

# Shortage of organ donation resulting from difficulties in the diagnosis of brain death by medical practitioners in Malaysia

*Nor Aina Mhd Khotib<sup>1</sup>, Noor Naemah Abdul Rahman<sup>1</sup>, Shaikh Mohd Saifuddeen Shaikh Mohd Salleh<sup>2</sup>*

<sup>1</sup>Department of Fiqh and Usul, Academy of Islamic Studies, University of Malaya, Kuala Lumpur, Malaysia

E-mail: nor\_ina@siswa.um.edu.my

<sup>2</sup>Consultant, Programme for Applied Sciences with Islamic Studies, Academy of Islamic Studies, University of Malaya, Kuala Lumpur, Malaysia

## Abstract

The issues of brain death and organ donation are closely related. Brain death is the irreversible loss of brain function, and from the medical perspective, a person who is brain dead cannot be recovered. The shortage of organs for transplantation is a worldwide problem. One of the reasons contributing to the shortage of organs is the refusal of medical practitioners to diagnose brain death. This paper will highlight four factors why medical practitioners in Malaysia may refuse to diagnose brain death. These factors include: 1) medical practitioners may not accept brain death as true death, 2) a misconception of the concept of brain death, 3) a lack of knowledge about brain death, 4) a lack of responsibility in carrying out professional duties. These four factors will be discussed on the backdrop of ethics as the ethical implications pertaining to brain death diagnosis in Malaysia.

## Introduction

Organ donation is the best method of treatment for patients with end-stage organ failure (Sui et al. 2011). Organs such as heart and lungs can only be obtained from brain dead patients. This is because the organs are still fresh from the oxygen supply received through ventilators as the brain dead patients would still be on the life support machine.

Shortage of organ donors is one of the problems faced by many countries, including Malaysia. Malaysia has a low rate of organ donation where the rate of organ donation from deceased donors is among the lowest in the world. A report from the National Transplant Resource Centre showed that there were only 26 actual donors in 2013. One of the causes of the small number of organ donors is the low rate of referral of brain dead patients. Referrals are made by doctors who treat patients diagnosed with brain death. Mortality due to brain death in intensive care units in some hospitals is high, but when brain death diagnosis is not done, then the patient would not be on record to be brain dead (Interview with Dr. Fadhilah Zowiyah Lela Yasmin Binti Mansor, Chief National Transplant Procurement Manager & Donor Coordinator - Malaysia).

When there is no diagnosis of brain death, then there would not be any referral. As a result, the number of potential donors would not be as high as it should be. However, it does not mean that if the referral rate is high then the number of donors is also high. At the end of the day, in Malaysia, whether a brain dead patient becomes a donor or not depends on the permission given by the next-of-kin (even if the patient is an organ pledger). Nonetheless, a high referral rate would show an effort among doctors, especially in the Intensive Care Unit, to diagnose brain death. Some of these patients diagnosed may turn out to be potential donors. The bottom line is if diagnosis of brain death is not done, then the probability of getting a donor is very low.

This paper aims to identify the factors contributing to the shortage of brain death diagnosis. Although Malaysia has accepted the concept of brain death in terms of legislation, religion and practice, it is hypothesized that there are still doctors who do not accept or do not apply the concept of brain death.

## Methodology

Questionnaires were distributed to doctors at the University of Malaya Medical Centre (UMMC). A total of 80 respondents were selected consisting of doctors working at four major departments of the hospital namely anaesthesiology, medicine, surgery and emergency medicine. The questionnaire data was collected anonymously to

ensure confidentiality. The pilot test was done, and the final version was distributed to respondents. This questionnaire was designed to identify the reasons as to why a low number of medical practitioners in Malaysia diagnose brain death. Many articles written on this matter attribute this to knowledge and attitude of doctors towards brain death. In this survey, a “good knowledge and attitude” can be defined when the doctor does not require any information on brain death, and can provide information to the families of brain dead patients confidently. This study has been approved by University of Malaya Medical Ethics. The findings were analysed; see the percentage for each answer.

An interview was also conducted with Dr. Fadhilah Zowyah Lela Yasmin Binti Mansor who is Chief National Transplant Procurement Manager and Donor Coordinator of the National Transplant Resource Centre, Malaysia.

