

The role of understanding the brain death concept in individuals' willingness to donate organs – preliminary study

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ABSTRACT

Purpose: The study tries to explore if there is an association between the level of understanding the brain death concept and the willingness to organ donation.

Methods: For the purpose of that study the two-step method was introduced. The first stage was planned to test people's ideas about brain death and then separate main groups of responses from these ideas. Those general categories were used in the second phase of the study. 550 respondents completed self-administered questionnaire comprised three sections: (1) understanding the term brain death scale; (2) willingness to donate scale; and (3) general demographic questions.

Results: It turned out that just over 50% of respondents correctly associated the death of the

human brain with the patient's death. The rest of the subjects was convinced that the diagnosis of brain death means that the organism had a chance to survive. Significant association between the participants' willingness to donate their organs after death and their understanding of the concept of brain death was found.

Conclusions: The results supported the prediction that having a thorough knowledge of the concept of brain death is associated with a greater willingness to become an organ donor after one's death. Our findings show how important providing professional education on transplantation in our society is.

Key words: transplantation, psychology, brain death

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INTRODUCTION

Organ transplantation, an experimental procedure 25 years ago, is now a routine life saving surgery. The benefits offered by organ and tissue transplantation are now indisputable. That modern method of therapy saves lives of thousands of people who suffer from the end-stage chronic conditions. Organ transplantation also improves the quality of life of many patients with organ deficiencies or those in need of body tissues. Thus, transplantation is recognized as one of the major medical achievements over the last half century [1].

Technology increasingly removed the limitation for organ transplants. Nowadays the limit is the lack of available organs. Almost all the literature on soliciting organs for a donation indicates the gap between supply and demand. In our country, the number of patients in need of an organ transplant is much bigger than the number of transplant operations. For instance, in 2009, 3399 Polish patients were waiting for transplantation but only 1102 transplantations were done then [3]. As we can see there is a critical shortage of donor organs necessary for human organ transplantation.

There are a number of widely reported factors, which contribute to the shortage of available organs. They include the inadequate number of cadaver donors, public misperceptions about the process of organ donation, poor recognition of potential donors by medical personnel, and the difficulty of obtaining consent from donors and their next-of-kin etc. [4]. It seems that one more possible cause of the failure to donate might be that nondonors do not understand the current death criteria. Until 40 years ago, people used to identify death with the cold body, stretching of the face, dimness of the eyes, the feet loosening and dropping both in Poland and in the world. Physicians used to diagnose and accept death by the irreversible stopping of respiratory and circulatory systems and the brain's functions [5]. In contrast to the colloquial ideas about death, which relate to termination of heart rate, currently used criterion of human death is brain death.

The term brain death was endorsed by the Ad Hoc Committee of the Harvard Medical School in 1968, primarily in response to the development of the ventilator which could mechanically maintain respiration and heartbeat for an indefinite length of time, coupled with the growing recognition of the need for transplantable organs. They made the proclamation that life support could be withdrawn from patients with irreversible coma or brain death and provided the first criteria for diagnosing brain death [6]. Just after the Harvard Committee, other reports were published by the Philadelphia Protocol in 1969, the Health Sciences Center of Minnesota University in 1971, the British Royal College of

Physicians in 1974, all accepting brain death as legal death. In the following years, laws accepting brain death were passed by the Committee of French Ministries, the Legal Commission of Australia, Belgium, Holland, Denmark, and Finland. The brain death concept came into being almost at the same time as organ transplantation [6]. In Poland, the legislation for organ transplantation was developed in 1995 and was changed twice: in 2005 and 2009. One of 2009's most important changes consisted of providing the new criteria of diagnosing death. Polish parliament resigned from the brain stem death as a criterion for patient death and has accepted that a death determines brain death [7].

Brain death can be a difficult concept to understand. The most common causes of brain death are head injury and subarachnoid haemorrhage, usually occurring unexpectedly in young, healthy individuals with no premorbid symptoms. There is often no external sign of injury and although the brain is dead, the patient is warm and pink due to inotropes and warming devices, and the chest rises and falls due to artificial ventilation [8]. Additionally, as Byrne and Nilges [9] along with the relatives of the brain dead observe, these patients are often treated as alive by their relatives and sometimes by the hospital staff (e.g. they talk to the death patient as care is delivered).

Thus, to make it easier to understand the factors affecting willingness to organ donation it is important to get to know how people comprehend the diagnosis of brain death. The main objective of this study was to examine how the concept of brain death is conceptualized and what are the implications for people's willingness to organ donation after death.

METHODS

For the purpose of that study the two-step method was introduced. The first stage was planned to test people's ideas about brain death and then separate from these ideas main groups of responses. To achieve this objective 50 subjects (college students, ranged in age from 18 to 29 years old, about equally male and female) read a scenario described the situation whereby a young adult Anna suddenly had died a tragic death and whose kin were now facing the information about brain death. After reading the story participants had to answer some open-ended questions: „If you heard that Anna had been proclaimed brain dead by three doctors independently, how would you understand this diagnosis? How would you interpret it?" Subjects were also asked to write down their imaginations of what would happen with Anna. In order to analyze the collected material, the procedure adopted in organizing qualitative data

was used [10]. As a result 4 main categories were distinguished among open-ended survey responses.

