

Supplemental Digital Content 1 - List of all included papers (n=64)

Authors (Year)	Type of Paper	Country	Aims/purpose	Study population	Methods	Key findings
Akbulut, S et al (2020)	Quantitative/Survey	Turkey	To evaluate the attitudes, awareness and knowledge levels of Turkish adult population about organ donation	300 adults	Survey	Only 47.2% of participants said they had inadequate information about brain death, and 85.2% refused to consent to donating organs of family members declared brain dead. The majority of participants said they got their information about brain death from television.
Al Bshabshe, AA, et al. (2016)	Quantitative/Survey	Saudi Arabia	To evaluate the general information and attitude of university students in their primary basic science stage (pre-education on brain death).	873 university students in their primary science stage (medicine, dentistry, pharmacy, applied medical sciences)	Written questionnaire interview of 20 items, using a non-random sampling method.	<ol style="list-style-type: none"> 1. 93% students had heard about brain death, 85% of those from the media 2. 73% believe there is no difference between BD and natural death 3. 22% equated BD with real death, 20% felt it was not death at all, the rest had no conclusive idea 4. 22.5% thought a BD patient might recover, 34.8% did not 5. 52% thought it might take days to accept brain death if one of their relatives was diagnosed
Appel, JM (2005)	Narrative/Opinion	North America - USA	To examine whether the law should permit individuals to opt out of acceptance death standards	N/A	N/A	<ol style="list-style-type: none"> 1. There is variability in the acceptance of the death definition 2. Death may be inconsistent for a single individual, be value driven and context dependent 3. Organ donation and costs/resource limitations are driving factors for a brain-based death definition
Asai, A, Kadooka, Y and Aizawa, K (2012)	Panel report	Asia/Japan	To organize and introduce the arguments for and against organ transplants from brain-dead donors in in contemporary Japan	N/A	N/A	<ol style="list-style-type: none"> 1. BD should only be regarded as death in exceptional cases for the purposes of organ donation. 2. Resistance to BD (concern that BD is inaccurate, BD patients breathe, have heartbeat and warm body, etc., excessively brain-centered view on life, fear of giving physicians right to terminate treatment) 3. Public consultation shows 40% for and 39% against defining BD as legal death - fundamentally, BD should not be regarded as equivalent to death of a human being, high value in bodily reactions. 4. Changes of consensus on life and death are slim
Bagheri, A (2007)	Review	Asia/Japan	To present the law of organ transplantation in Japan.	N/A	N/A	<ol style="list-style-type: none"> 1. Japan allows people to decide whether BD can be used to determined death, in agreement with family 2. Allow people to choose either cessation of cardio-respiratory function or loss of entire brain function as definition of death, depending on their own views.
Bernat, JL (2005)	Narrative/Opinion	North America - USA	To discuss currently controversies around brain death among HCP and the public.	N/A	N/A	<ol style="list-style-type: none"> 1. Brain death is an accepted and sound concept, but poorly understood by public and HCP 2. Renewed public interest in brain death due to McMath and Munoz cases after a period of acceptance for decades.

						3. Persistent misunderstanding of vegetative and brain death states by the public.
Bernat, JL (2014)	Narrative/Opinion	North America - USA	To discuss the controversies about brain death among HCPs and the public.	N/A	N/A	<ol style="list-style-type: none"> 1. Brain death is a widely accepted medical and legal practice. 2. Brain death is poorly understood by the public and HCPs. 3. Rekindling of the public interest in brain death in the last few years due to the McMath and Munoz cases' publicity. 4. Both HCP and public need greater education about the concept, and more work is needed to establish its biophilosophical justification. 5. Opponents of BD concept have been unsuccessful in catalyzing a public movement to change medical or legal practices. 6. Whether DCDD are dead at the moment of death declaration bothers physicians more than patients' family members. (Family members consider patient dead at the moment of heartbeat cessation) 7. Is public misunderstanding a knowledge deficit or a fundamental ambivalence? (BD patients do not look dead) 8. Intuitive nature of brain death means most people can accept BD with only vague knowledge of concept. 9. Laypersons and professionals feel discomfort that BD is legal fiction for purposes of organ donation 10. Improved public education needed to address mismatch between BD as successful public policy and confusion and malaise over it (journalists especially have a role).
Bernat, JL (2014)	Narrative/Opinion	North America - USA	To explore the uncertainties of the lay and professional communities about the medical and legal status of brain death.	N/A	N/A	<ol style="list-style-type: none"> 1. Brain death is widely accepted by HCP and public but controversy surrounds whether it is equivalent to human death. 2. Debate on brain death is primarily academic, with little social traction. 3. BD is a successful public policy, without need for fundamental changes
Brierley, J (2015)	Narrative/Opinion	Europe - UK	To discuss the UK court's decision on NDD.	N/A	N/A	<ol style="list-style-type: none"> 1. Re A (A Child), Jahi McMath were two cases of brain death of differences in views between treating clinicians and family members 2. Disputes should be resolved by the High court. The court appears to uphold that BD is equal to death of the person.
Chua, HC, Kwek, TK, Morihara, H and Gao, D (2015)	Review	Asia - Singapore	To examine the concept and determination of brain death among Asian countries and compare against the rest of the world.	14 countries in Asia	Survey	<ol style="list-style-type: none"> 1. Most Asian countries have accepted and adopted the whole brain concept of BD (or UK brainstem concept) 2. Criteria for BD determination is not consistent, especially for apnea testing. 3. China has the most onerous testing requirements - perhaps reflecting a distrust of the public in HCPs. Japan had a prior incident that also created public distrust.

