD and death determination controversies.<sup>21-25</sup> To address the ongoing controversy, the first phase in the development of international guidelines for death determination took place in 2014 to develop a single operational definition of human death.<sup>5</sup> The World Brain Death Project report, published in 2020, provides recommendations for the minimum clinical standards for determination of BD in adults and children, based on review of the literature and an international, multidisciplinary expert panel.<sup>26</sup>

#### **Controversies Around Brain Death**

A closer look at the historical evolution and persistent controversies revealed several key themes around death, especially BD. Table 2 outlines 6 key controversies in the literature. Perhaps the most debated is whether BD is a manifestation of biological death. Scholars who view BD as a manifestation of biological approach appear on the left of Table 2,<sup>27:35</sup> whereas those in disagreement appear on the right.<sup>2,36:43</sup> Another domain of controversy is whether current whole-brain concepts of death should be favored<sup>1,31,32,35,44,45</sup> over some version of a circulatory or higher brain concept.<sup>39,46-52</sup>

The basis of BD definitions continues to be questioned by some as being unscientific, or illogical, and contrived to facilitate organ donation.<sup>2,39,42,53-55</sup> Others have suggested that BD determination criteria are not measuring loss that is truly irreversible.<sup>54,64,65,68</sup> More recently with the rise of DCDD, controversy over whether DCDD donors are really dead has become an increasing issue of debate. This issue has plagued the practice of donation since its inception.59 The central argument here focuses on Bernat's distinction between the concepts of permanence and irreversibility.<sup>2</sup> Joffe provides several arguments for why the permanence standard is conceptually flawed, and thus states DCDD donors cannot be presumed dead at the time their organs are surgically recovered. On the other hand, Bernat's 2018 paper argues the answer to the fundamental question of whether the donor is dead when declared dead within a DCDD protocol is yes because the donor's cessation of circulation and respiration is permanent.58 Those who advocate a single brain-based definition of death emphasize that the permanent loss of circulation results in the irreversible loss of brain function.<sup>5</sup> Disagreement also persists regarding whether current criteria and tests used for the determination of BD are appropriate and sufficient to determine loss of function.<sup>5,17,36,38,61-63,66,67</sup>

# Healthcare Provider Knowledge and Attitudes of Death Determination

Without question, there are ongoing controversies among scholars regarding the definition of BD and its determination, but there also exists considerable variation between healthcare providers, between medical institutions, and even within providers at the same institution.<sup>69</sup> Table 3 illustrates 25 empirical studies retrieved that examined HCP understanding of BD. Twenty studies used a quantitative approach<sup>53,68-86</sup> and 3 used a qualitative approach.<sup>73,87,88</sup> Only 2 studies reported conducting literature reviews to illustrate gaps in HCPs understanding

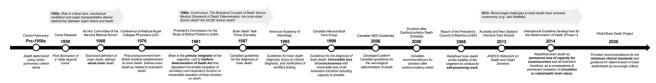


FIGURE 2. A brief timeline review of major historical events in brain death.

