

# Brain Death, the Pediatric Patient, And the Nurse

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At the level of statutory law and clinical practice, brain death is regarded as one of the few relatively settled issues of contemporary bioethics, yet for some, the conceptual basis for equating an irreversibly non-functioning brain with a dead human being remains controversial and puzzling (Shewmon, 2001). Brain death in children can make the issue even more troublesome because of underlying psychosocial and physiological differences between children and adults. One basis of this disagreement resides in the lack of a universally agreed upon scientific definition of what constitutes the death of a human being. Some health practitioners believe that a human is clinically dead when the brain, understood by some as “the master regulating organ,” has irreversibly stopped functioning (Bernat, 2006, p. 38). Conversely, McMahan (2006) argues that this definition lacks clarity and is fundamentally flawed because loss of integrative unity of the person as a whole is not a tenable reason for equating brain death with clinical death. McMahan (2006) believes that focusing solely on the brain raises more questions than provides answers.

In addition to the controversy related to definition, not much literature examines the issue of brain death in pediatrics; most research involves an adult population. However, children are different than adults in many ways. Psychosocially and physically,

The term “brain death” has ties to medical, legal, ethical, and philosophical discourse, and is therefore a complicated and potentially ambiguous term. Some state that with brain death a person no longer has a “master regulating” organ integrating his or her organism as a whole, and the proponents of this view equate this loss of integration with clinical death. Others believe this is not a tenable reason to deem an individual who is brain dead as clinically dead; thus, controversy exists surrounding this issue, and nurses are not resistant to this debate. Whether one supports the definition of brain death as clinical death or not appears to depend on one’s view of the mind-body relationship. Pediatric nurses are involved in this controversy because of the care they provide to both the affected child and family in this troubling time.

children are cared for differently, with the resulting difference in how brain function is assessed, and their dependence and inability to speak for themselves may contribute to their seeming more vulnerable and in need of advocacy and protection. Pediatric nurses also assist families through difficult circumstances and have important roles in helping families understand their child’s condition. This article will provide pediatric nurses with a brief history of brain death, examine how this issue is currently being addressed (with particular attention to the roots of the controversy), and explain why the issue should be approached philosophically.

## Background on Brain Death

### The ‘Birth’ of Brain Death

Advances in medical technologies have created ambiguities in what was previously a relatively uncomplicated situation. Traditionally, the diagnosis of human death posed few problems (Edwards, 2005). Is the person still breathing? Is the heart still beating? In other words, breathing and a heartbeat meant life. However, things have become more complicated since the invention of ventilators. It now became possible for critically ill children who could not breathe on their own to be maintained with mechanical ventilation and oxygen, and therefore, to sus-

tain an independently beating heart. Thus, technological advancements made the traditional method of assessing cardiopulmonary criteria in diagnosing death redundant (Edwards, 2005). Attention shifted from the capacity to breathe and maintain a heart beat to the supposed origin and control of these capacities – the brain (Ad Hoc Committee of the Harvard Medical School, 1968). Thus, the question of whether brain death constituted clinical death arose.

### Legal History

In 1968, the Ad Hoc Committee of the Harvard Medical School made the first major attempt to determine whether brain death was equivalent to clinical death. This committee consisted of 13 physicians, and their main purpose of meeting was “to define irreversible coma as a new criterion for death” (p. 337). However, this group gave no explanation as to why brain death should be considered a sufficient criterion for death except that doing so resolved two practical matters. First, the care of patients with a diagnosis of brain death and no hope of recovery was seen to be a misuse of valuable ICU resources. Second, these patients could potentially donate organs while their hearts were still beating because they would legally be considered dead (Truog, 1997). Then in 1981, the Law Reform Commission of Canada attempted to develop a fuller explana-