Crippen, D (2014)	Review	North America - USA	To discuss the McMath case and its legal implications for neurological determination of death and its determination.	N/A	N/A	<ol style="list-style-type: none"> 1. Family disagree with diagnosis of neurological death, despite meeting all criteria for brain death. 2. Misleading media statements and terminology ("sleeping", movement as life, "on life support"), sensational headlines coloring the concept of brain death. 3. Public increasingly suspicious of BD diagnosis in a warm, pulsating, ventilating body that appears viable. 4. Tradition of personal autonomy among the public (in America) 5. Weight of family values in the medical expert's decision to discontinue MV.
Crowley-Matoka, M and Arnold, RM (2004)	Narrative/Opinion	North America - USA	To comment on public attitudes towards brain death and the implications.	N/A	Commentary on a phone survey by Siminoff, Burant & Youngner	<ol style="list-style-type: none"> 1. Many seem to view brain death as "as good as dead" rather than "dead" 2. Need to balance the need for organ donors with public backlash/anti-donation with changes to definitions or practices of BD. 3. Tinkering with definitions of BD have hindered organ donation in Japan and Denmark. 4. Current knowledge about BD in the US is sparse. 5. While the public is familiar with the concept of BD, little clarity about its clinical features 6. Lack of empirical data on public understanding of brain death. 7. 42.4% of the public believed BD was as good as dead rather than dead, 16% classified BD as alive, and a minority believed it to be death. 8. Difficult to say if answers over phone will differ if there is a loved one BD in the ICU 9. Previous decades of scholarly debate has attracted little public interest 10. Denmark's opening up the BD question to public examination caused greater uncertainty and lower donation rates and was a huge economic investment. 11. Hard to expect prolong public education and discussion to provide clarity to an issue that experts have been unable to reach. Unlikely to provide a solution.
Daoust, A and Racine, E (2014)	Qualitative/Focus Group	North America - Canada	To examine the depictions of BD in major American and Canadian print media.	940 newspaper articles in USA and Canada	From 2005-2009 high circulation Canadian and American newspapers, analyzed using NVIVO 8	<ol style="list-style-type: none"> 1. BD used colloquially in 39% (n=366) articles and medical meaning is infrequently defined (2.7% and 3.6% in USA and Canada) 2. Neurological criterion for death determination mentioned in less than 10% of articles, and life support in 20% 3. There is a need to bridge media representations of neurological determination of death with experts' views. 4. Media misunderstanding that BD is not death until cessation of cardiopulmonary functions. 5. Similarities between American and Canadian print media coverage 6. Public or patient-family discussions should be held to reinforce the genuine nature of NDD 7. Expert work on BD should be contextualized to avoid damaging public confidence in NDD

De Georgia, MA (2014)	Review	North America - USA	To trace the evolution of brain death definition from 1968 and discuss its background, history and context.	N/A	N/A	<ol style="list-style-type: none"> 1. Much misunderstanding and confusion in the general public about the concept of brain death. 2. Brain death is widely accepted as a determination of death around the world. 3. McMath case brought to light the vague boundary of brain death in the publics' minds. BD is difficult to understand for a layperson, conceptual and philosophical arguments too far removed from parents' experience at the bedside. 4. Thorough knowledge of background, history and context of development of brain death is needed to fully understand its meaning.
Dubois, JM and Anderson, EE (2006)	Review	North America - USA	To examine attitudes of HCP and the public toward death criteria and their relation to attitudes and behaviours regarding organ donation	N/A	Literature review of empirical studies	<ol style="list-style-type: none"> 1. The public is inadequately familiar with the legal and medical status of brain death 2. Helping families understand and accept medical and legal criteria for death determination can increase comfort with decision
Dubois, JM and Schmidt, T (2003)	Mixed Methods	North America - USA	To assess willingness to donate under the HBD criteria and factors influencing those attitudes.	1000 heads of households 18+ years old, English speaking, in the USA.	Structured interview using case scenarios, open ended questions and 15 Likert-type questions. First pilot-tested then conducted via telephone interviews selected until random digit dialing, with several call-back attempts. Anonymous and voluntary participation.	<ol style="list-style-type: none"> 1. Death statutes should not just be tolerated but supported by the public because it requires public subsidization and public to donate organs 2. Far less of the general public may be open to organ procurement from HBD or PVS patients than medical personnel. Families may not share HCP views on death and organ procurement. 3. People rely less on the legal notion of death than perhaps the trust in the HCP in the determination and intuitive notions about death. 4. Only 8% said BD is death, but most offered incomplete but accurate descriptions. Only 2% offered statements suggesting possibility of recovery. 5. 60% agreed patients could be dead while heart was still beating, almost all when machines keep them breathing. 6. Public's support for NDD has to do with belief that brain has irreversibly lost all function and not legal criteria 7. NHBD may find widespread support among the public, as nearly all participants agreed to donate organs after BD patient off ventilator and heart stopped beating. 8. Redefinition of death or abandonment of DDR would lack support among US public.
Febrero, B et al. (2013)	Quantitative/Survey	Europe/Spain	To analyze the concept of BD among adolescents in southeast of Spain.	3547 adolescents in southeast Spain across 10 schools	Validated questionnaire, self-administered, anonymous. Random sample.	<ol style="list-style-type: none"> 1. 38% of adolescents knew the BD concept, considered it to be the death of an individual; 54% did not know the BD concept; 8% thought it did not mean a person's death 2. Association between age (older) and knowledge of BD. No association with audiovisual sources, but negatively associated with negative information from television.