## TABLE 2.

#### Persistent controversies about brain-based definitions of death: over 50 y of debate

Controversy domain	Key proponents	Key opponents
Whether BD is a manifestation of biological death?	Bernat <sup>31</sup>	Joffe <sup>38</sup>
	Burkle et al <sup>30</sup>	Maguire <sup>37</sup>
	Shemie <sup>29</sup>	Miller and Truog <sup>42</sup>
	Shemie et al <sup>5</sup>	Miller et al <sup>43</sup>
	Shemie and Baker <sup>35</sup>	Racine et al <sup>41</sup>
	Shemie and Gardiner <sup>27</sup>	Shewmon <sup>39</sup>
	Wijdicks <sup>32-34</sup>	Truog et al <sup>2</sup>
		Whetstine <sup>40</sup>
Nhether current whole-brain concepts of death should be favored over some	Bacigalupo et al <sup>1</sup>	Chiong <sup>46</sup>
version of a circulatory or higher brain concept?	Bernat <sup>31</sup>	Hamdy <sup>50</sup>
	Bernat and Larriere <sup>44</sup>	Johnson <sup>51</sup>
	Laureys <sup>45</sup>	Lipuma and DeMarco49
	Shemie and Baker <sup>35</sup>	Miller and Truog <sup>42</sup>
	Wijdicks <sup>6</sup>	Veatch <sup>48</sup>
		O'Keeffe and Mendz <sup>52</sup>
Whether current BD definitions are unscientific, illogical, or legal fiction	Hot et al <sup>53</sup>	Belkin <sup>56</sup>
contrived to facilitate organ transplantation?	Joffe <sup>54</sup>	Bernat et al57
	Miller and Truog <sup>42</sup>	Shemie and Baker <sup>35</sup>
	Shah <sup>55</sup>	
	Shewmon <sup>39</sup>	
	Truog et al <sup>2</sup>	
Nhether DCDD donors are really dead?	Bernat <sup>58</sup>	Joffe <sup>54</sup>
	Bernat et al <sup>57</sup>	Shewmon <sup>39</sup>
	Bernat <sup>31</sup>	Truog <sup>2</sup>
	Shemie and Gardiner <sup>27</sup>	
Whether criteria measure loss that is really irreversible?	Bacigalupo et al <sup>1</sup>	Edwards and Forbes64
	Bernat <sup>6,59</sup>	Joffe <sup>54</sup>
	Wijdicks <sup>7,20</sup>	Verheijde et al65
	The Academy of Medical Royal Colleges <sup>60</sup>	-
Nhether loss of all function can be measured using existing criteria sets?	Demarin et al <sup>61</sup>	Dalle Ave and Bernat <sup>66</sup>
	Drake et al62	Joffe <sup>38</sup>
	Markert et al <sup>63</sup>	Shewmon <sup>67</sup>
	Shemie et al <sup>5,17</sup>	Truog <sup>36</sup>

DCDD, donation after circulatory determination of death.

of death and death determination.<sup>64,89</sup> Most studies focused on the perspectives of physicians, nurses, and trainees and had global and cultural variation.

The vast majority of HCPs supported the BD concept.<sup>53,69,70,77-80,83,85,87,89,92</sup> However, the prevalence of the understanding of BD and its diagnosis ranges widely from <50% to 94.7%.<sup>69,74,76,78,80-82,93</sup> Studies identified that knowledge of BD correlated significantly with the level of training, role within the healthcare team and formal training on BD.<sup>69,78,94</sup>

Years of experience correlated positively with BD knowledge.<sup>71,77,80</sup> The majority of attending staff understand BD compared with as little as half of residents and medical students.<sup>69,77</sup> Many medical students and interns are uncertain about the concept of BD or do not accept its definition.<sup>69,82,86</sup> Several studies focused specifically on the perceptions and knowledge of nurses.<sup>64,78,79,87,88</sup> These studies highlight that although most nurses felt they understood BD, experienced nurses had better knowledge, whereas there was more uncertainty among nursing students.<sup>78,79,87,95</sup>

Greater exposure and role in the healthcare team are also associated with increased knowledge of BD. Several studies focused solely on the perspectives of physicians within specialties that directly related to organ donation (eg, intensive care units [ICUs], anesthesiology, neurosurgery).<sup>53,68,70,72,75,81,96</sup> Clinicians with greater exposure to BD determination such as those working in ICU and anesthesia were more comfortable and knowledgeable,<sup>72,81</sup> for example, intensivists were more knowledgeable than emergency and internal medicine physicians,<sup>71</sup> and ICU nurses more knowledgeable than non-ICU nurses.<sup>87,95</sup> Universityaffiliated physicians were also more knowledgeable than non-university-affiliated physicians.<sup>81</sup>

However, despite an overall understanding and acceptance of the concept and application of BD in clinical practice, many HCPs also held contradictory beliefs that BD was not equivalent to real death, did not result in complete loss of brain function, or was not irreversible<sup>53,69,70,76-78,80,82,83,88</sup>

Several studies identified a lack of formal training on BD, whether within the academic training process or as continuing education.<sup>73</sup> The amount of training appeared to correlate with the role within the healthcare team, with attending staff reporting more formal training than nurses, and trainees reporting the least amount of formal training.<sup>69,76</sup> The vast majority of healthcare providers expressed interest in and a need for formal training, as well as for incorporation of BD training into the academic curriculum for trainees.<sup>73,76,77,81,82</sup> Formal training is shown to correlate with improved attitudes and knowledge of BD.<sup>69,84</sup>

One specific gap in knowledge among HCPs is regarding the institutional and regional protocols and policies surrounding BD diagnosis.<sup>69,89</sup> For example, although most clinicians believed in the moral equivalence of BD to circulatory death,

