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Supplement 12. Religion and Brain Death/Death by Neurologic Criteria: Managing Requests to Forgo a Brain Death Evaluation or Continue Somatic Support After Brain Death/Death by Neurologic Criteria

This supplementary material has been provided by the authors to give readers additional information about their work.

Religion and Brain Death/Death by Neurologic Criteria: Managing Requests to Forego a Brain Death Evaluation or Continue Somatic Support After Brain Death/Death by Neurologic Criteria

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Abstract

Introduction Although most religions support the use of neurologic criteria to declare death, families sometimes object to determination of brain death/death by neurologic criteria (BD/DNC), or request continuation of somatic support after brain death declaration.

Methods We conducted a review of the literature and formulated recommendations with an expert panel on management of requests for accommodation.

Results and Conclusions Requests to forego a BD/DNC evaluation or continue somatic support due to objection to the declaration of BD/DNC are becoming increasingly more common. Management of these requests varies. We provide recommendations and suggestions on both prevention and management of these requests.

Introduction

Although brain death/death by neurologic criteria (BD/DNC) is accepted as the equivalent of cardiopulmonary death throughout much of the world,¹⁻³ when a person is declared brain dead, or when a BD/DNC evaluation is planned, families sometimes object and request to either forego a BD/DNC examination and await cardiopulmonary death or continue somatic support after brain death declaration (for an indication other than organ donation or maintenance of support for a fetus). These requests impact individual persons, their families, healthcare teams and other critically ill patients who require admission to an intensive care unit.^{4,5} Two surveys of healthcare professionals involved in BD/DNC declaration in the United States found these requests are made for a variety of reasons including belief that a person who is brain dead could regain neurologic function; desire to await arrival of additional family members prior to discontinuation of support; and lack of acceptance that a person can be dead if their heart is beating.^{4,5} Religion, however, is the foundation for the majority of these requests.⁶⁻²¹

Methods

Authors conducted the initial literature searches of the Cochrane, Embase and MEDLINE databases for the time period between January 1, 1992 and July 2017. Subsequent searches were performed to capture relevant articles between July 2017 and April 2020. Because of the significant lack of data from randomized controlled trials or large studies, GRADE evaluation of the evidence was not performed. However, evidence was reviewed by a multidisciplinary group of clinicians (see Introduction chapter) and recommendations were generated according to the following criteria. Strong recommendations (“It is recommended that”) were based on expert consensus that clinicians should follow the recommendation unless a clear and compelling rationale for an alternative approach was present, and where actions could be adopted as policy. Even though most evidence in this area is limited and of low-quality, strong recommendations were made as a precautionary, conservative approach, to prevent premature or erroneous determinations of death (false positives). Conditional or weak recommendations (“It is suggested that”) were generated when there were potentially different options and the best action may differ depending on circumstances, patients, resources or societal values, or where there is a need for further evidence or discussion among clinicians and stakeholders. In cases where there was insufficient evidence and the balance of benefits versus harms was neutral, no recommendations were made.

Brain Death and Religion

Since the introduction of neurologic criteria to declare death, religious scholars have argued about whether it is compatible with canonical traditions and teachings. Today, BD/DNC is generally accepted in most religions, but the frequency of this acceptance varies both between and within religions. See Table 1.²²⁻³⁵

Table 1. Religious Perspectives on BD/DNC

Religion	Perspective on BD/DNC
Buddhism	BD/DNC is accepted as death by some scholars, but this position is not universally held
Christianity	<ul style="list-style-type: none"> • American Baptists: there is no official statement on the criteria to declare death, but no opposition to use of neurologic criteria to determine death • Anglicanism: BD/DNC is accepted as death • Eastern Orthodoxy: BD/DNC is neither accepted nor rejected • Evangelicalism: it is accepted that no medical treatment can reverse BD/DNC and noted that “life support” should be removed in the case of BD/DNC to “facilitate the process of dying” • Jehovah’s Witnesses: there is no official statement on the criteria to declare death, but no opposition to use of neurologic criteria to determine death • Lutheranism: there are mixed opinions on use of neurologic criteria to determine death • Presbyterianism: BD/DNC is acknowledged to be widely accepted as death