Those general categories were used in the second phase of the study in which 550 college students participated. Subjects ranged in age from 19 to 28 years old and 260 were male and 290 female. A survey was conducted from October 2009 to January 2010. Respondents completed self-administered questionnaire comprised of three sections: (1) understanding the term brain death scale; (2) willingness to donate scale; and (3) general demographic questions. To examine the perception of the term brain death participants were given the question: „If you heard that someone had been proclaimed brain dead by three doctors independently, which of the following would be the most accurate interpretation of this diagnosis in your opinion?" Subjects had to choose one of four categories of response identified in the first phase of research. Willingness to organ donation was measured by Likert-type scale. Participants were asked to grade their willingness on a scale of 1 to 5 (strongly disagree, disagree, and don't know, agree, strongly agree). The following social demographic variables were examined: age, gender, educational level, faculty, place of living and religious beliefs.

Out of the concern for the highest ethical standards, all the participants involved in the research have been thoroughly informed about all possible aspects of the research. They have also been asked to give a formal consent to take part in the research. The participants have been also given the right to quit the research without suffering any consequences of the decision. The research, according to the Polish as well as the international law, was not a medical experiment and as such it was not in the interest of the Bioethics Committee. The research has been fully carried out based on the social science methodology [10], therefore adjusted to the Code of Ethical Practice for the Polish Psychological Association.

RESULTS

The first stage of the study was planned to test people's ideas about brain death and then separate main groups of responses from these ideas. In order to analyze the collected material, the procedure adopted in organizing qualitative data was used [10]. In general, that method focuses on seeking out the universal concepts of respondent's answers because of the similarity of their contents. As a result 4 main categories were distinguished among open-ended survey responses:

1. The patient is in a coma and any contact with him is impossible now. It is hard to say when he will start a normal life.

Sample responses from this category were as follows: „He is in a coma, and he will lie in bed

perhaps for years". „He is unconscious, probably in a coma. I've heard that it's possible to exist in such a state for a very long time".

2. The patient is dead because all of his vital functions ceased irreversibly.

Sample responses from this category were as follows: „Because the brain is responsible for all critical processes in the body, he is dead". „Brain death is synonymous with the death of a man, therefore the patient is the ideal organ donor". „I am sure that he is dead".

3. The patient is in a very poor condition and has little chance of survival.

Sample responses from this category were as follows: „He is in a state in which the brain does not work properly. It is therefore difficult to say whether he survives or not". „After a persistent and chronic treatment the patient has little chance of survival". „I know that he is sick seriously, but I am not sure when his death will come".

4. At the moment, the patient is unconscious. He will probably regain consciousness, but he will be handicapped and dependent on the care of other people for the rest of his life.

Sample responses from this category were as follows: „Now he is unaware. After regaining consciousness he will be 'like a plant' for the rest of his life". „He lost his consciousness. For the rest of life he will be paralyzed and helpless".

In the second part of the research both the participant's understanding of the term brain death and their willingness to donate organs were examined. The ways of thinking about brain death are given in Table 1.

Table 1. The ways of thinking about brain death.

Response category	Percentage of indications to each option
1) The patient is in a coma and any contact with him is impossible now. It is hard to answer when he will start a normal life.	27.3%
2) The patient died because all of his vital functions ceased irreversibly.	50.9%
3) The patient is in a very poor condition and has little chance of survival.	3.6%
4) At the moment, the patient is unconscious. He will probably regain consciousness, but he will be handicapped and dependent on the care of other people for the rest of his life.	18.2%

Source: on the basis of research results.

The above results show that 50.9% of the subjects chose the correct alternative: „The patient died because all of his vital functions ceased irreversibly". However, 27.3% chose: „The patient is in a coma and any contact with him is impossible now. It is hard to answer when he will start a normal life". In addition, 18.2% chose: „At the moment, the patient is unconscious. He will probably regain consciousness, but he will be handicapped and dependent on the care of other people for the rest of his life". Whereas 3.6% chose: „The patient is in a very poor condition and has little chance of survival". The data supports the findings of research conducted by Shanteau and Linin's [11]. This study showed that many people

do not understand the finality indicated by the term brain death.

The next goal of the research was to examine the participant's willingness to donate their organs after their sudden death depending on how they understand the concept of brain death. The main prediction was that relevant knowledge about the brain death would be associated with the subjects' consent to donate their organs to transplantation. Because the data were not sampled from the Gaussian distribution (had not passed the normality test) the prediction was tested by Kruskal-Wallis nonparametric ANOVA. The obtained results are given in Table 2.

