

Brain Death: Concepts and knowledge amongst Health professionals in Province of Sindh, Pakistan

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Abstract

Objective: Last few decades have seen improved resuscitative measures and use of life saving machines like ventilators. Due to these dramatic interventions, end of life decisions, including brain death and organ transplantation, have become more complex and a major problem in our clinical practice. This study was done to find the opinion and awareness of physicians regarding issues surrounding brain death in this region.

Methods: A total of 259 questionnaires were analyzed that encompassed physicians at different level of training and students in the final year of their training, from five major tertiary care centres, located at Karachi and Hyderabad and who are involved in decision making about brain death and related issues.

Results: One hundred and forty one (54 percent) respondents did not have a clear idea regarding the definition of brain death. Majority of doctors 122 (47 percent) would therefore not turn off the ventilator even in a brain dead patient. Sixty seven (26 percent) actually considered it Euthanasia. Most considered 24 hrs as optimal period before confirming the diagnosis of brain death. Most of the doctors favoured a confirmatory test, like an electroencephalogram, to confirm the diagnosis of brain death. Majority of the doctors (68 percent) would not consider stopping ventilatory support of a patient in a persistent vegetative state.

Conclusion: This study highlights the lack of understanding and confusion regarding issues surrounding brain death in this region especially among junior doctors and highlights the importance of including these issues in the medical curricula (JPMA 58:352;2008).

Introduction

The term "brain death" is widely accepted by health care professionals, physicians and 'General public' in most parts of the world.¹ It is not well studied whether there is a clear concept of brain death amongst our physicians, who are ultimately responsible for making critical decisions.

Studies done elsewhere suggest lack of awareness and misunderstanding on many issues regarding brain death, persistent vegetative state (PVS) and differentiation between severe brain injury versus brain death.^{2,3}

At times, the ethical and religious considerations have also been found to affect decisions regarding diagnosis of brain death.^{1,4,5} The concept of brain death was first

introduced in United States in 1968 (Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death, 1968) in part to facilitate organ donation.⁶ Since then the brain death criteria and legislation has been adopted in various parts of the world. However, the criteria regarding brain death varies in most parts of the world and it is also not universally accepted.⁷ Japan, for example, did not readily accept the concept of brain death.^{8,9} Many countries of the world, like Pakistan, do not have any well defined criteria for brain death and as organ transplantation becomes more common in this region these issues need to be better studied.

The meaning and definition of brain death was not only an academic challenge but also has given rise to many ethical, philosophical and religious debates.⁴ Besides brain death, several other neurological conditions, for example, persistent vegetative state (PVS), which is now seen more and more in this era of cardiopulmonary resuscitation, has also caused a lot of confusion and has raised several ethical issues. In PVS, the brain stem remains intact, allowing the patient to breathe without assistance, although they have lost the ability for consciousness, which in majority of the cases is permanent. This has led to the arguments by many philosophers that since consciousness and cognition are the essential brain functions, PVS patients should be considered dead.¹⁰⁻¹² In the United States and United Kingdom, PVS patients are legally alive although exceptions are there, for example, Karen Quinlan in US and Nancy Cruzan cases in UK.^{13,14} Furthermore, more complications occur when the concept of death in different religions is taken into consideration, as this differs in orthodox Christians, Jews and Muslims.^{15,16} Many international congresses and meetings have been held to explain and better understand socio-religious effects of brain death. The concept of brain death was accepted by a majority of scholars and jurists at the Third International Conference of Islamic Jurists in Amman, Jordan, in 1986.¹⁷

Despite substantial progress leading to defining of brain death as 'legal death', studies demonstrate that health care professionals are still confused or not well informed in their training about this issue. Pakistan represents a country of over 162 million. Unfortunately, no clear legislations or guidelines exist in the country regarding brain death. A bill was passed, in this regard, by the Senate's standing committee on health in 1994¹⁸, but it was never approved by the Senate. With improvement of health care facilities and transplantation service throughout this region, the issue of brain death and this debate is becoming a very pertinent issue.

This study is a survey amongst health care professionals, especially including medical residents and

junior doctors, in major tertiary care centres who tend to be more involved with these issues. This was to determine their level of knowledge, beliefs and attitudes regarding brain death, use of ventilator and related issues. This survey was conducted in the two largest cities of Pakistan, namely Karachi and Hyderabad. These cities are located in the province of Sindh, the 2nd largest province of Pakistan. The majority of people of this province follow Islamic faith. This survey is the first of its kind in this populous region to know doctors knowledge and attitudes surrounding the issue of brain death.

