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ETHICAL MATTERS

A National Multicenter Trial on Family Presence During Brain Death Determination: The FABRA Study

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Abstract
Purpose As brain death is a difficult concept for the lay public to understand, we hypothesized that allowing relatives of the patient to be present during brain death determination would improve their understanding of this condition and would eventually lead to an increased consent rate for organ donation.
Methods A prospective multicenter trial was conducted in five Dutch hospitals. Relatives were given the opportunity to be present during brain death testing. The family consent rate for organ donation was the primary endpoint examined, and the degree of the relatives' understanding of brain death was the secondary endpoint.
Results Between April 2010 and July 2011, we included the relatives of 8 patients in this study. The relatives witnessed brain death testing during this time. This sample size was too small to draw valid statistical conclusions. However, we have documented some noteworthy experiences of the relatives.
Conclusions Although, the hypothesis behind this study had promise, we were unable to reach our predefined goal. The possible causes for this shortcoming included the rarity of patients with brain death, the common practice in the Netherlands of obtaining consent for organ donation before brain death testing and the uneasiness of the staff in the presence of the patients' relatives during brain death determination. Although, we cannot draw a conclusion from statistical evidence, we would recommend that relatives be given the opportunity to be present during brain death testing and, specifically, during the apnea test.

Keywords Brain death · Brain death determination · Family presence

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Introduction

Brain death is an undesirable outcome of critical care medicine and is an artifact of nature that results from the ability of medical technology to prolong and disrupt the process of dying. However, the brain dead patient is the ideal multi-organ donor for organ transplantation. Progress that has been made in the prevention and treatment of conditions leading to brain death (especially subarachnoid hemorrhage and traumatic brain injury) has resulted in a decline in the actual number of brain dead patients in almost all industrialized countries of the Western world [1]. In the USA and Europe, another factor that has led to the decreased number of brain dead organ donors is that patients with severe brain injuries have been allowed to die by the discontinuation of life-sustaining treatments before their progression into brain death and as soon as the family has understood the futility of these treatments. This phenomenon also helps to explain the concomitant increase in organ donors after circulatory death. These trends in organ donation may result in the further widening of the gap between the number of heart-beating organ donors and the number of recipients.

In the Netherlands, the concept of brain death was accepted in the 1970s. In addition, in 1996, the Dutch Organ Donation Act (subsequently referred to as "the

Act") came into effect. The Act was created with the following four objectives in mind: (a) to clarify the legal position on organ donation, (b) to increase the supply of organs and tissues, (c) to ensure the fair distribution of organs and tissues, and (d) to prevent trade in organs and tissues [2]. In 1997, and in line with the Act, the Dutch government legally established the brain death criteria that were proposed by the Dutch Health Council. The committee of the Health Council endorsed the most stringent definition of brain death, or the "whole-brain death" concept. Since then, brain death has been determined according to the national Brain Death Protocol [3, 4].

In the Netherlands, the determination of brain death consists of three phases (Fig. 1). In phase 1, the cause of the coma is established, and the ascertainment of the irreversibility of the coma as well as the identification of such possible confounding factors as metabolic disturbances, hypothermia, neuromuscular blocking agents, and hypotension are made. If this phase of the analysis has been completed, a clinical neurological examination is performed (phase 2) and consists of the determination of the absence of consciousness (Glasgow Coma Score of 3) and the absence of all brain stem reflexes (as assessed by a neurologist or neurosurgeon). The third phase consists of two confirmatory tests: an electroencephalogram (EEG) and a subsequent apnea test. Both tests are mandatory under Dutch law to declare a patient brain dead and to proceed with organ donation. This requirement is in contrast with the brain death guidelines in the USA (which also have interstate variability) [5] and in other European countries, where the EEG is used less frequently as a confirmatory test [6]. The phases of the determination of brain death need to be done by a medical professional within this particular field of expertise, a neurologist or a neurosurgeon must test for brain stem reflexes, a neurologist with a registration in neurophysiology should assess the electroencephalogram and an intensivist or anesthesiologist must perform the apnea test.

A second initiative, which was integrated into the Act in 1998, established a national Donor Register (DR). The DR, which was designed as an opt-in system, allows individuals to register their preferences regarding organ, bone, and tissue donation and also their refusal to donate. Those who are not registered in the DR can still donate with the explicit consent of their next of kin. If the patient has registered his or her consent or objection, the physician is expected to inform the family of these wishes and to explain the steps that are involved in the donation process, if applicable. The donation consent that is given by the patient according to the DR permits the physician to initiate organ-preserving treatment. A consenting registration in the DR is generally respected, but it is uncommon that organs are removed against the will of the relatives. In other words, the family generally retains the right in all scenarios to veto the patient's previous consent.