## Results

The table below shows the summary of the results obtained from the study which shows the percentage of the responses given by the doctors to the questions asked. 80 respondents were selected but one of them not give a complete answer. Therefore, only 79 respondents were analysed.

| Questions/ Percentage %                           | YES  | NO  |
|---|------|-----|
| Do you know what is "brain death"?                | 100% | 0%  |
| Are you involved in the diagnosis of brain death? | 37%  | 63% |
| Have you ever treated brain dead patients?        | 76%  | 24% |

| Questions/ Percentage   | Strongly disagree | Disagree | Not sure | Agree | Strongly agree |
|---|-------------------|----------|----------|-------|----------------|
| My knowledge about brain death is sufficient for me to manage brain dead patients.            | 6.4%              | 31.6%    | 26.6%    | 31.6% | 3.8%           |
| I do not need more information on the issue of brain death.                                   | 16.4%             | 63.3%    | 7.6%     | 7.6%  | 5.1%           |
| I feel confident that I am able to explain the issue of brain death to the patient's family.  | 7.6%              | 27.8%    | 27.8%    | 31.7% | 5.1%           |
| Doctors should take part in discussions of brain death with the family of brain dead patient. | 6.3%              | 0%       | 3.8%     | 51.9% | 38%            |
| Brain dead patients should become organ donors.   | 5.1%              | 19%      | 27.8%    | 36.7% | 11.4%          |
| I would like to become an organ donor if I am diagnosed to be brain dead.                     | 8.9%              | 3.8%     | 21.5%    | 33%   | 32.9%          |
| Diagnosis of brain death is a way to increase the number of organs for transplant             | 12.6%             | 19%      | 17.7%    | 34.2% | 16.5%          |

The results show that there are many doctors who need additional information regarding brain death. 63.3% of doctor disagreed when asked if they do not need more information on the issue of brain death. If they do not have enough knowledge, it will affect their explanation to the patient's family. That would contribute towards doctors having low confidence when explaining about brain death.

The respondents were also asked whether Malaysia accepted the concept of brain death as death. In total, 54.4% answered true, 15.2% answered false and 30.4% did not know. While slightly more than half of the respondents answered this question correctly, it is quite alarming that the remaining 45.6% either answered wrongly or did not know. On another matter, the majority of the respondents (89.9%) agreed that doctors should take part in discussions of brain death with the family of brain dead patient.

## Discussion

**Medical practitioners may not accept brain death as a true death:** Studies conducted in several countries such as Israel, Italy and Switzerland showed that there are doctors who do not accept brain death as legal death (Cohen et al. 2008). Approximately 1/5 of doctors from studies conducted in these three countries do not accept brain death as death.

Although the concept of brain death is accepted and adopted in many countries, it is still not recognized in countries such as Egypt, Syria and Pakistan (Mohd Rani 2005, Al-Khader 2002). Therefore, for this study, a hypothesis was made that Malaysian doctors who graduated from Egypt do not accept the concept of brain death because Egypt does not recognise the concept of brain death as death.

Attitude towards the acceptance of brain death will impact on the organ donation process. Most doctors who do not accept brain death are those who are not involved with the process of organ procurement or who are unfamiliar with the donation process. Abidin et al. (2013) in their study done at University of Malaya Medical Centre showed that there are still some doctors who are unwilling to accept the concept of brain death, although the Malaysian Medical Council (MMC) has issued guidelines on the acceptance of brain death in 1996 (Merican 2006). In this study, however, from the demographic data compiled through the questionnaires, none of the respondents had their medical background from countries which do not accept brain death as legal death. As such, the hypothesis could not be tested.

**Misconception of the concept of brain death:** The study conducted at UMMC in 2013 found that 10.6% of doctors thought only neurologist could certify brain death (Abidin et al. 2013: p6). In this study, a similar misconception still occurs, as 24.4% of the respondents answered that doctors involved in the process of organ procurement can diagnosis brain death, and half of them do not indicate that a neurosurgical specialist as the person who can diagnose brain death. This misunderstanding can reduce the number of brain death diagnosis. In Malaysia, it is a legal requirement that doctors involved in certifying brain death consist of two specialists, with at least three years of postgraduate clinical experience who are trained in brain death assessment and diagnosis. They should preferably be anaesthesiologists, physicians, neurologists and neurosurgeons (Merican 2006: p13).