Table 2. Results of Kruskal-Wallis nonparametric ANOVA.

Group	N	Sum of ranks	Mean of ranks	Median	Minimum	Maximum
Death	280	90771	324.18	4.000	1.000	5.000
Coma	150	33791	225.27	3.000	1.000	5.000
Unconscious now	99	22978	232.10	4.000	1.000	5.000
Very poor condition	20	3435.5	171.78	3.000	1.000	4.000

Source: on the basis of research results.

The P value is < 0.0001, considered extremely significant, which means that there are big differences between the four groups of respondents. Results of Dunn's Multiple Comparisons Test are included in Table 3.

They clearly show that these subjects who have misconceptions about the brain death are less likely to be cadaver organ donors in comparison to those of them who associate brain death with a person's demise.

Table 3. Results of Dunn's Multiple Comparisons Test.

Comparison	Difference	P value
Death vs. Coma	98.909	* P < 0.001
Death vs. Unconscious now	92.086	* P < 0.001
Death vs. Very poor condition	152.41	* P < 0.001
Coma vs. Unconscious now	-6.823	ns
Coma vs. Very poor condition	53.498	ns
Unconscious now vs. Very poor condition	60.321	ns

Source: on the basis of research results.

Note: ns – not significant; * significant

DISCUSSION

The results of the research prove that there is a strong connection between the familiarity with the notion of brain death and the respondents' willingness to donate their own organs. The subjects who, out of the four definitions selected at the first stage of the research, selected the correct one, demonstrated their will to donate their own

organs in a more distinct way. The willingness to become an organ donor among those respondents who did not associate brain death with a person's demise turned out to be significantly lower.

These results do not seem surprising, if we consider the fact that in our country a person is pronounced dead on the basis of the brain death

criterion. Hence, if an individual recognizes the fact that brain death is equivalent to a person's death, they will probably not face dilemmas concerning the occurrence of death, while thinking about taking organs from a dead person's body. On the other hand, those who interpret the brain death diagnosis in terms of life - e.g. as going into a coma, temporary loss of consciousness etc. - will probably still have hopes (even the slightest) that the patient will recover, which automatically makes the decision about starting the transplantation procedure appear at least controversial.

The research findings also give indirect evidence regarding the importance of educating our society within the scope of broadly understood transplantology. Forming overall positive attitudes towards organ transplants is not enough, since, as it turns out, the lack of support for the idea of transplantation is not a crucial problem. It turns out that most Poles support the transplant as an effective method of treatment. This is demonstrated by the results of research conducted by Bazel, Kurczewska and Maik [12] and the results of several subsequent replicated studies conducted by public opinion research centres, e.g. CBOS [13] and IPSOS [14].

It seems that the fear that the organs could be taken during an individual's life may be far more responsible for a person's unwillingness to donate organs. The discoveries of cognitive psychology, according to which lack or insufficient amount of information is one of the most important sources of fear or insecurity experienced by people [15], seem to corroborate that assumption. The aforementioned concerns may be further enhanced by reports on erroneous pronouncement of death and other health care abuse. Hence, contrary to the past transplant awareness promoting campaigns should nowadays put a greater emphasis on informing the public about the legal, medical, psychological, and many other aspects of organ transplantation. For example the campaign consisted of radio and television advertisements should project the general message that brain death is a real death and encourage the audience to think about organ transplantation problems.

Finally, the conducted research shows the significance of the role of doctors discussing organ donation with families of persons who have been declared brain dead. As it was mentioned earlier, most of dead organ donors are people who died as a result of sudden, unexpected, rapid death, such as motor vehicle crash or car accident etc. These people are often diagnosed as dead because the brain death criteria have been fulfilled. There is often no external sign of injury and although the brain is dead, the patient still looks like a living person. Thus, for the patient's relatives, brain death can be a difficult concept to understand. Thorough

explanation of the notion of brain death seems essential to obtain consent to donation [16].

At the end of the presentation the main study's limitations are also worth considering. Firstly, it has to be admitted that the experiences of participants may not be representative of those people who met the real situation of making decisions about donating organs for transplantation. Secondly, the study did not include its range of representatives of all social groups, but was limited to the student population. Thus, future studies should further explore these issues and should attempt to replicate these exploratory findings with more diverse samples. Despite these limitations, the results of presented study confirmed the fact that education about the process of organ donation (especially on issues of brain death) should be a fundamental component of health education in our country.

CONCLUSIONS

The main finding of presented surveys is that relevant knowledge about the brain death is strongly associated with the participant's consent to donate organs for the purpose of transplantation. This result allows to conclude that certainty as to the occurrence of the death is a factor which significantly affects the transplantation decision making process. The study has also shown a high level of misunderstanding of the brain death concept among the subjects. It turns out that quite a lot of people understand the term brain death as a condition less serious than the terminal, therefore, in order to expand the pool of willing organ donors in our country it is worth taking care of education of our society on issues of brain death.

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