Methods

This study surveyed 5 major tertiary care hospitals in the province of Sindh, Pakistan. Three hospitals were situated in Karachi namely, The Aga Khan University Hospital (AKUH), Dow University of Health Sciences (DUHS) and Jinnah Postgraduate Medical Centre (JPMC). Two hospitals in Hyderabad included Isra Medical University Hospital and Liaquat University of Medical Sciences (LUMS). These hospitals represented the largest tertiary care teaching hospitals in the province of Sindh. According to a National Survey, these facilities share 90% burden of patients' in the province. A sample size of 250 was calculated using doctors' registration data maintained by provincial government of Sindh in the 2 major cities from approximately 2500 doctors practicing in these tertiary centers. Sample population only included the physicians that were involved in treating life threatening illnesses. Those physicians who are not usually involved in such decisions, like dermatologists, family physicians and pathologists etc. were excluded from this study.

Surveying method was in the form of self-administered questionnaires personally given to our randomly selected sample. Questionnaire was prepared to test the knowledge and attitudes regarding brain death in health care professionals.

The surveyed population included interns, residents, resident medical officers, fellows, consultants and medical students in the final year of their training at the Aga Khan University Hospital. Questionnaire was standardized by identifying related issues regarding brain death reported in literature relevant to medical professionals. Questionnaire was formed in English language as the mode of teaching in all medical institutions of Pakistan is English. Questionnaires included questions regarding definition of brain death as well as conceptual details like "turning off ventilator means Euthanasia or not". Information regarding optimal time period and confirmatory tests in diagnosing brain death were also asked. Several questions were related to persistent vegetative state patients on ventilators and religious beliefs affecting the decision in the management of

Table. Physicians' opinion on 'Observation time' after the diagnosis of Brian Death.

Observation time	Number of Physicians
6 hrs	82
12 hrs	46
24 hrs	85
>24 hrs	38
No response	6

such patients. The questionnaire was pre-tested in Aga Khan University Hospital, optimization was carried out and then data collection was done from May to July, 2005. Data analysis was performed with Statistical Package for the Social Sciences (SPSS)15.0 statistical software. SPSS Inc. Headquarters, 233 S. Wacker Drive, 11th floor Chicago, Illinois.

Descriptive data was generated for all questions. Measures of association for categorical data were the chi-square statistics.

Results

A total of 259 questionnaires were analyzed. The study included 28 (10.8%) final year medical students, 87 (33%) residents, 25 (10%) resident medical officers (RMO), and 37 (14%) Medical Officers and 32 (12%) consultants. The level of training in rest of doctors was not known. One hundred and thirteen doctors (44%) agreed that a person whose brain stem is declared dead while the heart is functioning normally, is actually dead while 115 (44%) doctors disagreed to this definition. Twenty six doctors (10%) were either not sure or did not know the definition. Majority of the doctors, i.e. 146 (56%), thought that at least 2 physicians should be involved in diagnosing brain death while 86 (33%) stated that the opinion of 3 physicians should be obtained to declare brain death. Two hundred and four doctors (78%) considered a neurologist's opinion necessary for diagnosing the patient as brain dead, while 36 (14%) disagreed to it and 18 (7%) were either not sure or did not know the answer to the question.

The next 3 questions were focussed on observation time, confirmatory tests and EEG monitoring before diagnosing brain death. Two hundred and fifty one doctors (97%) responded to the question regarding optimal time period to diagnose brain death.

Eighty two (32%) considered 6 hours, 46 (17%) considered 12 hours, 85 (33%) considered 24 hours while 38 (15%) labelled more than 24 hours as optimal time period.

As far as confirmatory tests were concerned, 102 doctors (39%) were in favour of only clinical diagnosis and considered confirmatory tests as optional while 135 (52%) doctors disagreed to it and 22 (8%) were either not sure or

did not know about the need for confirmatory tests. EEG testing was thought to be a pre-requisite to diagnose brain death by 194 doctors (75%) while 47 (18%) disagreed to it and 18 doctors (7%) were either not sure or did not know about EEG testing.

One hundred and thirty seven doctors were in favour of "turning off" ventilator after the diagnosis of brain death and 84 doctors (32%) disagreed while 38 (15%) did not know or were not sure about "turning off" the ventilator system. Sixty seven doctors (26%) thought that turning off ventilator is a means of euthanasia in brain dead patients and 94 doctors (36%) disagreed to it while almost equal number of doctors 93 (36%) were not sure or did not know about it. Thirty doctors (11%) agreed to turn off the ventilator in patients with unrecoverable neurological injury (vegetative state) but not technically brain stem dead and 176 (68%) disagreed while 45 doctors (18%) were either not sure or did not know about it. Religious beliefs can alter decision regarding disconnection of ventilator in brain dead patients according to 136 doctors (52%) while 83 (32 %) disagreed to it while 40 doctors (15%) were either not sure or did know about it

Consultants had clear understanding of brain dead patients as compared to trainees at all level ($p=0.07$) and furthermore, significant number of consultants agreed to turn off the ventilator in patients declared brain dead as compared to trainees ($p=0.001$). Religious beliefs of consultants significantly affected the decisions regarding turning off ventilator in brain dead patients as compared to trainees ($p=0.04$).