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tion of why brain death should be considered equivalent to clinical death and what parameters would determine the diagnosis of "brain death." The Commission, consisting of judges and lawyers who consulted many scientific and legal groups on this issue, undertook this task at the request of the Canadian public "to see removed the present ambiguity arising from the apparent contradiction between the classical signs of death...and the neurological signs" (Law Reform Commission of Canada, 1981, p. 3). Their explanation included the idea that the brain is the supreme organ of the body, and that as the regulator of the whole organism, when the brain no longer functions, there is the loss of the integration of the organism. This means that the organism is now irreversibly disintegrating, and this disintegrated state equates to clinical death (Law Reform Commission of Canada, 1981). From a pediatric perspective, other than consulting one eastern Canadian children's hospital, the Commission's document does not refer to children; it only refers to "persons."

Official guidelines for determining brain death in children, infants, and neonates did not exist in Canada until 1999 when a subcommittee of the Canadian Neurocritical Care Group (CNCG) created them at the request of the Canadian Neurological Society, the Canadian Association of Child Neurology, and the Canadian Society of Clinical Neurophysiologists. The guidelines were needed because official Canadian guidelines had yet to exist, although brain death diagnoses in pediatric settings were being used in Canada since as early as 1987 (Parker et al., 1995). At that time, Canadian pediatricians were using the Canadian Medical Association's (1987) adult guidelines, even though the guidelines specifically stated their use should be avoided in the pediatric population because they had yet to be "well studied" in this group (p. 200B). This section has a focus on the legal history of brain death in Canada because Canadian guidelines (for both children and adults) were created much later than American guidelines, thus requiring a separate discussion of the North American legal history of brain death.

### What Is Brain Death? A Need for Philosophy

It seems apparent that how one conceives of the relationship between the mind and the body and what it

means to be a person will have implications for understanding what it means for a person to die. It appears that at least some of the controversy surrounding the issue of brain death exists because there are philosophically different views on what constitutes a person or personhood. Is it the ability to contribute to society that makes someone a person? Or is someone a person because one has his or her own thoughts? Is it possible for the mind to be separate from the body? And if so, at what point is the body unoccupied by the mind? If the body can be unoccupied by a person or a mind, is this what justifies treating the body as an object? The complexity and the likelihood that these questions will have many different responses suggest the issue of whether or not a person who is brain dead is not clinically dead may be best approached philosophically.

For nurses to approach questions philosophically, Sarvimaki (1999), a nurse philosopher, suggests nurses review, criticize, and discuss the issue at hand to clarify the main points of the question and thereby raise the awareness of where nurses stand on the issue. Sarvimaki (1999) argues that one purpose of nurses asking these questions is to question unclear reasoning and knowledge, and to argue for better alternatives – both much needed outcomes in this debate. The role of philosophical inquiry in nursing is to help nurses to think more clearly and completely about the issue at hand and about nursing itself, "which finally, may help us to do better nursing" (Sarvimaki, 1999, p. 12).

Beliefs and assumptions about what makes a human being a person and what constitutes death of that person are central to positions taken on the issue of brain death. The literature reviewed for this article reflects three common understandings of the nature of human beings. The first is a *biological* understanding of the organism as a whole. From this view, brain death is considered the loss of the integrated physiological unity of the human being (Shewmon, 2001). The irreversible loss of functioning of the whole brain leads to the loss of integration of the organism as a whole (Bernat, Culver, & Gert, 1981). Conversely, with a *psychological* understanding of persons, it is the loss of consciousness, with an associated loss of the soul and mind, which constitutes the loss of life because the person no longer has mindful awareness of self or others (Sgreccia, 2004;

Shewmon, 2001). The third view is a *sociological* understanding. The person is viewed as a legal entity who contributes to society; persons are in relationship to the human community and culture. If a person lacks brain function, he or she is viewed as dead because of the inability to actively commit to this membership to society (Ad Hoc Committee of the Harvard Medical School, 1968; Shewmon, 2001). This understanding does not change whether the person is young or old because "there are no unique legal issues when determining brain death in children as compared with adults" (American Academy of Pediatrics [AAP], 1987, p. 298).