For the general public, the concept of "brain death as death" is often difficult to understand. The body of the brain dead patient is warm and pink, the chest rises and falls due to mechanical ventilation, there is visible evidence of a heartbeat and there is production of urine. For the relatives, the brain dead patient can be perceived as a comatose, but alive, patient.

It is an established practice in most intensive care units for relatives to not be present for the brain death testing [7]. However, some authors have suggested that the witnessing of brain death testing by relatives may be helpful for their understanding of the concept of brain death before organ donation [7–12], although, there is little evidence that this would work in daily practice. A study by Pugh et al. [12] contacted 28 neurotrauma intensive care units in the United Kingdom by telephone to identify the senior staff member who is generally involved in the testing for brain stem death. Next, they sent a questionnaire to 147 consultants and 167 senior nurses who had been identified in the telephone survey, and 79% of the consultants and 77% of the senior nurses returned the questionnaire. Overall, 32% of the consultants and 42% of the nurses had experience with the presence of patients' relatives during brain death testing, and 69% felt that this was helpful for the relatives. Nurses were more likely than physicians (84% versus 53%) to believe that witnessing the tests would help the relatives to accept that the idea that the patient had died, and 48% of nurses thought that the relatives would gain comfort from being present during the testing.

A study by Bell et al. [8] created a questionnaire for members of the Neuroanaesthesia Society of the United Kingdom that concerned brainstem death testing. Twenty-two percent of the respondents stated that they would allow the family to observe these tests if the relatives asked to be present.

A study from Ormrod et al. [11], which was also from the United Kingdom, examined the experiences of the relatives of brain dead patients. In this series (27 relatives of 23 patients), thirteen individuals were given the opportunity to witness brain death testing, but only five (including 2 members of one family) relatives observed the tests.

It will be difficult to alter the current trend of the decrease in brain dead organ donors in many Western countries that has resulted from improved preventative and therapeutic treatment options. Upon analyzing the possible ways to improve donor rates, family refusal is the one factor that could be modified [13, 14]. For this reason, we initiated a national multicenter trial in April 2010, focused on family presence during brain death determination, which was termed the FABRA (FAmily presence during

BRAin death determination) study. However, the trial was not successfully conducted over an 18-month period because a sufficient number of relatives were not included (we aimed to include relatives of at least 50 brain dead patients to achieve a statistically valid number). Although, the anecdotal results concern a small number of individuals and valid statistical conclusions cannot be drawn, we believe that this type of study is worth reporting because the hypothesis holds great potential. In this article, we have provided the results of this study and have attempted to determine the reasons behind the failure to include a sufficient number of subjects.

Materials and Methods

This trial was set up as a prospective multi-center trial at five Dutch hospitals. The study was initiated between April 2010 and August 2010 at the intensive care units of three university hospitals and two large non-university hospitals. The institutional review boards at the participating hospitals approved the study protocol. After reviewing the study protocol, the boards chose to make informed consent of the relatives mandatory before their participation in the study, due to the possible psychological stress involved for the relatives of the patients.

For inclusion in the study, we selected patients with severe and irreversible brain injury who had been admitted to intensive care and for whom brain death was suspected (as determined by evidence of severe brain injury on CT scan, by relevant information provided by relatives concerning the medical condition of the patient and by a GCS of 3 with absent pupillary and corneal reflexes and controlled mechanical ventilation) (Fig. 1). In addition to this, inclusion criteria patients needed to be medically suitable for organ donation and their family members (legal representatives) should be present at the hospital. The relatives that were included in the study were asked if they would be willing to be present during the testing of the brain stem reflexes and during the apnea test. This conversation took place at the time when the physician announced to the relatives that the patient had severe and irreversible brain damage and that further treatment would be futile. Important to add here is that in the Netherlands, when the