Empirical			Empirical studies examining nors understanding of deam at	טו מפמנוו מווט מפופרוזוווזמנוסוו טו מפמנוו (וו =∠כ)	death (n=23)	
Study reference	Country	Study design	Method of data collection	Study population	Aim	Findings
Alnajjar et al <sup>e</sup>	Saudi Arabia	Quantitative	Cross-sectional questionnaire	113 through sixth y medical students and interns	To assess knowledge of BD, among medical students and interns	There was a low level (59.2%) of understanding of the BD concept and significant uncertainty around the concept. Many were uncertain that it meant the patient's demise and few knew it was a terminal event. Education around BD should be incorporated into the medical school curriculum
Bijani et al <sup>84</sup>	Iran	Quantitative	Pre- and posttesting	50 head nurses and clinical supervisors	To evaluate the effect of workshops and rethinking on the knowledge and attitude of HCPs toward BD and organ donation.	Intervention group (reflective thinking and clinical scenario-based education group (reflective thinking and clinical scenario-based educational program) had a significant improvement in attitude and knowledge after training compared with the control group (P < 0.05) reparting D and organ donation.
Chatterjee et al <sup>83</sup>		Quantitative	Before and after online survey	118 (pre) and 62 (post) HCPs with increased exposure to brain injury	To assess HCP knowledge and attitude procedural criteria for BD and potential change after an educational intervention	There was broad and unchanging support (86.8%) for concept of BD among HCPs, but confusion persists over whether the loss of consciousness and spontaneous breath are truly sufficient for death.
Cohen et al <sup>71</sup>	Israel	Quantitative	Attitudinal survey	Physicians and nurses in ICU, Erm anesthesiology and internal medicine departments in 21 hospitals (organ and nonorgan procurement centers)	To analyze the attitudes of HCPs to BD and related to this to obtain their level of comfort with performing key donation-related tasks	Seventy-nine percent of respondents had a positive attitude toward BD. This was significantly associated with increasing age and higher professional status and was most prevalent in the ICU
Dubois and Anderson <sup>89</sup>	United States	Review	Literature review of empirical studies	N/A	To examine attitudes of HCP and the public toward death criteria and their relation to attitudes and behaviors regarding organ donation	A review of major studies showed high levels of support for the BD concept and organ donation but lower levels of knowledge of BD and why it is equivalent to death.
Edwards and Forbes <sup>64</sup>	United Kingdom Narrative	Narrative	N/A	N/A	Aims to highlight the gap in nursing literature of the discussion of the definition of human death—to show that nurses should engage in such discussion	The definition of human death that guides practice in the United Kingdom and elsewhere is fundamentally flawed. Instead of suppressing their own intuitions, and the intuitions of patients' relatives in the management of patients diagnosed as brainstem dead, nurses should critically examine the definition of death, which currently informs clinical practice
Ferhatoglu and Gurkan <sup>s1</sup>	Turkey	Quantitative	Survey	244 surveys of ICU clinicians in Turkey	To assess attitude and knowledge of ICU clinicians on determination and barriers to BD diagnosis	Most ICU clinicians felt confident diagnosing BD, atthough many did not correctly answer all questions relating to BD diagnosis. University or university-affiliated ICU clinicians were both more knowledgeable on BD and more interested in additional training.
Floden et al <sup>87</sup>	Sweden	Qualitative	Interviews	15 ICU nurses from 6 hospitals in Sweden	To get to get ICU nurses' perception and experiences of organ donation and BD	There is ambiguity and variation in the perception of ICU nurses on the BD diagnosis that is not found in circulatory death. However, nurses trust physicians to make the diagnosis and generally believe in the diagnosis. There is greater trust in the diagnosis if the nurse is present, and if there is use of cerebral angiography to confirm the diagnosis.
Hot et al <sup>53</sup>	Turkey	Quantitative	Questionnaire	401 responses from physicians from Turkey randomly selected from 6 cities in Turkey	To determine the attitudes among Turkish physicians toward BD and to examine the effect of religion and education on the issue	Of the physicians who responded (50% response rate), 76% reported they regarded BD as real death, whereas 24% did not perceive BD as real death. Ninety-five percent viewed death as the stopping of heartbeat and breatthing, and 77% of relatives of brain-dead patients have difficulty understanding BD.

TABLE 3.