**Lack of knowledge about brain death:** Lack of knowledge of brain death is a result of little exposure to the concept of brain death among doctors. One way to give a clear understanding is to introduce a formal subject related to brain death and organ donation in the early clinical year of medical training (Cohen et al. 2008: p215). Lack of knowledge related to brain death will result in discomfort among doctors when explaining brain death to family members of patients. Previous studies have shown that the level of understanding of physicians on brain death is poor (Youngner et al 1989, Harrison & Botkin 1999).

This situation is caused by a lack of education and exposure while in medical school. Before this, there are many reports which only assess medical students and physicians' understanding on the issue of organ donation, but these do not focus on basic issues of brain death (Schaeffner et al. 2004, Afonso et al. 2004). There are several studies regarding the knowledge and attitudes of doctors on the issue of brain death carried out in Korea (Jeon 2012), Pakistan (Sherani 2008), Egypt (Hamdy 2013), Japan (Kato 2004) and Poland (Kubler 2009). The studies found that there are doctors who are not clear about the definition of brain death, and some of them reject the concept of brain death such as those in Egypt, as "not quite dead".

From the result of this study, 76% of respondents have treated brain dead patients but 63.3% of them still require more information on the issue of brain death. The current knowledge that they have is still not sufficient to manage brain dead patients.

**Lack of responsibility in carrying out professional duties:** Based on the interview with Dr. Fadhilah Zowyah Lela Yasmin, it is found that many doctors did not make a diagnosis of brain death to patients who were brought to the Intensive Care Unit (ICU). The patients would be put on life support machine in order to assist the heart and respiratory process. Most of these patients would eventually die when in fact, from the medical perspective, they are already brain dead. Dr. Lela Yasmin is of the view that it would be more ethical for doctors to make a diagnosis of brain death on patients suspected of being brain dead rather than leaving them on the life support machine.

Furthermore, it is the responsibility of doctors to explain brain death and organ donation to the patient's family. A study conducted by Abidin et al. showed that the shortage of organs in Malaysia is caused by passive attitude among doctors to identify a suitable organ. Almost two-thirds of respondents had never approached the family of brain-dead patients to explain about organ donation. Acceptance and application of the concept of brain death as legal death is a major issue in organ donation because the rise of acceptance of brain death can increase the number of organ donors. When the question about diagnosis of brain death as a way to increase the number of organs for transplant was asked, 12.6 % answered strongly disagree, 19% disagreed and 17.7% answered not sure. This may be one of the reasons for the reluctance of doctors to diagnose brain death since they do not view the diagnosis of brain death as a means to

increase the number of organ donors. In fact, when the diagnosis of brain death is not implemented, potential donors cannot be identified.

## Conclusion

Doctors should be given adequate training and information on brain death which can be started from the beginning of their undergraduate studies. Abidin et al said that they should understand the concept of brain death, and have to be aware of this possibility when treating patients, and be able to recognize and diagnose brain death in the presence of a potential organ donor. We need to change the attitudes of doctors to make them more responsible on the issue of brain death. Doctors should have a more positive attitude towards brain death. Finally there must be exposure on brain death to the public through the media and religious bodies. This will help to facilitate doctors job to provide information to the patient's family.

Doctors play an important role in the issue of brain death and organ donation. Their understanding and good behavior in the issue of brain death is very important. They should be responsible for each task given. Continuing medical education and increasing awareness are the key in increasing the number of brain death diagnosis.

## Acknowledgement

We are grateful to the Dr. Lam Chee Loong and Dr. Ee Chin Loh (Both are Senior Lecturer and consultant Palliative Medicine) for their cooperation in this study and also to the Medical Ethics Committee, University Malaya Medical Center for the ethics approval (MECID.NO: 20144-158). The study is funded by Postgraduate Research Fund, University of Malaya (PG032-2013B).