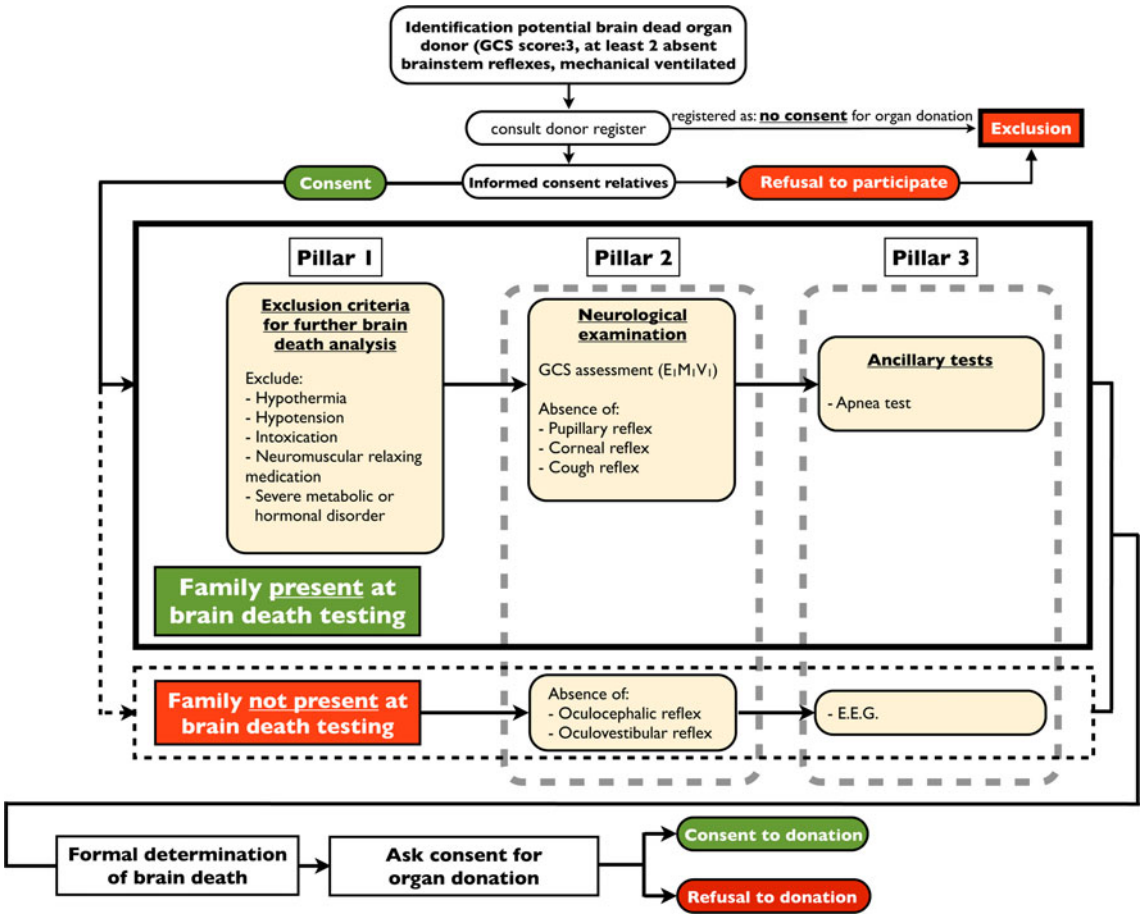

Fig. 1 Flow chart of the methods of the study

multidisciplinary ICU team decide that prolonging life-sustaining measures, like mechanical ventilation, is not in the patient's interest anymore, the decision will be made to withdraw these measures to let the patient die. Further life-sustaining measures are judged futile, the palliative care of course not. The relatives of the patient will be informed about the decision to withdraw life-sustaining measures, but have no legal right to stop this. If the patient is suitable for organ donation, relatives are asked for consent, and life-sustaining measures will be continued to preserve vital organ function. If they refuse consent, mechanical ventilation will be withdrawn, administration of vasopressors will be stopped, and the patient will die after circulatory arrest.

After brain death was confirmed, the relatives were asked to provide consent for organ donation. The relatives were present for the scoring of the GCS, the tests for pupillary, corneal and cough reflexes, and the administration of the apnea test.

The family consent rate for organ donation was appointed the primary endpoint for this study, and the degree to which brain death was understood as the death of the individual was made the secondary endpoint. To test this secondary endpoint, we contacted by telephone the relatives who had witnessed the brain death tests three and six months after the death of their relative.