Religion	Perspective on BD/DNC
	<ul style="list-style-type: none"> • Roman Catholicism: BD/DNC is generally accepted as death • Seventh Day Adventists: there is no official statement on the criteria to declare death, but no opposition to use of neurologic criteria to determine death • Southern Baptists: there is no official statement on the criteria to declare death, but no opposition to use of neurologic criteria to determine death • United Methodists: there is no official statement on the criteria to declare death, but no opposition to use of neurologic criteria to determine death • Unitarian Universalists: there is no official statement on the criteria to declare death, but no opposition to use of neurologic criteria to determine death
Hinduism	BD/DNC is accepted as death by some authorities, but this position is not universally held
Islam	<ul style="list-style-type: none"> • Shiism: BD/DNC is generally accepted as death • Sunnism: mixed opinions on BD/DNC
Judaism	<ul style="list-style-type: none"> • Conservative Judaism: BD/DNC is accepted as death • Orthodox Judaism: mixed opinions on BD/DNC • Reform Judaism: BD/DNC is accepted as death

The many sects of Christianity have different perspectives on the use of neurologic criteria to declare death.²³ Until the 1980s, Roman Catholic doctrine held that determination of death remained the province of the medical profession, not the Church. But with the growing acceptance of BD/DNC and, particularly, the practice of organ donation from brain dead decedents in Roman Catholic hospitals, came the realization that it relied on a new concept of death based on an idea that was not universally accepted. As a result, Roman Catholic doctrinal leaders began to study the issue in the 1980s and 1990s through sequential Vatican pontifical academies and councils to determine if it was compatible with their traditions. These studies culminated in a pronouncement in 2000 by Pope John Paul II that BD/DNC and organ donation from a brain dead decedent were fully consistent with Roman Catholicism.^{25,26} After the death of Pope John Paul II, and at the request of Pope Benedict XVI, in response to disagreement by some influential Catholic authorities, the Vatican Pontifical Academy of Sciences reaffirmed the papal ruling and delineated more specifically the diagnostic signs of BD/DNC.²⁷ Accordingly, use of neurologic criteria to declare death is generally accepted by Roman Catholics.²³ While there is no similar official statement from Protestants on criteria for determination of death, there are no mainstream Protestant sects that reject BD/DNC.²⁴

The acceptance of BD/DNC within Judaism remains divided, although the majority of rabbis accept it. A survey of multid denominational rabbis found that while only 5% of rabbis believed a person who is brain dead could recover, 22% did not believe a person who is brain dead is dead and 18% believed mechanical ventilation should be continued after BD/DNC.³⁶ Jewish religious doctrine is not issued by a central authority but, rather, accrues like case law as the result of learned discourses by rabbinic scholars as they apply ancient Jewish law (Halakhah) based on the Torah, Talmud, and other sources to contemporary problems. This type of scholarship has led to differences in the acceptance of BD/DNC.

The principal Talmudic point of dispute over death determination is whether it is the cessation of breathing (brain-controlled) or heartbeat (not brain-controlled) that is the critical characteristic of death in Jewish law. Currently, BD/DNC is generally accepted by Reform and Conservative rabbis, but within Orthodox Judaism there remains an ongoing rabbinic disagreement. The strictest Orthodox rabbis, including those in most ultra-Orthodox communities, reject BD/DNC and require circulatory and respiratory cessation for physicians to declare death.^{23,28} By contrast, the more biologically oriented Orthodox rabbis accept BD/DNC and, therefore, permit organ donation from a brain dead donor.^{23,29}

Within Islam, the situation is similarly complicated with varying degrees of acceptance of BD/DNC among influential Islamic scholars and academics who have differing interpretations of Qur'anic writings and other sources.³⁰ Shiites generally follow a fatwa issued in the 1970s by Ayatollah Khomeini, opinion leader of the Islamic Republic of Iran, equating BD/DNC and cardiac death,³¹ but uniform consensus on BD/DNC has not been reached by Sunnis. The Organization of Islamic Conferences' Islamic Fiqh Academy determined that BD/DNC and cardiac death are equivalent at the Third International Conference of Islamic Jurists in October of 1986.³⁰ The Islamic Organization of Medical Sciences considers BD/DNC to be an intermediate state between life and death.^{32,33} Some other organizations, albeit relatively few in number, reject the concept of BD/DNC completely.³² Amongst those who recognize the notion of BD/DNC, there are varying perspectives on the criteria: although the vast majority require the use of whole brain death criteria, some consider brainstem death criteria to be sufficient.³⁰ Although BD/DNC is commonly declared in a number of Islamic nations, practices remain non-uniform.³² Additionally, studies on the treatment of brain dead Muslim decedents show that their families frequently do not accept declaration of death by neurologic criteria.³⁴

In Indigenous religions, death is defined abstractly. It is often considered a taboo to even mention death because discussing it could be seen as an invitation. Medical interventions are generally frowned upon during the dying process. However, many indigenous religions believe that one's spirit is in both the present world and another world at the time of death and that failure to appropriately care for the dead may lead to harm for both the deceased and the entire community.²³