Among pediatric intensivists, there is confusion about the BD concept. There is also significant variability in the understanding of the tests that are compatible with the criterion of BD.	Mit	A wide range of BD understanding among HCPs in ICUs. Attending physicians have the greatest understanding, followed by nurses. In contrast, approximately half of the students and residents do not have a basic understanding of BD.	The majority of Muslim HCPs believe that if American Academy of Neurology guidelines are followed and person is declared BD then they are truly dead. There are no difference in views based on religiosity. Half believe families should be able to choose whether brain death evaluation is performed and whether organ subort is discontinued after brain death.	Eighty-two percent of HCPs believed BD was irreversible, but only 69 believed it was equivalent to death. Additionally, many did not understand the legislation around the need for ancillary testing in BD or know that the clinical exam is usually sufficient.	Most of the 599 medical staff and 212 nursing staff accepted BD, but only 60% passed a 5-item-validated BD knowledge tool. Of concern, more than half of respondents who did <i>not</i> pass the BD test reported feeling confident and comfortable explaining BD to next of kin.	Seventy percent of nursing students understood the BD concept, but 27% had doubts and 3% believed a brain-dead patient could recover to a normal life. Greater BD knowledge was associated with the y of schooling.	Seventy-five percent of nursing students understood that BD was equivalent to a person's death. Knowledge of BD correlated positively with age and partner's attitude toward organ transplantation.	Inadequate identification of potential donors, delayed diagnosis or misdiagnosis of BD, and misinformation given to the relatives of patients were leading factors that affect organ donation negatively.	Although 90.1% of students feit they knew the definition of BD, only 81.3% accepted it.	To analyze the level of understanding of the BD concept Sixty-two percent of the personnel understand BD and believed that among personnel in Spanish and Latin American this was the death of the individual. Of the rest, 30% did not healthcare centers and to determine the factors understand it, and the remaining 8% believed it did not mean the death of the patient. Eighty-three percent of physicians understood BD, compared with 75% of nurses.
To determine whether pediatric intensivists in Canada are aware of the controversies regarding BD	To determine the understanding of the conceptual basis and diagnostic tests used for BD by neurosurgeons in Canada	To evaluate understanding of BD among HCPs within ICUs at a single institution	To evaluate how Muslim allied HCPs view death by neurologic criteria	ofessionals in a community To determine attitudes and knowledge of medical and Spain nursing staff on organ donation	To assess Australian emergency department clinicians' acceptance and knowledge regarding BD	To determine the knowledge of nursing students about the concept of BD	To analyze the knowledge and acceptance of the BD concept among nursing students	To determine the knowledge, tendency, and attitude about BD and organ transplantation among anesthesiology and reanimation professionals who are the major influencers and have responsibility about this subject	To evaluate attitudes toward organ transplantation among students in healthcare	To analyze the level of understanding of the BD concept among personnel in Spanish and Latin American healthcare centers and to determine the factors affecting this attitude
64 practicing pediatric intensivists	128 completed surveys from Canadian neurosurgeons	217 attendings, residents, nurses, medical students and ICU team members in 6 ICUs	49 Muslim American health professionals	236 health professionals in a community hospital in Spain	599 medical and 212 nursing staff in Australian EDs	721 nursing diploma students across 3 universities in southeast Spain between 2005 and 2006	492 nursing students in the University of South of Poland 2011–2012	564 members of the Anesthesiology and Reanimation Society	273 students (from medicine, dentistry, nursing, and physiotherapy)	4378 personnel from Spain, Mexico, Cuba, and Costa Rica, across 12 hospitals and 32 primary care centers in 4 countries within the International Collaborative Donor Project
Survey/clinical knowledge assessment	Survey/clinical knowledge assessment	Survey	Survey	Survey	Survey and clinical knowledge assessment	Survey	Survey	Survey	Survey	Survey
Quantitative	Quantitative	Quantitative	Quantitative	Quantitative	Quantitative	Quantitative	Quantitative	Quantitative	Quantitative	Quantitative
Canada	Canada	USA	North America— USA	Spain	Australia	Spain	Spain	Turkey	Poland	Spain and Latin Quantitative America
Joffe and Anton <sup>75</sup>	Joffe et al <sup>38</sup>	Lawson et al <sup>69</sup>	Lewis et al <sup>85</sup>	Lomero et al <sup>76</sup>	Marck et al $^{77}$	Martinez- Alarcon et al <sup>73</sup>	Mikla et al <sup>79</sup>	Mutlu and Utku <sup>72</sup>	Rydzewska- Rosołowska et al <sup>s6</sup>	Rios et a <sup>po</sup>