Results

Between April 1, 2010 and July 1, 2011, we screened 27 relatives of patients for eligibility (Fig. 2) of which 8 relatives eventually consented to participate in the study. Twenty-one patients' relatives were screened in the primary hospital (Erasmus MC University Medical Center, Rotterdam, The Netherlands), 6 were screened in the participating hospitals. None of the participating hospitals included a patient for the study. Reasons for exclusion in the participating hospitals were refusal to participate ($n = 2$), already obtained consent for organ donation on the emergency room ($n = 3$) and one patient that retained a ventilatory drive. Of the eight relatives that witnessed the brain death testing 7 consented for organ donation, one relative declined organ donation. The reasons of admission for the patients who's relatives participated in the study were a subarachnoid hemorrhage ($n = 5$) and a traumatic brain injury ($n = 3$). The overall major reasons of exclusion were a prior registration in the Donor Register stating refusal to donate ($n = 6$) and refusal to participate ($n = 9$).

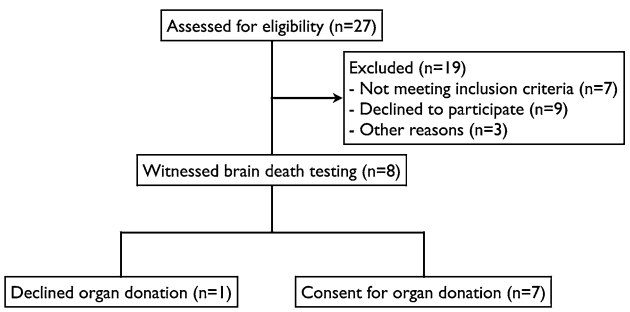

Fig. 2 Results flow chart

The sample size of this study was too small to make a valid statistical conclusion or to reach a conclusion concerning the primary endpoint. However, regarding the secondary endpoint, we recorded noteworthy, though anecdotal, experiences from the patients' relatives.

Experiences of Relatives

The relatives who had witnessed brain death tests were contacted by telephone between three and 6 months after the death of their loved ones, and these anecdotal personal experiences provided information regarding the effect of a family presence during brain death determination.

"We knew that my mom had died when the intensivist stopped the respirator and when we saw an absence of breathing." (son of a brain dead patient after witnessing the apnea test)

The fact that she had no response to pain was not considered to be a sign of death for us, as we saw the nurses test the motor response many times before she was declared brain dead (and she didn't respond at these times either); at this particular moment, she was comatose and not brain dead. (son of a brain dead patient)

We were shocked when the nurse reconnected the respirator after the apnea test had been performed. For us, she was dead when she was not breathing, but then she breathed again. (spouse and son of a brain dead patient)

"When we observed that she was not reacting to the painful stimulus on her fingers, we knew that she was not suffering anymore." (spouse of a brain dead woman)

When I saw the hemorrhage in her head on the CT scan, it was clear to me that she would not survive. (spouse of a brain dead woman)

Those tests were a type of theater for me. I understand that they need to be done, but they did not convince me. (spouse of a brain dead woman)

We also witnessed the electroencephalography test. We did not understand what was going on, and the woman who made the recording was not very helpful at explaining this test. (daughter of a brain dead woman)

I knew that she was dead and that the tests were just a formality. (spouse of a brain dead woman)
It was reassuring that the ventilator had been turned off and that I didn't see her gasping for breath. (daughter of a brain dead woman)

Discussion

We had hypothesized that the observation of the testing process would help relatives to understand that the patient had died when brain death was established. The relatives who observed the testing were pleased that it had been offered and said that it had helped their understanding of brain death. It was striking that the relatives were surprised about the thoroughness of the testing. In this small sample of participants, the apnea testing was the most convincing test for the relatives in terms of the realization that the patient had died. Some relatives were disturbed to see that the respirator was reconnected after they and the medical team had observed a lack of breathing by the patient. The relatives saw the moment during the apnea test as the moment of death and questioned why resuscitation was necessary when death seemed so obvious. None of the relatives who observed the tests and none who we have spoken to subsequently indicated any reservations regarding their attendance during the testing.

The FABRA study failed to include a sufficient number of patients and, therefore, could not conclude that family presence during brain death determination was an efficient tool to provide a better understanding of "brain death as death" or to raise the consent rate for organ donation. However, we have examined what may have caused this and have suggested the following five possible reasons for this failure:

1. The rarity of brain death as an outcome of neurocritical care

In the Netherlands, brain death is a rare outcome of neurocritical care. Over the past 15 years in the Netherlands, there has been a decline in the number of organ donors following brain death; the number has dropped from 915 donors (88.6% of the total number of donors) to 637 donors (58.4% of the total). However, the number of donors following circulatory arrest has increased accordingly from 118 donors (11.4% of the total number of donors) to 453 donors (41.6% of the total) [1, 15]. Therefore, the decline in the number of brain dead donors has been completely compensated for by the increase in the number of circulatory arrest donors [1]. The recognition of certified donors is the goal in the Netherlands [16], although, the refusal rate from relatives of the patients is high. In the Netherlands, this refusal rate was 65% in 2005, 71% in 2006, 59% in 2007, and 69% in 2008. At the Erasmus MC University Hospital in Rotterdam, the refusal rate is approximately 45%. At one of the participating centers (VU Medical center in Amsterdam), only two brain dead patients were evaluated during the FABRA study period (personal communication, Dr. A. Beishuizen).