Freeman, TB (2015)	Narrative/Opinion	North America - USA	A personal narrative of the perceptions and dissociation between medicine and human processes of recognizing and accepting death.	N/A	N/A	<ol style="list-style-type: none"> 1. The knowledge of the brain death diagnosis does not preclude a feeling of life, due to ongoing breathing (even with ventilator) and heartbeat. Cessation of heartbeat is death. 2. Temporary ventilator disconnection is a reasonable (and routine in BD exams) way of helping families to understand and accept brain death. 3. Families that refuse organ donation may not believe in the reality and finality of brain death. 4. Many families do not understand or accept brain death, despite donating for altruistic reasons, are confused about when a patient has died, or believe death only occurs when the heart stops.
Friedrich, AB (2019)	Narrative/Opinion	North America - USA	To argue that in rare cases, reasonable accommodations should be allowed for refusal of brain death determinations based on grief.	Jahi McMath	N/A	<ol style="list-style-type: none"> 1. Due to the appearance of life in a brain dead patient, time may not allow the family to conclude their loved one is dead. 2. Grief may be enough to justify a belief that a loved one is alive. 3. Families should be allowed to refuse brain death determinations based on grief, as an expansion of the reasonable accommodation policy. 4. Small changes could have improved the experience for the Jahi family (identify needs of marginalized/non-elite family, treatment of family with dignity and respect, giving family time to be with Jahi prior to withdrawal of ventilation, incorporate religious families from the beginning).
Greer, DM et al (2020)	Guideline report	International	To formulate a consensus statement of recommendations on determination of BD/DNC	N/A	N/A	The report provides recommendations for the minimum clinical standards for determination of brain death/ death by neurologic criteria in adults and children with clear guidance for various clinical circumstances
Haddow, G (2005)	Qualitative/Focus Group	Europe - UK	To explore families' beliefs about death, the dead body and impact on donation decision.	19 Scottish donor families	Semi-structured interviews lasting 1-3 hours	1. Relatives had a personal realization of when death occurred due to HCP communication, attending to ICU technology and previous awareness of BD from medical dramas on TV, even before medical confirmation ("social death")
Joffe A, Byrne R, Anton N et al. (2009)	Quantitative/Survey	North America – Canada	To determine if university students consider the donation after cardiac death donor as dead.	Canadian medical (n = 142) and nursing (n = 76) students in a medical ethics class and philosophy students (n = 102)	Survey with 4 patient scenarios on organ donation after 5 mins of absent circulation; 2 groups brief background vs detailed background information	<ol style="list-style-type: none"> 1. Most respondents were not confident that a donation after cardiac death donor was actually dead 2. Medical students were significantly less likely to agree that the patients in the scenarios were "dead," or that the physicians were being truthful in describing the patients as dead 3. 42-51% of those given detailed information vs. 55-58% of those given brief information agreed the patient was definitely dead 4. 36-39% given detailed info vs. 48-52% given brief info agreed the physician was truthful informing family that at 5 mins absent circulation, the patient is definitely dead