These views do not necessarily exist in isolation, but the beliefs and assumptions that underlie these perspectives interact in the understanding of what it means to die and in definitions of brain death. However, biological understandings predominate in health care literature. It may be important to remember other understandings may be significant to patients and their families.

### Why Is this Issue Important For Pediatric Nurses?

Pediatric nurses have a significant role in the care of the child diagnosed with brain death and his or her family, particularly nurses working in pediatric intensive care units (PICUs). Nurses are invested in the "good" of their patients (Haggerty & Grace, 2008), whether this good is found in supporting their young patients toward health or to ease dying. Nurses share a responsibility with other health care professionals to provide quality care to the child, and this can become even more evident in end-of-life care (Daly, 2006) because of the profound impact losing a child has on a family.

It is important for pediatric nurses to contribute to discussions about brain death because of their proximity to the bedside and the child's family. As nurses care for critically ill patients, they monitor and pass on information, alerting other providers to changes in patient status that may assist in the determination of brain death (Ashwal & Serna-Fonseca, 2006; Henneman & Karras, 2004). Nurses play key roles in the organ donation process, including working in operating rooms where the child is taken for organ retrieval (Edwards & Forbes, 2003). Pediatric nurses also play a key role in providing emotional support to the child's family in their time of

loss (Daly, 2006), and this duty is hard for nurses to accomplish without first coming to terms with one's own viewpoint on what constitutes person and personhood, and how this influences the meaning of the brain death diagnosis. When nurses understand the use of the diagnosis and wrestle with what it means for them philosophically, they can better help families cope with the confusion and conflict they often feel because of the incongruence between their concept of death and the medical and legal concept of death (Edwards & Forbes, 2003).

Issues in the care of children diagnosed with brain death also affect nurses who may not be pediatric nurses by specialty but are operating room and transplant nurses who work mainly with the adult population. Anesthetist Philip Keep reports that transplant and operating room nurses may experience distress when assisting in organ procurement because they may feel they are taking living patients' organs without their consent (Boseley, 2000; Edwards & Forbes, 2003). The apparent struggle with what constitutes life and death is reflected in Keep's reflection on organ retrieval in the operating room:

Nurses get really, really upset. You stick the knife in, and the pulse and blood pressure shoot up. If you don't do anything at all, the patient will start moving and wiggling around, and it's impossible to do the operation. The surgeon has always asked us to paralyze the patient (Edwards & Forbes, 2003, p. 230).

This quote highlights the distress (and moral distress) nurses may experience when caring for patients diagnosed with brain death, as well as the incongruity of a definition of death that does not preclude a certain amount or kind of "life."

### Specific Concerns that Arise in the Pediatric Setting

Within the literature and in terms of where the controversy exists surrounding brain death being equated with clinical death, there is not much difference between issues debated for adults or for children. In other words, those who understand brain death as equivalent to clinical death do not mention the age of the person as part of their arguments. As well, the diagnosis of brain death itself is based on the same principles in children and

adults (Ashwal & Serna-Fonseca, 2006). However, differences exist in how health care professionals make the diagnosis using a brain death examination.

To diagnose a person as brain dead involves two brain death examinations done by two physicians and usually completed 12 hours apart, which, if the indicators are present, determine if the patient meets brain death criteria (CNCG, 1999). Indicators include assessing vital signs and testing for cerebral functions, brain stem reflexes, and completing an apnea test (Ashwal & Serna-Fonseca). Diagnostic tests, such as electroencephalography (EEG) and cerebral blood flow scans, are sometimes used in conjunction with the brain death examination (Ashwal & Serna-Fonseca, 2006).