Discussion

The term "brain death" was introduced by Ad Hoc Committee of Harvard Medical School more than 45 years ago.⁶ This term allowed patients who were considered alive to move into category of 'dead'. Life support could then be removed from these patients. But since the inception of this term, various studies have shown that lay persons and, more importantly, health professionals are confused and do not accept this term.^{5,19} Various social and religious factors seemed to affect this confusion or un-acceptance. Several bioethicists argue that it is not only a biologic phenomenon but also a social issue and its social, normative and religious aspects have to be given importance as well.^{4,19} The problem gets more complicated in countries like Pakistan where even the laws concerning brain death are non-existent. No systemized studies have been done to evaluate the opinion and attitudes of health professionals regarding brain death. With advances in technology and life support systems now increasingly available, this issue has to be addressed.

The results of our study indicate a fair amount of

confusion that seems to exist among health professionals regarding these issues. For example, more than 50% of health professionals did not consider 'brain dead' to be one of the criterion of death. Even in doctors who considered brain dead patients as actually dead, 42 thought that ventilator should not be disconnected after diagnosis of brain death. Furthermore, 63 doctors who did consider brain death to be one of criterion of death, were of the opinion that removing life support from these patients was a form of "Euthanasia".

This suggests a great amount of confusion amongst health professionals on the diagnosis and significance of declaring patients as brain dead. This issue has been addressed very clearly in Western countries and organ procurement is allowed in patients who are declared brain dead.^{20,21} The policies for these patients clearly mention the fact that declaring patient brain dead means clinically and legally dead and life support can be withdrawn after the diagnosis. But even in the western world with clear policies, various studies suggest that significant amount of confusion is still present in the general public and health professionals concerning brain death.²⁰ Factors leading to such misunderstanding could be several and need more investigation in both the developed and the developing world.

Studies from this region, including India and South Korea, have found similar problems with lack of knowledge and awareness in these countries.^{23,24} There is, however, exceptions to the understanding of these issues in select populations where education has made a difference.²⁵

These discussions are also now being done all over the Islamic world. Due to complexities of this issue from the religious point of view, more dialogue is needed amongst the religious scholars.²⁶ An excellent review by Dr. Mohammad Mehdi Golmakani is available on this topic.²⁶

Number of physicians required to declare patients as 'brain dead' is different in various parts of the world usually ranging from 2 to 3. In our study, 146 patients thought that at least 2 physicians should make the diagnosis of brain death while 86 considered 3 physicians' opinion to be more feasible. Two hundred and four doctors thought that a neurologist should be involved in the decision making process in diagnosing brain death. This is concerning as this might show the discomfort or lack of competence of physicians making such diagnoses. One might argue that the decision should be made by a neurologist or a specialist trained in this field, like an intensivist, but the necessary degree of expertise is not always available in every hospital. There are no studies to suggest that assessment by second physician improves the diagnosis.²²

In our study only 20 doctors belonged to the specialty of neurology of which 3 were at the consultant

level. For practical purposes a neurologist's opinion may not be possible for every case of brain death. This is also not the requirement in most regions of the world.

There was no universal consensus amongst the respondents about the optimal period of observation before they thought that the diagnoses should be confirmed. EEG and other confirmatory tests are mostly considered as optional tests in order to label the patient as 'brain dead' and the diagnosis is mostly, considered clinical. Our group also showed lack of understanding in this regard as majority (194 and 102) were in favour of an EEG and other confirmatory tests before diagnosing brain death. The diagnosis of brain death, as discussed, is mainly clinical. Confirmatory tests have been considered optional in adults but are only mandatory in paediatric age group. In several European, Central and South American, and Asian countries, confirmatory testing is required by law⁽⁷⁾. Even in these countries, questions are raised about the necessity of these tests to diagnose brain death.

Only 30 doctors in our study agreed to discontinue life sustaining measures in patients in persistent vegetative state. One hundred and thirty six doctors had their decisions influenced by religious beliefs. Interestingly, chi-square analysis revealed consultants' decisions to be affected by religious beliefs than trainees. But consultants were found to have significantly better knowledge of brain death patients and were in favour of discontinuing ventilation in such cases. This suggests a healthy trend with increasing level of training and experience. As only 32 consultants were included in our study, it can be considered as one of the limitations. A definite conclusion therefore cannot be drawn regarding the difference of knowledge between consultants and trainees.