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Empirical	studies exai	mining HCPs	s understanding	Empirical studies examining HCPs understanding of death and determination of death (n=25)	death (n=25)	
Study			Method of data			
reference	Country	Study design	n collection	Study population	Aim	Findings
Rodriguez- Arias et al <sup>91</sup>	Spain	Qualitative	Interviews to discuss clinical scenarios	587 HCPs likely to be involved in the process of organ procurement across 14 hospitals with transplant programs in France, Spain, and the United States	To examine HCP experience, beliefs, and attitudes toward BD, cDCD, and uDCD.	Healthcare personnel believe BD is a more reliable standard than circulatory criteria at determining death. Most healthcare personnel find it morally acceptable to retrieve organs from brain-dead donors but less so in DCD patients. Potentially, this is because of the lack of a rigorous brain exam in DCD or the belief that irreversibility is not proven with the loss of circulatory function.
Sheerani et al <sup>70</sup>	Pakistan	Quantitative	Survey	259 questionnaires were analyzed, of physicians at different levels of training and final y students from 5 major tertiary care centers at Karachi and Hyderabad, and involved in making decisions about BD and related issues	To find the opinions and awareness of physicians regarding issues surrounding BD	Fifty-four percent did not have a clear idea of the BD definition. Additionally, 47% would not turn off the ventilator in a brain-dead patient, and 26% actually considered it euthanasia. Physicians tended to favor the use of confirmatory tests to confirm BD.
Victorino et al <sup>73</sup> Brazil	<sup>73</sup> Brazil	Qualitative	Structured interviews	Structured interviews ICU nurses and physicians in 1 hospital	To identify and discuss the different meanings and experiences of nurses and physicians from and adult ICU in relation to the diagnosis of BD and the maintenance of potential organ donors	Brain death understanding varies according to the personal beliefs, culture, and educational background of individuals, especially understanding of BD diagnosis as a tool to aid decision-making, diagnosis as guarantee of rights, difficulties encountered in establishing the diagnosis, clinical criteria adopted in Brazil, and its ethical-legal aspect. Overall, there is a lack of formal education in BD diagnosis
White <sup>88</sup>	Australia	Qualitative/ descriptive		Structured interviews 40 Australian ICU nurses from 7 metropolitan ICUs	To investigate the extent to which a sample of 40 Australian intensive care nurses regarded BD as a meaningful conception of death	Analysis revealed 5 categories of perception constituting a spectrum ranging from complete acceptance to complete rejection, with almost half (48%) of the sample believing that the brain-dead patient as less than completely meaningfully dead.
Yang et al <sup>74</sup>	China	Quantitative	Survey and clinical knowledge assessment	476 medical providers (72 attendings, 84 residents, 210 medical students, 110 nurses) from 2 academic hospitals in Hunan, China.	To explore reasons for the failure of BD legalization in China.	Almost all (92%) of the HCPs (attending physicians, residents, medical students and nurses) have heard the term "brain death." When given a description of a brain-dead patient 50% considered the patient dead, 52% would withdraw life support, and 41% would allow organ procurement. Ethical acceptance was the most important independent predictor for BD acknowledgment, followed by high knowledge scores, and the belief that the soul lives in the brain.
BD, brain death;	; cDCD, controlled d	lonation after circula	tory death; DCDD or DCD,	donation after circulatory determination of death;	BD, brain death; cDCD, controlled donation after circulatory death; DCDD or DCD, donation after circulatory determination of death; HCP, healthcare professional; ICU, intensive care unit; uDCD, uncontrolled donation after circulatory death.	controlled donation after circulatory death.

TABLE 3.( Continued)

fewer understood their legal equivalence.<sup>69</sup> Several studies commented on the lack of uniformity and understanding the conceptual basis and diagnostic tests used for BD, and concluded there is significant variability in understanding of the tests that are compatible with the criterion of BD.<sup>68,75</sup> The determination protocols and the need for ancillary testing vary between and within countries, leading to a lack of consistency for the BD diagnosis worldwide.<sup>97,98</sup>

In total, only 2 Canadian studies were identified, and both took a narrow participant focus, one on pediatric intensivists,<sup>75</sup> and the other on neurosurgeons.<sup>68</sup> The main objective of these 2 studies focused on examining the variability in the understanding of tests that are compatible with the criterion of BD.