In neonates, infants, and children, physicians use slightly different methods during brain death examinations that take into account the different anatomy and physiology between these age groups (CNCG, 1999). Another difference noted between the adult and pediatric literature is that closer attention seems to be extended to the families of dying children. One specific example is cited by Parker and colleagues (1995), stating that the goal should be to "make the most agonizing of all life's events (the death of a child) as bearable as possible for all concerned" (p. 915) and calling for more support for the grieving parents.

### Controversy Over a Concept

Clinical guidelines for determining brain death in patients have been published over many years. However, discrepancies exist in these guidelines that reflect the ambiguity of scientific evidence and the absence of philosophical agreement in this area (Baron, Shemie, Teitelbaum, & Doig, 2006). Two main positions have taken on the question of the "reality" of the brain death diagnosis. The majority of the literature does not address the issues from an age-specific perspective; however, the issues will be examined using the author's personal experience in pediatric nursing.

The first position taken is that the brain is the master supreme regulating organ of the body, without which the body is dead, and this loss of integration between the brain and the body constitutes clinical death (McMahan, 2006). From this perspective, even if all other organs in the body remain intact and functioning,

the person is considered to be dead because the mediation of the brain no longer integrates the system as a whole. This way of thinking gives primacy to physiological functioning, and essentially, reflects the inseparability of the mind, housed in or dependent on the brain, from the body.

The second position is mainly held by advocates against the use of the brain death diagnosis. Predominantly, they argue that the diagnosis was only created to facilitate the procurement of transplantable organs, and they claim to find no other genuine benefit from its use (McMahan, 2006; Shewmon, 1998a, 1998b, 2001; Truog, 1997; Truog & Robinson, 2003). Supporters of this position claim the body does not lose its integrative abilities when the brain is no longer functional, and that the brain is separable from the body (Shewmon, 1998a, 1998b, 2001). As noted, each position relies on a different understanding of the relationship between the mind and body.

### The Mind-Body Relationship

Edwards (2001) describes four views of the mind-body connection. The first is strictly a biological connection where an individual's thoughts and feelings are viewed as empirical events, or chemical reactions, that are biological in nature, and the mind is only physically connected to the body. The second view is that people are biological and psychosocial beings where mental capacities are dependent on the body, but those mental capacities are not viewed as biological properties or chemical reactions taking place in the brain. The third view is described as one where a person's soul or spirit is not physical in nature and that a person can continue to survive without a body because the mind and body are viewed as *separable*. Opposite to the third view, the fourth is a total and *inseparable* connection between the mind and body, and this mind-body connection is viewed as one whole organism.

These differing views on the mind-body relationship influence whether one supports or questions the use of the brain death diagnosis. For example, if one believes the mind is what makes a human being a person, and this is dependent on and housed within the brain, then when the brain has irreversibly stopped functioning, the person may be considered clinically dead. What is the clinical implication of this viewpoint? The removal

of life support with or without organ retrieval depending on the family's view of the body, mind, and soul? Others, however, believe the mind and body have a more separable connection where the body can still exist when the mind is no longer "present." What is the clinical implication of this viewpoint? That some parents/professionals will agree to keep children who appear to be in a vegetative state alive? Or is it that those who hold this view cannot imagine taking organs from this person because the life of the body, despite the irreversible functioning of the brain, still constitutes life?

These questions are philosophical in nature. Sarvimaki (1999) argues philosophical questions are those "that cannot be answered by empirical observations, or rather, by empirical observations alone" (p. 10). There is no single way to explain and understand the mind-body relationship, or if brain death equates to clinical death, but evidently, the responses may have profound impact on practice. If these questions could be answered using empirical facts or observations alone, then much of the controversy around brain death would not exist today. But Sarvimaki (1999) still emphasizes the importance of the influence that empirical facts should have on answering any philosophical question.