2. The common practice of asking relatives before brain death testing

In the Netherlands, the current practice is to ask for organ donation permission *before* the formal brain death testing, although the Act states otherwise. In our opinion, this was the most significant reason behind the failure of this trial to include a sufficient number of subjects. From a retrospective medical chart review of all effectuated brain dead organ donors between 1987 and 2009 at our hospital, we found a remarkable shift of the time at which organ donation was first discussed with a patient's relatives [17]. For this article, we divided the data from 228 brain dead patients into two time periods (1987–1998 and 1999–2009). In the first period, organ donation was first discussed with relatives *after* formal brain death determination in 87% of the cases. In 13% of the cases, the issue of organ donation was raised *before* the first EEG. After 1998, we observed a shift in this practice, as the first discussion of organ donation occurred *after* formal brain death determination in only 18% of the cases. In 58% of the cases, organ donation was discussed *before* the first EEG but *after* the confirmation of an absence of all brain stem reflexes. Furthermore, in 24% of the cases, organ donation was discussed *after* the prognosis was deemed poor but *before* a neurologist or neurosurgeon assessed and determined the absence of brain stem reflexes, as is required by the Dutch brain death determination protocol. One possible explanation for these changes in the sequence of the clinical and confirmatory tests with respect to the discussion of organ donation with the patients' relatives is the introduction of the DR, which allowed the physician to consider the possibility of organ donation sooner than was required prior to its introduction in 1998. If the physical condition of the patient rendered organ donation possible, the physician was expected to consult the DR to determine the registered wishes of the patient and to make a more informed, faster decision regarding this process.

According to the FABRA study protocol, relatives should have been asked to witness brain death testing *before* the request for organ donation (as was stated as mandatory by the medical ethical review boards). Although it is stated in the Dutch Organ Donation Act [4] that consent must be sought *after* declaration of death, this is contrary to the common practice at most hospitals in the Netherlands, as was discovered by our retrospective

analysis [17]. When we developed this study we used the Act as point of departure to formulate our inclusion and exclusion criteria. We have not anticipated on the fact that only a few hospitals were willing to divert from their routine to seek consent after the formal determination of brain death to make the study possible. The determination of brain death according to the Act was and is followed in every hospital to the letter only the moment to seek consent has changed over time. We already described this practice in an earlier report [17] but from an analytic point of view we think it can be considered as one of the major reasons why we failed to include a sufficient number of patients for this study.

3. Electroencephalography

During the study period, various neurologists refused to conduct an electroencephalography when the relatives had not given their consent for organ donation. The reason for this refusal was that this test is only necessary in the context of organ donation. Prolongation of life-sustaining measures like mechanical ventilation or the administration of vasopressors is already judged as futile and not any more in the interest of the patient. Conducting an electroencephalography will not change that conclusion and the decision to withdraw life-sustaining measures. Neurologists are reluctant to perform the electroencephalography when the need for this (confirmation of brain death for organ donation after relatives have consented) remained uncertain.

4. Uneasiness of medical, nursing, and technical staff with having relatives present

To our surprise, we were confronted with opposition from medical and technical staff (not from the nursing staff) in regards to their participation in the FABRA study. A technician from the department of electroneurophysiology was quoted as saying: "It was very confrontational when the family of the patient was present when I came to perform the EEG. I was not used to seeing the grieving children of a young dying woman present at the bedside. The son of the patient began to ask questions about the EEG and what it measured that I could not answer. Afterwards, I was very upset." A fellow intensive care doctor (anesthesiologist) said the following: "This is the most difficult study that I have ever participated in. It made me very uneasy when the relatives of the patient were present during the brain stem testing." The medical specialists had fewer objections. A senior neurologist was quoted as saying: "I have no problem with family members observing the brain stem reflex testing, as I have nothing to hide." A senior intensivist said the following: "I think it is good that relatives observe the apnea testing. It can be reassuring to see that the patient is not breathing anymore."