Hindu authorities in India accept BD/DNC, which is practiced widely there, but some Hindus are uncomfortable with the medical determination of death.^{23,35} Discussions in the literature on the Hindu perspective on death focus on whether a death is good, based on astrological signs and performance of rituals, or bad, which can have profound effects on a person's next lives and bring bad luck onto their family. Determinations of BD/DNC are infrequent because most persons in India die at home, rather than in the hospital.²³

Buddhists believe death occurs when vitality, heat and consciousness leave the body, a time which may not occur until well after cessation of both neurologic and cardiopulmonary function. Because the Buddha emphasized the necessity for all persons to find their own path, there are few figures other than Buddha and the Dalai Lama whose opinions and decrees are universally upheld. Two Buddhist scholars supported the use of neurologic criteria to declare death, but one later recanted this position.^{23,35}

A challenging situation arises in cases in which physicians intend to declare BD/DNC according to prevailing medical practice and law, but they are met with objections by families based on their religious

convictions. Successfully handling these cases requires respect for religious beliefs, knowledge of the relevant law, compassion, and flexibility.²⁰

Demographics of Requests to Forego a BD/DNC Examination or Continue Somatic Support after BD/DNC

Very few requests to either forego a BD/DNC examination or continue somatic support after declaration of BD/DNC were reported in the literature before 2005,^{6,13,15} but the frequency of requests has increased in the past few years, punctuated by a number of highly publicized lawsuits related to these requests (most notably, of Jahi McMath and Aden Hailu).⁸⁻¹⁶ Reported requests may be more common due to escalated familial proclivity to seek accommodation, but it also may be due to increased frequency of BD/DNC declaration or publication bias.^{4-21,37} Based on survey results from 2015 and 2016, nearly 50% of practitioners who care for persons with devastating brain injuries in the US have been asked to provide accommodation at least once during their career.^{4,5} Requests to either forego a BD/DNC examination or continue somatic support after declaration of BD/DNC, most of which are made because of religious beliefs, are described in the literature for persons across the lifespan from infancy to 87-years-old.⁴⁻²¹ Nearly all cases of this type of request reported in the literature originate in the US (case reports come from California, District of Columbia, Florida, Kentucky, Michigan, Nevada, New York, Ohio, Texas, Utah, and Vermont, but surveys of neurologists and intensivists demonstrate that such requests have been made all over the US).^{4-15,17-21} It is unclear if the predominance of USA cases is reflective of the low number of such requests internationally or of publication bias.^{4-21,37} More recently, however, there have been highly publicized lawsuits about requests to continue somatic support after declaration of BD/DNC made in Canada and the United Kingdom.^{16,38,39}

Management of Requests to Forego a BD/DNC Examination or Continue Somatic Support after BD/DNC

There remains debate in the literature as to whether or not families should be asked to consent for performance of a BD/DNC evaluation or discontinuation of somatic support, and whether or not requests to either forego a BD/DNC examination or continue somatic support after declaration of BD/DNC should be accommodated.^{4,5,7-9,13,16} In a survey of pediatric neurologists and intensivists in the US, 72% of respondents stated that it is not necessary to obtain consent before performing a BD/DNC evaluation, but 42% believed that consent should be obtained before discontinuing somatic support.⁵ Similarly, in a survey of adult neurologists in the US, 78% of respondents did not believe consent needed to be obtained before performing a BD/DNC evaluation, but 42% agreed consent should be obtained before somatic support is discontinued.⁴ While some authors believe requests to either forego a BD/DNC examination or continue somatic support after declaration of BD/DNC should universally be accommodated,^{8,9} others believe death is a medical determination and families should not be given the option to accept or decline that determination.¹³

In the US, management of requests to either forego a BD/DNC examination or continue somatic support after declaration of BD/DNC varies by the state in which a person is hospitalized, the healthcare professionals involved in their care, and the hospital to which they are admitted, and ranges from

continuation of support until cardiopulmonary arrest,^{4,5,7,17,37} withdrawal of somatic support with a family's authorization,^{4,5,7,20,37} withdrawal of somatic support against a family's wishes,^{5,7,15,16,21,37} transfer to another hospital or country,^{4,5,7-16,18,19,37} or discharge home for continuation of somatic support.¹³ In some cases, in response to these requests, a BD/DNC evaluation is not performed, either due to legal stipulation that a BD/DNC determination should not be made in the setting of a religious objection (as is the case in New Jersey) or due to physician or hospital preference.^{4,7,19} Actions are often motivated by a desire not to upset the family and fear of negative media coverage or lawsuits.^{4,5,17} If these requests are accommodated, somatic support may be continued after BD/DNC for a brief period, as short as a few hours, or a prolonged period, until cardiopulmonary arrest.^{4,5,7,37} In some cases, only certain therapies that were being provided prior to declaration of BD/DNC are continued in the setting of requests to provide somatic support after BD/DNC, but in other cases, drugs, fluid, and nutrition are all continued, and additional medications may be started.^{4,5} Controversies regarding these requests are sometimes settled internally in a hospital, but in other cases, they are decided in a courtroom, which can be a lengthy process.^{4-21,37}