Two main perspectives (supporters vs. non-supporters) are held in the discussion of whether individuals who are brain dead are also clinically dead. Slightly different views remain that the mind and body are inseparable; therefore, brain death equates with clinical death. Some argue a person's consciousness equals life, and clearly, a person cannot maintain consciousness without at least part of a functioning brain (Eberl, 2005). Other views of this perspective are held by individuals who draw on sociological and religious standpoints, which argue that the inability to contribute to society (Eberl, 2005) or fulfill God's purpose (Metz, 2007) is death. These are difficult arguments because each person may have different views about what counts as a contribution to society. Further, these views may not pertain to children because they do not contribute to society or religion in the same way as adults.

Others may advocate the use of the brain death concept in health care as a way to relieve the pressure of the burden these patients may have on

their families or the PICUs where they are receiving care (Gigli & Valente, 2004). This suggests that these patients' lives are meaningless and expensive for their families and the health care system. The use of brain death criteria in these situations helps to reallocate resources to more meaningful areas (Gigli & Valente, 2004).

On the other side of this issue are those who claim that individuals who are brain dead are not clinically dead. Although not specifically mentioned in the literature, supporters of this perspective may view the mind-body relationship as a *separable* connection, where the body can still maintain "life" without the mind. A leading activist against the use of the brain death concept is Dr. Alan Shewmon. As previously mentioned, Shewmon (2001) argues that the body does not lose its integrative abilities when the brain is no longer functioning, citing research where, without the function of the brain, children and adults have been able to maintain homeostasis of physiological events, including the absorption of nutrients, elimination of wastes, maintenance of body temperature, wound healing, and even the growth of a fetus. Shewmon (2001) also observes that over time, patients' conditions generally improve, and they require less medical interventions and care. If life is understood from a strictly biological perspective, McMahan (2006) suggests that Shewmon's arguments and evidence force the advocates of brain death to admit defeat.

As noted above, some authors suggest the major advantage of having a brain death definition in the medical system is to support the procurement of transplantable organs (McMahon, 2006; Shewmon, 1998a, 1998b, 2001; Truog, 1997; Truog & Robinson, 2003). Surprisingly however, the field of transplant medicine is not where most controversies about the diagnosis of brain death occur (Baron et al., 2006). Baron and colleagues (2006) suggest that controversies arise not over the "existence" of brain death, but rather, because of inconsistent application or implementation of the diagnostic criteria of brain death. Identified issues include the lack of physician expertise in making the diagnosis, inconsistent clinical criteria, conflicting use of a second brain death examination and a set time interval between the two examinations, responses to confounding factors, and the lack of age-specific pediatric guidelines.

## Possible Alternatives To the Use of the Brain Death Diagnosis

Considering alternatives to the use of the brain death diagnosis can be problematic and difficult because the diagnosis is a legal determinant of clinical death, a major contributor to the availability of organs for transplant and in freeing up valuable ICU beds. However, despite utilities of the diagnosis, confusion and controversy continue to arise, and as a result, options need to be discussed to address the disadvantages of the use of the diagnosis to find common ground. This discussion is also important to encourage pediatric nurses to explore and clarify their own philosophical assumptions and beliefs about the issue because it affects children and their families.

In discussing alternatives to the use of the brain death diagnosis, facilitating organ procurement and transplantation is the basis of most arguments made by the authors. This is likely the case because legally, procurement of organs for transplantations depends upon the diagnosis of brain death, and this field of practice is likely influenced by any discussion of alternatives to its use.

McMahan (2006), an ethics philosopher, suggests that organ procurement should not rely on the patient being declared brain dead, but rather, on the patient having given prior consent (in a written will or personal directive) to removal of their organs. This would eliminate the need for a brain death diagnosis in relation to organ donation because the patient has already given prior approval for this. Essentially, the patient would have given prior approval for their body to be "killed" to donate organs and "that the treatment of a living but unoccupied human organism is governed morally by principles similar to those that govern the treatment of a corpse" (McMahan, 2006, p. 48).