Members of the technical staff from the department of electroneurophysiology are rarely confronted by grieving relatives during their work. Thus, we can understand the uneasiness of these health care workers during this study.

The family presence during brain death determination is comparable to the presence of family during resuscitation. Traditionally, when a patient has suffered a circulatory arrest in a hospital, the family is taken into the waiting room while the resuscitation is initiated. However, this scene has been changing since the 1980s. Many countries and many hospitals, including those in the Netherlands, have debated whether family members should be allowed at the patient's bedside at the time of resuscitation. However, this has become common practice. Early reports demonstrated that three-quarters of relatives felt as if their adjustment to the death of their loved one was made easier by their presence, and 64% felt that their presence was beneficial to the dying person. If given the opportunity, 94% would again choose to be present in this situation [18, 19]. Family members with no medical background have reported that being at a loved one's side during resuscitation and that saying goodbye during the final moments of life was comforting [20]. Nowadays, family presence during resuscitation is seen as a normal in family centered care and has given rise to the declaration of position statements from many international medical societies [21–24]. The American Heart Association stated in their 2010 guidelines that "in the absence of data documenting harm and in light of data suggesting that it may be helpful, offering select family members the opportunity to be present during a resuscitation seems reasonable and desirable (assuming that the adult patient has not raised prior objection)."[25] Public opinion polls in the USA have shown a strong majority sentiment in favor of relatives being able to be present during resuscitation. Several studies have indicated that the majority of nurses endorse family presence during resuscitation, and this endorsement can be compared with between 50 and 70% of physicians and only about 20% of residents who endorse family presence [26]. These results are in line with our experiences in family presence during brain death determination. We have not experienced any objections from ICU nurses or from staff ICU physicians, but we have received objections from residents and fellows from intensive care.

Limitations

During the time of this study, we were confronted with several setbacks. First and foremost, there was a low supply of potential organ donors who were brain dead. As reported earlier, an intensivist in this study only evaluated two brain dead potential organ donors in a one-year period. At our

hospital, we were confronted with problems regarding the consent of patients' relatives. Many intensivists had difficulty introducing the study in the same conversation as the discussion of the patient's grave condition. Aside from this observation, there was no clear indication as to the proper time to seek consent for organ donation. As per the protocol, we wanted to ask for consent after the complete and formal determination of brain death. However, this approach was received with much resistance because the common practice was different than the formal brain death protocol. This common routine was difficult to change, and this resistance made the fulfillment of the primary endpoint not feasible. The reasons why the participating hospitals failed to include a patient for this study are difficult to grasp. The already mentioned absolute low number of potential brain dead patients certainly plays an important role but is not a reasonable answer. Sometimes, they were confronted with patients with devastating neurological injury that were admitted from the emergency room with already obtained consent for organ donation. But overall, we think that the participating hospitals failed to include any patient seen the ingrained and common practice to ask for organ donation before official brain death determination.

However, the documented experiences of the relatives who witnessed the brain death assessment were very helpful for our understanding how they have experienced to witness some of the tests. These anecdotal experiences provided insight into the psyche of the mourning relatives and were helpful for the revision of the brain death protocol at a national level.

Conclusions

Although, the hypothesis behind our study was promising, it was difficult in practice to conduct. Unfortunately, we were only able to include the few relatives who were willing to observe the brain death determination testing. One of the reasons for this scarcity of study subjects was the extreme rarity of brain death as an outcome of neurocritical care in the Netherlands. It is possible that the FABRA study could be repeated in a different country with more brain dead patients. To conduct a study similar to the FABRA study, it is important to note that is the common practice in most hospitals in the Netherlands to inquire about organ donation before a formal brain death determination. Allowing relatives who had already given consent for organ donation to be present for the brain death testing would be helpful for their understanding of "brain death as death", but this would do little to alter the organ donation viewpoint of those attending. For these cases, there is a strong parallel between family presence during brain death testing and family presence during resuscitation. When resuscitation was introduced in the 1980s, there was resistance from the residents to let family members be present, and this level of resistance is similar to what we experienced during the FABRA study. However, it is now common practice in many hospitals throughout the world, and it has been judged to be beneficial, for family members to be present during this procedure.

For this reason, although we cannot conclude with statistical evidence that family presence during brain death determination was beneficial, we would recommend that relatives be given the opportunity to be present. Specifically, the observation of the apnea test may serve as a reassuring experience enabling the relatives to come to terms with the patient's death.

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Conflict of interest None.

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