						5. 65% given detailed info vs. 50% given brief info were not confident that the patient is definitely dead in at least one scenario"
Johnson, LS (2016)	Narrative/Opinion	North America - USA	To argue for the universal adoption of reasonable accommodation policies until the New Jersey statute as a model.	N/A	N/A	<ol style="list-style-type: none"> 1. Public policies that accommodate reasonable, divergent viewpoints concerning death as a way to resolve the conflicts. 2. Historical racism and cultural insensitivities towards marginalized groups may give some individuals/communities reason to doubt or distrust a diagnosis of BD.
Kato, Y (2013)	Narrative/Opinion	Asia/Japan	To examine the 1997 vs the 2009 revision of the Japanese law on organ transplantation.	N/A	N/A	<ol style="list-style-type: none"> 1. Japan, NY state and New Jersey have exemptions for death determination based on neurologic criteria 2. Japan has cardio-pulmonary criteria as the default definition of death, with brain death exclusively when organs are to be procured from donors. 3. Antipathy to brain death determination among Japanese was the driving factor. 4. Majority of Japanese are for brain death definitions, but doubt on the scientific validity and mistrust in the healthcare service (Wada case in 1968) contributed 5. Emphasis on conscience
Kellehear, A (2008)	Review	Europe - UK	To provide a sociological outline of the problems around brain death criteria through a review of key literature.	N/A	N/A	<ol style="list-style-type: none"> 1. Overlooking social/historical/cultural understandings of death in favour of biomedical/bioethical and legal writing has led to public and HCP misunderstandings about brain death criteria. 2. It is unreasonable/unethical to not accommodate cardiopulmonary death when it enjoys near universal acceptance across cultures and religions. 3. A conscience clause for all conscientious (not just religious) objectives to BD recognizes the reasonable views in a pluralistic society.
Kilcullen, JK (2014)	Review	North America - USA	To examine the public's view of BD and view on revising the label of the brain-injured patient.	N/A	N/A	<ol style="list-style-type: none"> 1. Modern technologies created the possibility of a loved one being alive but stripped of the experience of being alive in a socially defined way 2. BD gave families finality and end to the financial burden, and hospitals beds 3. Widespread public acceptance of the general idea of BD 4. Misgivings among the public recently erupted with Jahi McMath case. This also fuels other mistrusts in healthcare. 5. Limited relationship between public understanding of BD and willingness to donate. 6. Commonly difficult to accept death in a person who appears warm and alive. Signs of life (breathing, heartbeat, warmth) support belief of life and hope for recovery. 7. Media significantly influences public view of organ donation, often mischaracterizing brain death and fostering confusion (medical shows, major newspapers). 8. Public wants to do away with "legal fiction" and allow patient/family consent to permit organ donation when

						patient's neurologic injury leaves them profoundly and irreversibly disabled.
Knox, SL (2006)	Review	Oceania - Australia	To explore the consequences of the sequestration and medicalization of quotidian death for cultural representations of death in contemporary film.	N/A	N/A	1. By becoming "locatable" (through concept of BD), death has gained a novel symbolic anatomy that privileges the head, face and an imagining of the brain and its workings. 2. Screen representations evidence the preoccupation, culturally with mechanisms by which individual identity may be preserved.
Laureys, S (2005)	Narrative/Opinion	Europe - Belgium	To emphasize that BD equals death.	N/A	N/A	1. Concept of death has evolved as technology progressed - redefining it from ancient cardiorespiratory centered diagnosis to a neurocentric one. 2. Ethical, moral and religious concerns continue to surface and include prevailing malaise about possible expansion of the death definition. 3. Misleading term of brain death as suggesting two different types of deaths may explain public and professional confusion about BD. 4. Public acceptance of multi organ donation depends on certainty of death diagnosis and confidence in DDR. 5. Much of the controversy result from confusion/ignorance by public or policymakers about the medical reality of BD - need for public awareness programs.
Lewis, A (2018)	Narrative/Opinion	North America - USA	To explore historic and contemporary ethical and legal disputes about determination of death by neurologic criteria	N/A	N/A	1. One of main reasons for families to object to determination of death by neurologic criteria is due to variation of religious perspectives between and within faiths. 2. Legal proceedings around BD pregnant patients both to maintain or discontinue organ support have yielded opposing decisions.
Lim et al (2020)	Quantitative	Malaysia	Assess knowledge & determine factors influencing attitudes towards organ donation	400 patients	Questionnaires	The greater the knowledge of brain death and organ donation, the more positive attitude toward organ donation
Long, T (2007)	Qualitative/Focus Group	Europe - UK	To explore the concept of brain stem death and its meaning to family members.	Two primary datasets using 28 interviews of family members of BD patients.	Primary datasets from 2 qualitative studies	1. Lack of agreement between health professionals is reflected to some extent by the public, who are reported to have concerns and a lack of knowledge regarding this diagnosis 2. Public concern has been clearly articulated in countries such as Denmark and Japan where public views have been responsible for delaying intended legislation confirming the diagnosis of brain death 3. Japan's first heart transplant, surgeon accused of donor's death and illegal experimentation. Bills to legitimize BD opposed by majority of public.