Management of requests to either forego a BD/DNC examination or continue somatic support after declaration of BD/DNC remains controversial. On the one hand, there is the desire to uphold the values of autonomy, freedom of religion and privacy, but on the other hand, accommodating these requests and foregoing an evaluation of BD/DNC or continuing somatic support after BD/DNC can lead to issues with resource allocation, social justice, moral distress, confusion about responsibilities, fears of violating professional and bodily integrity, concerns about being disrespectful to the dead and the possibility of delaying familial grief.^{4,5,7,8,12,20} In January 2019, the American Academy of Neurology published detailed guidance on management of these requests, but other medical societies have not generated recommendations on this topic.⁴⁰

Recommendations and Suggestions

1. In an effort to preemptively avoid conflict with families regarding determination and declaration of BD/DNC, it is suggested that:
 - a. Hospitals work with local religious and cultural leaders to learn about their communities and proactively discuss the management of brain-dead decedents,
 - b. Healthcare teams be trained in cultural sensitivity and communication, and treat all persons and families with respect,
 - c. Family support and education be provided when it is suspected that a person with devastating brain injury may progress to BD/DNC,
 - d. A multidisciplinary support team (ethics, nursing, social work, palliative care, spiritual care, religious officials) be included in discussions about BD/DNC,
 - e. Healthcare organizations proactively create guidance on the management of requests for accommodation, including indications for provision of accommodation and notation of specific interventions that can be initiated/continued/withheld after brain death in the setting of accommodation requests,

- f. Families should be provided with support and education before, during, and after discontinuation of somatic support,
 - g. Families be invited to observe the BD/DNC determination.
2. It is recommended that reasonable efforts should be made to notify a person's next-of-kin before performing a BD/DNC determination.
3. It is recommended that there is no need for consent for performance of the clinical evaluation, apnea testing or ancillary testing for determination of BD/DNC.
4. It is recommended that healthcare teams seek guidance and support from their local ethics and legal teams and hospital administration if a family requests to either forego a BD/DNC examination or continue somatic support after declaration of BD/DNC.
5. It is recommended that attempts should be made to handle requests to either forego a BD/DNC examination or continue somatic support after declaration of BD/DNC within a given hospital system before turning to the legal system.
6. It is suggested that, while it is reasonable to continue somatic support after BD/DNC for a finite period of time, assuming that the specific time frame for doing so is brief and uniform, and that a family is informed of the time frame in advance, this should ordinarily should not be done for a period greater than 48 hours, and policies should clearly stipulate the time that support will be continued, rather than using the phrase "a reasonable amount of time."
7. It is suggested that if BD/DNC has been declared, but a family voices religious objection to this declaration, the family should be informed that escalation of existing levels of treatment, including cardiopulmonary resuscitation, will not be provided.
8. It is suggested that if only one physician was involved in determination of BD/DNC, an additional clinician in the hospital should provide the family with a second opinion regarding determination of BD/DNC if it is felt that this may assist the family in accepting the decedent's death.
9. It is suggested that, in the setting of a request to either forego a BD/DNC examination or continue somatic support after declaration of BD/DNC, a family should be provided with a finite period of time to seek to arrange transfer to another facility and the healthcare team should speak to a potential accepting institution if requested to do so.
10. It is suggested that, even in the setting of requests to continue somatic support after declaration of BD/DNC, support should be discontinued if a hospital bed is required for a living patient and no other bed is available.

Questions to Inform Research Agendas

1. How frequently are requests to either forego a BD/DNC examination or continue somatic support after declaration of BD/DNC made and for what duration is support continued?
2. What are common characteristics of families who request to either forego a BD/DNC examination or continue somatic support after declaration of BD/DNC?
3. Are there international differences on requests to either forego a BD/DNC examination or continue somatic support after declaration of BD/DNC and how do health care systems manage these requests?
4. What are the most effective strategies to address family or religion-based objections to BD/DNC and to educate local religious leaders?

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