## References

- Abidin, Zada L Zainal, Wee Tong Ming, Alexander Loch, Ida Hilmi, and Oliver Hautmann. 2013. "Are Health Professionals Responsible for the Shortage of Organs from Deceased Donors in Malaysia?," *Transplant international: official journal of the European Society for Organ Transplantation* 26: 187-94 .
- Afonso, R C, D a B Buttros, D Sakabe, G C Paranhos, L M C Garcia, M B Resende, and others. 2004. "Future Doctors and Brain Death: What Is the Prognosis?," *Transplantation proceedings* 36: 816-17.
- Al-Khader, Abdulla A. 2002. "The Iranian Transplant Programme: Comment from an Islamic Perspective.," *Nephrol dial transplant*, 17: 213-15.
- Cohen, Jonathan, Sharona Ben Ami, Tamar Ashkenazi, and Pierre Singer. 2008. "Attitude of Health Care Professionals to Brain Death: Influence on the Organ Donation Process.," *Clinical transplantation* 22: 211-15.
- Hamdy, Sherine. 2013. "Not Quite Dead: Why Egyptian Doctors Refuse the Diagnosis of Death by Neurological Criteria.," *Theoretical medicine and bioethics* 34: 147-60.
- Harrison AM, and Botkin JR. 1999. "Can Pediatricians Define and Apply the Concept of Brain Death?," *Pediatrics* 103: 82.
- Jeon, K.O., B.N. Kim, H.S. Kim, N.-I. Byeon, J.J. Hong, S.H. Bae, and others. 2012. "A Study on Knowledge and Attitude toward Brain Death and Organ Retrieval among Health Care Professionals in Korea," *Transplantation Proceedings*, , 859-61.
- Kato, Shinzo. 2004. "Organ Transplants and Brain-Dead Donors: A Japanese Doctor's Perspective," *Mortality* 9: 13-26.
- Kubler, a, M Lipinska-Gediga, J Kedziora, and M Kubler. 2009. "Attitudes to Brain Death and Organ Procurement among University Students and Critical Care Physicians in Poland.," *Transplantation proceedings* 41: 1473-76 .
- LS, Hooi, and Lela Yasmin Mansor, *Sixth Report of the National Transplant Registry Malaysia 2009* (Kuala Lumpur, 2011) <[http://www.crc.gov.my/pdf/6th\\_NTR\\_report2009.pdf](http://www.crc.gov.my/pdf/6th_NTR_report2009.pdf)>
- Merican, Mohamed Ismail. 2006. "Guideline Of The Malaysia Medical Council".
- Mohd Rani Jusoh. 2005. "Mati Otak: Konsensus Pengamal Perubatan," in *Sempadan Bioteknologi Menurut Perspektif Islam*, ed. by Shaikh Mohd Saifuddeen (Kuala Lumpur: Institut Kefahaman Islam Malaysia (IKIM), pp. 139-52.
- Schaeffner, Elke S, Wolfram Windisch, Klaus Freidel, Kristin Breitenfeldt, and Wolfgang C Winkelmayr. 2004. "Knowledge and Attitude Regarding Organ Donation among Medical Students and Physicians.," *Transplantation* 77: 1714-18.
- Sheerani, Mughis, Mian Zainul Sajadeen Urfy, Bhojo Khealani, Junaid Patel, Qamarunnisa, and Suresh Rath. 2008. "Brain Death: Concepts and Knowledge amongst Health Professionals in Province of Sindh, Pakistan.," *Journal of the Pakistan Medical Association* 58: 352-56.
- Sui, W G, Q Yan, S P Xie, H Z Chen, D Li, C X Hu, and others. 2011. "Successful Organ Donation from Brain Dead Donors in a Chinese Organ Transplantation Center.," *American journal of transplantation: official journal of the American Society of Transplantation and the American Society of Transplant Surgeons* 11: 2247-49.
- Youngner, S J, C S Landefeld, C J Coulton, B W Juknialis, and M Leary. 1989. "'Brain Death' and Organ Retrieval. A Cross-Sectional Survey of Knowledge and Concepts among Health Professionals.," *JAMA: the journal of the American Medical Association* 261: 2205-10.