						<p>4. It is reported that both medical and lay opinion have evolved to an almost total acceptance of a single definition of BSD.</p> <p>5. Paradoxical communication and ICU environment contribute to emotional and cognitive conflict. Paradox of communication of death in the face of continuing heartbeat and respiration a trigger for emotional and cognitive conflict for family members. BD diagnosis may represent irreversible loss of mental life but not actual death (cessation of heartbeat and respiration).</p> <p>6. Technology of life support contradicts diagnosis of BSD. Some family believed their relative dead but saw them as alive; technology obscures impending death and amplified family member's schema of a dead body (cold, motionless, does not breathe)</p> <p>7. Terminology like "kept alive on a ventilator" and "life support" undermine the message that death was inevitable. BSD suggests death is exclusive of the body.</p> <p>8. Family members and HCP seek to rationalise the emotional and cognitive conflict stimulated by diagnosis of BSD. Cessation of brain function, for family members, is when the critically injured person enters the death process, whereas for HCPs, it marked the end of the death process.</p>
Long, T, Sque, M and Addington-Hall, J (2008)	Review	Europe - UK	To provide insight into how a diagnosis of BSD or BD may be perceived by family members approached about donation.	N/A	Review of the literature	<p>1. Diagnosis of BD is intricately linked to the issue of organ donation and may influence family members' decision-making.</p> <p>2. Perception that death has occurred differs from one person to another.</p> <p>3. Increase in organ transplant may not be achieved until BD/BSL/DDCD is debated more widely by society, greater consensus is reached, and family members have a better understanding of these diagnoses.</p> <p>4. Public concerns about BD diagnosis include: being diagnosed as dead too soon for organ donation, they or relatives are not dead at the time of organ donation, knowledge and understanding of family members/public regarding brain death</p> <p>5. Family members knowledge/understanding of BD/BSL: lack of information, poor understanding of meaning, dissatisfaction with decision made at request, confusion with other brain conditions like coma & PVS.</p> <p>6. Cognitive dissonance among family due to lack of information by HCP, personal beliefs/knowledge/experience of death and signs of viability of the body</p> <p>7. Haddow study showed respondents articulated a moment of social death before medical confirmation of BSD due to previous knowledge of BSD from television dramas.</p>
Luce, JM (2015)	Narrative/Opinion	North America - USA	To discuss the well-publicized case of Jahi McMath and	N/A	N/A	<p>1. Most families of BD patients accept the diagnosis and agree to withdrawal of support.</p>

			confusion over BD criteria.			<p>2. Cases like McMath are uncommon but demonstrate public confusion about concept of BD and rejection of this concept by some families.</p> <p>3. Confusion around BD may be due in part by lack of uniformity in state laws regarding legal basis of death (i.e. New Jersey vs. California)</p> <p>4. Hospitals should develop policies regarding how to work with families who do not accept BD and physicians should learn how to communicate with these families.</p>
Molina, A, Rodríguez-Arias, D and Youngner, SJ (2008)	Narrative/Opinion	Europe - France	To refute the claim that one should choose their own definition of death, and to support that public discussion is needed regarding when to violate the DDR.	N/A	N/A	<p>1. It would be more productive of social trust to have honest public discussion about the circumstances under which the DDR could be violated.</p> <p>2. Pluralism in the definition of death can lead to a slippery slope and should not be determined by personally determined definitions.</p>
Nowak, E, Pfitzner, R, Kozlik, P, et al. (2014)	Quantitative/Survey	Europe - Poland	To assess young peoples' knowledge and attitudes toward stating death in transplantology and impact on attitude toward organ donation.	400 medical and 400 non-medical students from 4 public universities in Poland	Anonymous questionnaire examining demographics and transplantologic issues from 2010-2012	<p>1. The number of non-positive attitudes toward organ transplantation was higher in respondents unwilling to accept BD as the death of a human being, which was related to one's opinion about the reliability of the diagnosis, awareness of an alternative diagnosis of irreversible cardiac arrest and general transplantologic knowledge.</p> <p>2. Level of trust in BD diagnosis is relatively low among non-medical respondents (38.5% vs. 78.5%).</p> <p>3. Professional knowledge about BD did not correlate with level of trust for BD diagnosis as strongly - suggesting doubts about BD criteria (31.5%), distrust of medical staff's education (25%) and objectivity (20%) as contributing factors.</p> <p>4. The majority of young Poles are willing to accept BD as an equality valid if not more significant diagnosis compared to irreversible cardiac arrest.</p>
Pope, T (2018)	Narrative/Opinion	North America - USA	To call for legal certainty in brain death.	N/A	N/A	<p>1. Legal certainty of BD increasingly challenged since McMath case 2013, spurring other families to challenge clinicians, exposing long-standing but little-known fracture in BD's biological and conceptual foundations.</p> <p>2. Concerns that legal challenges to BD are eroding public trust in BD concept.</p> <p>3. In past years, increasing family lawsuits for BD exemption, and likely more claiming religious exemption than before. Conscience-based objections have also gotten renewed emphasis. In all, legal status of BD is unlikely to remain the same.</p>