McMahan (2006) further argues that once a brain is no longer perfusing, the organism is merely a physical body and is no longer a person being *occupied* by the specific human qualities that are the essence of human beings. The person as a particular person has ceased to exist even though his or her organism remains alive. According to McMahan (2006), it would be permissible to kill an unoccupied organism if the person who once occupied that organism had given prior consent to the removal of

his or her organs, or in the case of children, parental consent was given.

McMahan's (2006) suggestion that a person's body can be unoccupied by the qualities that make him or her a human being implies a separable connection between the mind and body. Although he does not make specific pediatric references, in the case of children, organ procurement consent would be obtained from the child's parents.

Involving the ethical principles of consent and nonmaleficence is another alternative to using brain death criteria, and while some ideas overlap with those expressed by McMahan (2006), there are some differences. Truog (1997), who advocates against the use of brain death criteria, suggests that to abolish the use of confusing criteria and a controversial definition of clinical death, while still maintaining the supply of transplantable organs, health care professionals should decide if prior consent was obtained. This is similar to McMahan's (2006) suggestions but also follows the principles of non-maleficence. McMahan (2006) suggests that organ procurement should only be permitted with the consent of the donor or the appropriate next of kin or parent, and only when doing so would not harm the donor. "Individuals who could not be harmed by the procedure would include those who are permanently and irreversibly unconscious (patients in a persistent vegetative state or newborns with anencephaly), and those who are imminently and irreversibly dying" (McMahan, 2006, p. 34).

Another option to the strict use of the brain death diagnosis has evolved in Japan, the only country that allows an individual to choose his or her own definition of death for the purpose of organ transplantation (Bagheri, 2007). When death comes, the prior decision about whether death should be determined from the cessation of cardio-respiratory function or from the loss of entire brain function is applied (Bagheri, 2007). This is an approach worthy of further discussion, but it seems to only deal with the symptoms of this problem and not the actual cause of the confusion surrounding the definition of brain death. This has relevance for pediatric patients because parents could make this determination on behalf of their child in a way that fits their beliefs about life, personhood, mind, body, and soul.

The adoption of these relatively new alternative approaches to organ

procurement and the use of the brain death diagnosis would require sizeable changes in the laws regulating brain death (Truog, 1997). These alternatives deserve to be considered by all health care professionals due to the considerable disagreement that exists surrounding the issue of brain death.

### This Issue Should Be Approached Philosophically

Approaching the issue of brain death and the surrounding controversy and confusion can be done by using the tools of philosophical inquiry. This may help nurses to more clearly see the real issue. Attempting to "solve" this issue by turning to empirical or objective facts is not sufficient. Differences exist in how these facts are understood and which facts are thought to be important.

This issue is mainly philosophical because people view the same empirical and scientific facts around brain death and interpret them differently. Why is this the case? From the author's perspective, regardless of whether brain death equates with clinical death, the heart of the issue is the individual's underlying beliefs and assumptions about what constitutes life and death. Those who accept the brain death concept believe that a functioning brain constitutes life or seem to believe the brain is the "center" of life. Those who criticize the use of brain death basically argue that what makes us "alive" is not just in the brain or not in the brain at all. Without a functioning brain, the person remains alive. What they think constitutes "life" is different than what the advocates of brain death believe.

Unfortunately, there is little discussion of the concept of brain death in the nursing literature. This lack of discussion may be because nurses are not involved in the diagnosis of brain death. Yet, since the adoption of the definition in the 1960s, there have been major ramifications for nurses involved in the care of these patients who are in permanent and irreversible vegetative states (Edwards & Forbes, 2003).

Sgreccia (2004) suggests that health care professionals need to develop a concise definition of brain death, one with which most people agree. Perhaps then a morally valid decision can be taken on whether brain death is indeed clinical death. Pediatric nurses need to have the knowledge and the language to discuss the issue, as well as understand the controversy that may never be

completely resolved. There are no easy solutions regarding the death of a child, but there are better and worse ways for health care professionals to interact with parents and each other. Understanding the issues and considering them philosophically will help pediatric nurses provide better care for children and their families.

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