Eight studies focused on DCDD<sup>2,6,29,42,57,58,91,99</sup> with some expressing concerns that the observation period after circulatory death in DCDD may be inadequate for irreversibility and may allow for the rare possibility of autoresuscitation, the spontaneous unassisted resumption of heart function after cardiac arrest.<sup>27</sup> On the contrary, other studies noted that without additional intervention, brain functions would cease irreversibly,<sup>57,91</sup> and this declaration of death was consistent with medical practice.<sup>58,92</sup>

## **The Future of Death Determination**

It appears much of the space within the literature devoted to death determination is occupied by persistent academic controversies, with a relative paucity of articles focusing on practicing HCPs' understanding of death determination and related domains. Common ground can be found in calls for improvement-oriented changes from a need for uniformity and standardization in death determination.3,100 Other authors state the need for new legislation to ratify religious exemption to death determination by neurologic criteria.65 Many studies call for increased education to address deficits in HCPs' understanding of death determination and particularly BD.53,68,69,75,77,101 Likewise, many studies state the need for increased dialogue and even open public debate56,93 to ensure the trustworthiness and satisfaction of the general public. The call for improvements in uniformity have been focused on both the cardiorespiratory and BD determinations should be formulated on a coherent definition and criterion of death.6,31,102

More recently, steps have been taken in drafting an international guideline for the determination of death.<sup>5,27,29</sup> During an invitational forum of international content experts and representatives of several professional societies,<sup>5</sup> a single operational definition of human death was developed: "the permanent loss of capacity for consciousness and all brainstem functions, as a consequence of permanent cessation of circulation or catastrophic brain injury."

The next step in this process will be to hold a broader group of international stakeholders to develop clinical practice guidelines, based on comprehensive reviews and grading of the existing evidence.<sup>5</sup>

# DISCUSSION

This scoping review of 89 papers revealed important themes and highlighted considerable variability in HCP knowledge of the BD construct. Controversies over the definition and determination of death have evolved in the last 70 y. Capron's statement, "well settled yet still unresolved" remains well-suited to capture the climate of these ongoing debates.<sup>103</sup> Previous circulatory-based criteria of death determination are no longer sufficient in a time when circulation can be maintained for extended periods despite permanent cessation of brain function. This review highlights the fact that current controversies over BD definition are primarily academic; most physicians who pronounce BD in daily practice are unaware of them.<sup>59</sup> There have been criticisms that the previous decades of intense philosophical analysis of BD have been misdirected in so far as it has neglected the concerns and perspectives of caregivers, families, and clinicians.<sup>104</sup> Only 25 studies empirically examined HCPs' knowledge and understanding of death and death determination, with only 2 studies focused on Canadian HCPs' knowledge and attitudes.<sup>68,75</sup>

Studies of HCP perspectives are underrepresented but suggest that neurological determination of death is not as controversial in practice as in the literature. Clinically, most physicians feel confident in the diagnosis of BD and are comfortable with the concept especially with greater exposure and experience. However, the knowledge and rationale behind why this is equivalent to death are where there is inconsistency. This uncertainty about BD determination is especially prevalent among less experienced HCPs. This suggests there is a need and a desire for ongoing and formal education in this area. Variability in the criteria and test for the diagnosis of death between and within countries leads to confusion among HCPs, who often do not understand the requirements, especially surrounding the need for ancillary testing. These inconsistencies can propagate confusion among HCPs but also to a deterioration of public trust in the diagnosis. Clarity and uniformity are needed in both the definition and determination of death. It appears that medicine is evolving toward a single unified determination of death.<sup>35</sup> A key question to be addressed is can our society evolve toward accepting the movement away from heart-based definitions of death toward single central unifying determination of death based on the complete and permanent cessation of brain function?<sup>35</sup>

# Limitations

Though comprehensive in scope, the review was limited to English and French language publications, and no French studies were included. We may not have included articles published after our updated search (July 2021).

# CONCLUSIONS

This review provides a comprehensive understanding of the current climate regarding HCPs' understanding and knowledge of the meaning/definition of death and its determination. There is a paucity in the literature of practicing HCPs' perspectives on this topic, particularly from Canada. Studies identified reveal considerable variation in BD understanding between HCPs and institutions; as such there is a need for more education and training, especially among HCPs who must facilitate difficult conversations with families. Instead, much of the literature is crowded with persistent controversies over BD and its determination. More research needs to focus on empirical studies of practicing HCPs' attitudes and knowledge regarding death, particularly BD. Revisions should be undertaken if public trust in the medical system is to remain intact. Positive steps have been taken toward the development of an international guideline for the determination of death whereby a single operational definition of human death was developed. A critical final step in a scoping review is to broadly engage relevant stakeholders in the findings to better understand perceptions of death and death determination on a national landscape.

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