Pope, TM (2014)	Review	North America - USA	To review recent legal developments around death determined by neurological criteria in the USA.	N/A	N/A	<ol style="list-style-type: none"> 1. While there are ongoing academic debates, the law has remained relatively stable in the USA. 2. Opponents to BD have been unsuccessful catalyzing a public movement sufficient to change medical practice or public laws. 3. Public's apparent confusion about brain death shows that the legal stability may not demonstrate societal consensus. 4. New Jersey (1991 Declaration of Death Act) provides "indefinite accommodations" in the case of religious objection to BD, to be declared dead only using cardiorespiratory criteria. 5. New York recognizes a wider range of objections (religious, moral) to BD but the duty of accommodation is less demanding. 6. California requires accommodation of all types of accommodations, but accommodation is limited and finite. 7. Families regularly bring lawsuits to mandate continued physiological support, religious objections or just mistrusts the diagnosis. 8. Confusion in how media reports on BD has damaged public confidence. 9. Jahi McMath 2013 California and Issac Lopez 2014 Kentucky were two recent prominent cases of BD involving children. 10. Reports of genuine BD misdiagnosis/premature diagnosis (intention or negligent) have received intense media coverage and subsequent caused public alarm.
Pope, TM (2017)	Review	North America - USA	To explore the legal status of BD in the US.	N/A	N/A	<ol style="list-style-type: none"> 1. 2015 Aden Hailu cases in Nevada increased rate of family clinician conflict in the USA. Widely reported in the media, it has been causing families' distrust and challenge of the BD diagnosis. 2. McMath's case has had a significant impact on the resolution of other BD conflicts. 3. Near consensus position of BD increasingly subjected to persuasive criticism and concerns, and disagreements reignited.
Potter, K (2017)	Narrative/Opinion	North America - USA	To explore the controversy in the determination of death and the impact of cultural beliefs.	N/A	N/A	<ol style="list-style-type: none"> 1. In Western cultures, mind and body are perceived as separate with personal identify residing in the brain. In eastern culture, the mind and body are more unified, and death encompasses the entire body. Japanese place importance on the heart, causing difficulty diagnosing a warm heart-beating person as dead. Death is more of a social construct than a medical event. 2. Surgeon for first heart transplant arrested for murder in Japan, and cause distrust in organ transplantation for many years. Despite significant public discourse and law changes, BD concept is still surrounded by controversy.
Racine, E (2015)	Narrative/Opinion	North America - Canada	To argue that a co-evolving view (lay and scientific) of the	N/A	None	<ol style="list-style-type: none"> 1. Definitions need to reflect lay views to be valid. 2. Expert views provide authoritative insight and knowledge into death.

			definition of death should be used.			3. Death determination should be based on the best provisional knowledge, not as a quest for certainty
Rios, A et al. (2018)	Quantitative	Spain	To assess if Spanish medical students understand the concept of brain death	9598 Spanish medical students	Self report measure of BD knowledge questionnaire	1.67% of respondents understood the BD concept, the rest did not know what it meant. 2.The variables related to correct understanding were a) being older, 2) studying at a public university, and 3) studying at one of the universities in the south of Spain.
Rios, A, et al. (2020)	Quantitative/Survey	Spain	To analyze the knowledge of the BD concept among the Ecuadorian population resident in Spain.	461 residents of Spain born in Ecuador, over than 15 years.	PCID-DTO-Rios validated questionnaire, random selection of respondents, anonymous and self-administered.	1. BD is little known in this population. 22% know the BD concept and accept it as the death of the person. 61% do not know the BD concept, and 17% do not think BD is the death of a person. 2. Age and marital status are related to correct knowledge of BD. 3. No objective relationship with attitude towards organ transplantation.
Rios, A, et al. (2020)	Quantitative/Survey	North America - USA	To analyze the knowledge of BD concept among the Puerto Rican population in Florida.	259 respondents born in Puerto Rico and residing in Florida, over 15 years old.	Validated questionnaire (PCID-DTO-Rios), random selection of people selected with support from immigration assistance associations in Florida. Anonymous and self-administered	1. 35% know the BD concept and consider it the death of an individual. 44% do not know the BD concept and 21% do not consider it death. 2. Sex, marital status, couple's opinion and religion were significantly related to correct knowledge of BD.
Rios et al (2020)	Quantitative	Spain	To analyze the knowledge and acceptance of BD among the Algerian population living in Spain	441 Algerians living in Spain	Validated questionnaire (PCID-DTO-Rios), random selection	1.The Algerian population immigrating to Spain has little knowledge of the BD concept, which has a direct relationship to their attitude toward organ donation
Rios et al (2020)	Quantitative	Spain	To analyze the knowledge and acceptance of BD among the Cuban population living in Spain	636 Cubans living in Spain	Validated questionnaire (PCID-DTO-Rios), random selection	1.Approx. 50% of the Cuban population living in Spain knows and accepts the concept of BD as the actual death of the individual 2.This population has a favorable attitude toward organ donation
Rodríguez-Arias, D and Véliz, C (2013)	Narrative/Opinion	Europe/Spain	To propose the need for public deliberation on death determination.	N/A	N/A	1. Conceptual reformulations of death determination creates confusion among public, media and HCPs. 2. Language undercuts public understanding, lay persons are less likely to debates claims presented by experts as facts.