Our study suggests significant amount of confusion regarding the meaning of "brain death" and its diagnosis, in this region, especially among junior doctors and the doctors in training. The importance of understanding brain death in view of organ procurement rule cannot be denied. Efforts should be made to clear the confusion regarding this issue while taking into consideration various religious, cultural and social sensitivities. Curriculum needs to be more vigorous in defining and teaching how to evaluate these conditions. Currently, the medical curriculum in Pakistan, both undergraduate and post graduate, does not provide ample discussion regarding these issues. Clear laws are also needed, especially in this region, on these complicated issues.

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References

1. Spoor MT, Sutherland FR. The evolution of the concept of brain death. *Am R Coll Physicians Surg Can* 1995; 28:30-2.
2. Pernick M.S. Brain death in a cultural context: The reconstruction of death 1967-1981. In S. J. Younger, R. M. Arnold, and R. Schapiro (Eds), *The definition of death: Contemporary controversies* (pp. 3-33). Baltimore: Johns Hopkins University Press.
3. Giacomini M. A change of heart and a change of mind: technology and redefinition of death in 1968. *Soc Sci Med*. 1997; 44: 1465-82.
4. Green M.B and Wikler D. Brain death and personal identity. *Philosophy and public affairs*. 1980; 9:105-33.
5. Jennet B, Plum F. Persistent vegetative state after brain damage. *Lancet* 1972; 1: 734-7.
6. Ad Hoc Committee of the Harvard Medical School to examine the definition of brain death. A definition of irreversible coma. *JAMA* 1968;205: 337-40
7. Widjicks E.F.M. Brain death worldwide: accepted fact but no global consensus in diagnostic criteria. *Neurology* 2002; 58:20-5.
8. Morioka M. Bioethics and Japanese culture, brain death, patients rights and cultural factors. *Eubios J Asian Int Bioetics* 1995: 5;87-90.
9. Morioka M. Reconsidering brain death. A lesson from Japan's fifteen years of experience. *Hasting Center Report* 2001; 31:41-46.
10. Bernat J.L. The boundaries of the persistent vegetative state. *J Clin Ethics*. 1992: 3; 176-80.
11. Zeman A. Persistent vegetative state. *Lancet* 1997; 350: 795-8.
12. Shewmon, D.A. The brain and somatic integration: Insights into the standard biological rationale for equating brain death with death. *Journal of Medicine and Philosophy*. 1998; 26: 457-78.
13. Annas G.J. Nancy Cruzan and the right to die. *New Eng Journ Med* 1990: 323; 670-672. Barlett, E.T. and Younger, S.J. Human death and destruction of the neocortex. In R. M. Zaner (Ed), *Death: Beyond whole-brain criteria* (pp. 199-216). Dordrecht, Boston, and London: Kluwer Academic Publishers
14. Curry PD, Bion JF. The diagnosis and management of brain death. *Curr Anesth Crit Care* 1994;5: 36-40.
15. Dوبروسين RR. Organ donation in Jewish law. Summary of discussion at Beth, Israel. June 22, 1996.
16. Campbell C.S. Fundamentals of life and death: Christian fundamentalism and medical science. IN Younger S.J, Arnold R.M and Schapiro R (Eds), *The definition of death: Contemporary controversies* (pp. 194-209). Baltimore: Johns Hopkins Press.
17. Organ transplantation: an Islamic perspective. In: Al Bar MA, edi. *Contemporary topics in Islamic medicine*. Jeddah: Saudi Arabia Publishing and Distributing House 1995: 147-53.
18. Cadaveric donation (editorial). *Dawn*. The internet edition. 15 February 2001. Available at: <http://Dawn.com>
19. Jennet B. Brain death. *Br J Anaesth* 1981; 53:1111-9.
20. Haupt WF, Rudolf J. European brain death codes: a comparison of national guidelines. *J Neurol* 1999; 246:432-7.
21. Robertson J.A. The dead donor rule. *Hastings Center Report*. 1999; 29:6-14
22. Dobb GJ, Weekes JW. Clinical confirmation of brain death. *Anaesth Intense Care* 1995; 23:37-43.
23. Kim JR, Elliott D, Hyde C. Korean health professionals' attitudes and knowledge toward organ donation and transplantation. *Int J Nurs Stud*. 2004; 41: 299-307.
24. Wig N, Gupta P, Kailash S. Awareness of brain death and organ transplantation among select Indian population. *J Assoc Physicians India*. 2003;51:455-8.
25. Singh P, Kumar A, Pandey CM, Chandra H. Level of awareness about transplantation, brain death and cadaveric organ donation in hospital staff in India. *Prog Transplant*. 2002;12: 289-92.
26. Golmakani MM, Niknam MH, Hedayat KM. Transplantation ethics from the Islamic point of view. *Med Sci Monit*, 2005; 11: RA105-109.