						<p>3. The absence of public outcry is not evidence of society acceptance, due to the complexity, confusion and lack of transparency.</p> <p>4. The public should participate in the debates around death determination to avoid paternalistic expertocracy and prevent the exploitation of the lack of public knowledge to achieve compliance.</p>
Ross, LF (2018)	Narrative/Opinion	North America - USA	To argue that the definition of death should focus on when we can say the individual is no longer human with the right not to be killed.	N/A	N/A	<p>1. The optimal solution is to allow stakeholders to choose their own definition of death within a reasonable range of options.</p> <p>2. The concept of death relies on religious and philosophical beliefs of which there is no societal consensus.</p> <p>3. A single metaphysical concept of death is currently and may always be out of reach.</p>
Siminoff LA, Burant C, Youngner SJ (2004)	Qualitative/Focus Group	North America - USA	To examine the public attitudes and beliefs about the determination of death and its relationship to organ transplantation.	1351 Ohio residents >=18 years	Randomly selected and surveyed using random digit dialing, survey developed from focus groups and pilot study, using scenarios of hypothetical patients.	<p>1. Over 98% had heard of brain death but only 33.7% believed someone who was BD was legally dead.</p> <p>2. 86.2% identified the BD patient as dead, 57.2% identified the patient in a coma as dead and 34.1% identified in the patient in a PVS as dead.</p> <p>3. 33.5% were willing to donate organs of patients they classified as alive for at least one scenario (seemingly in violation of the DDR)</p> <p>4. A majority of respondents were unaware, misinformed or held beliefs incongruent with current definitions of brain death.</p>
Siminoff LA, Mercer MB & Arnold R (2003)	Qualitative/Focus Group	North America - USA	To examine factors related to families' understanding of brain death and how those factors affect families' decisions about organ donation.	403 families of organ donor-eligible patients with a brain dead relative.	Interviews conducted with HCP who spoke to families about organ donation and family decision makers at 9 trauma hospitals.	<p>1. 96 % of families were told their family was brain-dead but only 28.4% were able to provide a completely correct definition of brain death.</p> <p>2. 30% agreed that a person is dead only when the heart stopped beating</p> <p>3. No association between definition of BD and willingness to donate.</p> <p>4. Those who donated were less likely to agree with statement that someone is dead only when the heart stops.</p> <p>5. Respondents who accepted their loved one was dead when informed patient was brain dead were more likely to donate than those who considered death when MV was turned off and the heart stopped.</p> <p>6. Term BD has a variety of meanings in everyday speech, undermining public's understanding of the medical meaning.</p>
Shah, SK (2018)	Narrative/Opinion	North America - USA	To argue that diagnosing BD as a hidden legal fiction is helpful to understand its historical development and current status.	N/A	N/A	<p>1. If courts and legal scholars openly treated BD as legal fiction, this could be a useful way to resolve current and future controversies</p> <p>2. That BD is legal fiction not aligned with standard biological concept of death must be made transparent and acknowledged.</p> <p>3. Urgent need to research how to best communicate BD to the public to build on empirical research to understand confusion about BD and how to dispel it.</p>

Tessmer, CS, et al. (2007)	Quantitative/Survey	South America - Brazil	To examine public understanding of brain death and how the term brain death affects decisions about organ donation.	3159 participants in urban area of Pelotas, Brazil >= 20 years old.	Cross-section study of a sample population. Structured questionnaire, completed in individual interviews.	<ol style="list-style-type: none"> 80.1% would authorize organ donation after death of a relative who had declared a willingness to do so. When "brain death" is used, only 63% would authorize organ donation for a relative, and only 1/3 would donate if the subject had not been discussed. When death is substituted with brain death, willingness to donate decreased 20%, showing individuals did not understand or accept the term brain death. Women accept/understand less about BD than men.
Thomas, AG (2012)	Narrative/Opinion	Oceania - Australia	To discuss the death debate and controversies of the report of the president's council on bioethics	N/A	N/A	<ol style="list-style-type: none"> Public debate about BD often leads to oversimplified media statements, with potential to undermine public support for organ donation Public discussion can entrench disagreement rather than diminish it. May be more likely to achieve consensus by undermining the DDR than debating the definition of death.
Veatch, RM (2004)	Narrative/Opinion	North America - USA	To analyze possible implications of classifying patients in PVS or irreversible coma as either dead or alive and implications on public policy.	N/A	N/A	<ol style="list-style-type: none"> Lay people generally classify legally living (PVS, irreversible coma) as dead OR as living but are still willing to procure their organs (2/3 of those who said patient is alive). Either make exceptions to the DDR to permit organ procurement or amend death definition to them classify as dead. Siminoff study suggest 13.8% believed brain-dead patient as alive, 57.2% considered a comatose patient to be dead and 34.1% considered PVS to be dead. It is easier and less controversial to classify irreversible coma and PVS as dead by definition, while incorporating a conscience clause to permit religious or philosophical objections with minimal problems.
Veatch, RM (2018)	Narrative/Opinion	North America - USA	To reflect on the current controversies of brain death.	N/A	N/A	<ol style="list-style-type: none"> Persistent controversies include: <ol style="list-style-type: none"> Can patients/families have the right to refuse testing i.e. apnea testing Which criteria should be used in measuring brain function loss Whether clinician error in applying tests is too great Whether the criteria measure loss that is really irreversible Whether loss of all functions of the entire brain can be measured with existing criteria sets Whether current whole brain concepts of death should be favoured over a circulatory or higher brain concept A default definition should be legislated, and individuals should be able to choose among a range of alternatives.
Yang, Q and Miller, G (2015)	Narrative/Opinion	North America - USA	To explore differences in the east vs. west perceptions of BD	N/A	N/A	<ol style="list-style-type: none"> The West elevates rationality, autonomy and neuro-essentialism, causing acceptance of BD Interpretation of preserved vital signs as life hinders utility of brain death in the East. Social factors like trust in the healthcare system and cultural frameworks is are factors in BD acceptance.

Zeiler, K (2009)	Narrative/Opinion	Europe - Sweden	To discuss the philosophical basis for the New Jersey Death Definition Law and Japanese Transplantation Law.	N/A	N/A	<ol style="list-style-type: none"> 1. Both the New Jersey Death Definition Law and Japanese Transplantation law open up more than one death concept within one legal system. 2. New Jersey law has an exemption for which people who reject WBD criteria on religious grounds will allow them to opt out of the criteria. 3. Japanese law opened up two alternative death concepts - allowing either declaration of death either by heart-lung criteria or WB criteria with heart-lung death as the default. Belief that human essence lies in one's body not solely the brain. 4. Certain legal pluralism in disputed areas should be allowed as long as they do not harm the lives of others intolerably. 5. No culture-independent version of death can be taken as a golden standard, with variations between and within societies.
Volk M. L., G.J.W. Warren, R.R. Anspach, et al. (2010)	Quantitative/Survey	North America - USA	To determine attitudes among the American public regarding foreigners coming to the United States for the purposes of transplantation, and (2) to investigate the impact this practice might have on the public's willingness to donate organs	1049 American adults	Probability-based national sample, survey	<ol style="list-style-type: none"> 1. 30% (95% CI 25–34%) felt that people should not be allowed to travel to the United States to receive a deceased donor transplant, whereas 28% felt this would be acceptable in some cases; 30% (95% CI 33–42%) indicated that this practice might prevent them from becoming an organ donor 2. deceased-donor transplantation of foreigners is opposed by many Americans 3. media coverage of this practice has the potential to adversely affect organ donation
Neiders & Dranseika (2020)	Quantitative/Survey	Europe - Latvia	To better understand people's preferences about death determination criteria	1416 Latvians	Online vignette-based survey	<ol style="list-style-type: none"> 1. There were widely differing preferences concerning death determination criteria, suggesting the pluralist solution fits best with the way our study participants think about death determination 2. Participants tend to prefer less restrictive criteria for determination of their own deaths than for determination of deaths of their closest relatives 3. Preferences observed in our sample are largely in accord with the Dead Donor Rule for organ procurement for transplantation
DuBois JM, Waterman A.D., Iltisa A. and Anderson J. (2009)	Mixed Methods	North America – USA	To investigate what the public thinks about key ethical and policy questions associated with rapid organ recovery	70 African-American, Caucasian and Latino community members in St. Louis, MO	Focus groups and surveys, before and after being educated about ROR	<ol style="list-style-type: none"> 1. Most participants believed mistakenly that they could donate organs following an unexpected cardiac arrest (76%) 2. After the focus group, 84% would want to donate organs after unexpected cardiac arrest; 81% would support organ cooling to enable this 3. African-American and Latino participants expressed greater fears than Caucasians that if they consented to organ donation, physicians might do less to save their life; however, support for ROR was not significantly lower in these subgroups

						4. Public support for ROR was present. Adequate consent processes and safeguards should be established to foster trust and support for ROR.
Honarmand et al (2020)	Mixed Methods	North America - Canada	To conduct a national survey of public perceptions regarding cardiac DCDD.	1001 Canadians adults, representative of the Canadian population	Electronic survey sent by email and social media, with quantitative and open-ended components	The majority of Canadians sampled support cardiac DCDD. Most respondents supported the implementation of direct procurement and perfusion (738 respondents or 73.7%; 95% CI, 70.9 to 76.3) and normothermic regional perfusion (655 respondents or 65.4%; 95% CI, 62.4 to 68.3) in Canada
Pessoa et al (2020)	Quantitative	Brazil	To evaluate the knowledge of the population about BD and organ donation	868 participants	Survey	Participants had conflicting knowledge of BD. For example, 26.8% of the population believed BD was reversible
Stadlbauer, et al (2020)	Quantitative	Austria & Switzerland	To assess knowledge and attitudes toward organ donation	754 Adolescents (11-20 years)	Survey	Only 59% of adolescents believed that a person is really dead when he/she is declared brain dead
Tarzi et al (2020)	Quantitative	Syria	To evaluate the attitude and knowledge of organ donation among Syrians and the willingness of this population to donate their organs	303 adults	Survey	When assessing knowledge about BD, only 40% answered three or more questions correctly (out of 5). Although more positive attitude towards organ donation was found in those with better brain death knowledge, this did not translate into more willingness to donate organs in this group of participants.
Verble, M et al (2020)	Qualitative	USA	To determine the concerns of families approached for DCD and explore how those might be addressed to increase DCD donation rates	4 different ODO agencies from 148 cases (patients)	Self report /document analysis	Family concerns that block DCD differ in many ways from those of BD families. Results from DCD family concerns were grouped into 3 overlapping categories: practicalities, suffering, process.

BD = brain death; BSD = Brainstem death; HCP= healthcare provider; DCDD = donation after the circulatory determination of death; NDD = neurological determination of death; ICU = intensive care unit; ROR = Rapid organ recovery