



Knowledge and attitudes towards brain death and organ donation in hospitalized patients and their relatives

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Abstract

Aim: Organs are generally procured from cadavers in developed countries while they are mostly obtained from living donors in developing countries. Firstly, the diagnosis of brain death should be established in order to obtain organ from a cadaver. Secondly, the family or legal guardian should have to donate organs. The knowledge and attitudes of relatives of donor towards organ donation is important in a patient diagnosed as brain death. Thus, this study was performed to determine knowledge and attitudes towards brain death and organ donation in patients (their relatives) hospitalized in general surgery clinic where organ donation is performed.

Material and Methods: The patients hospitalized in General Surgery Clinic, and their relatives (n=80) were included to the study. The clinic also performed renal transplantation. The questionnaires developed by researchers were used to collect data.

Results: Of the subjects included, 75% were women while 25% were men. Mean age was 40.71±15.53 years. Majority of subjects had inadequate knowledge about brain death or organ transplantation. Of subjects, 76.25% reported that they support organ donation. Only 2.5% had donated their organs. Subjects (n=19) reporting that they would not donate organ of their relative diagnosed as brain death proposed following reasons: religious thoughts (15.8%), refusal of disrupting body integrity (94.8%) and being blinded to decision of potential donor about organ donation.

Conclusion: Although sample size is small in our study, it was shown that majority of individual have no sufficient information about brain death and organ transplantation and that organ donation rates are extremely in our society.

Keywords: Attitude; brain death; knowledge; organ transplantation; practice

INTRODUCTION

The brain death (BD) defines irreversible loss of functions of brain and intracranial neurological structures in brain stem (1,2). A healthy individual can be a living donor by donating his/her kidney, liver, lung, intestines, blood or bone marrow while a donor with brain death can be a donor for heart, liver, kidneys, lung, pancreas and small intestines as well as many other tissues and organs such as cornea, skin, vessel, cardiac valves, tendon, ligament or bone (3).

In Turkey, number of transplantations from living donors was increased from 438 in 2002 to 4399 in 2019 by 10-folds while number of transplantations from cadaver was increased from 307 in 2002 to 1366s in 2019 by approximately 4.4-folds (4). Organ transplantation rate from live donor is 76% in our country in 2019 and this indicating an extremely high rate. In USA, majority of 17,553 organ and tissue donations (61.8%) were from persons with brain death (5).

The hemodynamic, hormonal, metabolic and inflammatory changes triggered by brain death lead a cascade of events affecting number and quality of organs which could be retrieved from potential donor (6,7). Thus, the diagnosis of brain death should be established early for successful transplantation; the suspicion of brain death should have to prompt evaluations as soon as possible; family members should be organized and it should be questioned whether they are donors; and organ dysfunction should be maintained at maximum level (8). Since the diagnosis of brain death is not a simple or routine procedure, the terms and tests required to establish diagnosis of brain death was published in "Organ and Tissue Transplantation Regulations" in 2012 (9).

Although diagnosis of brain death alone isn't sufficient, negative attitude of family towards organ donation is one of the main reasons of refusal of organ donation after brain death (10,11). The families seesaw between providing benefits to other and protecting body of their loss while donating organs (12). The causes for refusing organ

Received: 27.05.2020 **Accepted:** 29.07.2020 **Available online:** 21.10.2020

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donation include unwillingness to disrupt body integrity, religious beliefs, distrust to healthcare professionals and negative thoughts against society (10). In particular, lack of donation instructions by the deceased or donor registration make donation process difficult for families (12,13).

Somewhat knowledge regarding brain death is a prerequisite to understand donation process and decision-making process regarding donation. The fact that organ donation is only survival chance for many patients with terminal diseases (14) and large gap between organs donated and organ requirement (4) warrant to address this issue persistently. The study aimed to determine knowledge and attitudes towards brain death and organ donation in patients hospitalized patients in a general surgery clinic and in their relatives.

MATERIAL and METHODS

This prospective study was conducted at a general surgery department between October, 2019 and January, 2020. The study protocol was approved by the İzmir Katip Çelebi University Faculty of Medicine Ethics Committee (Institution Review Board: 2019 / 501). The study was conducted in accordance with the principles of the Declaration of Helsinki. Data were collected using a 10-item questionnaire designed based on literature about brain death and organ transplantation. The questionnaire was completed by patients hospitalized in general surgery clinic and their relatives via face-to-face interview method. The subjects declining to participate or those with incomplete questionnaire were excluded. Thus, data from 80 responders were included to final analysis. Data regarding age, occupation, whether they donate their organs and level of knowledge about brain death were questioned in all participants.

The normal distribution of data was assessed using Komogorov-Smirnov test. Numerical data were compared between groups using independent sample t test while categorical data were compared using Chi-square test. A p value<0.05 was considered as statistically significant.

RESULTS

Of the subjects included, 75% were women while 25% were men. Mean age was 40.71±15.53 years. The educational level was high school or above in 62.5% of subjects (Table 1). It was found that majority of subjects had inadequate knowledge about brain death or organ transplantation (Table 2 and Table 3).

Table 1. Demographic data of subjects

	n	%
Gender		
Female	60	75
Male	20	25
Marital status		
Married	44	55.0
Single	36	45.0
Age (mean± sd)	40.71±15.53	
Educational level		
Illiterate	2	2.5
Literate	4	5.0
Primary school	24	30.0
High school	30	37.5
University	20	25.0
Occupation		
Unemployed	10	12.5
Government official	28	35.0
Worker	12	15.0
Self-employment	10	12.5
Retired	20	25.0

It was found that most subjects had insufficient knowledge about brain death and false beliefs. Table 2 presents answer to questions about brain death.

Table 2. Answers of subjects to questions about brain death

Questions (n=80)	Yes (n) %	No (n) %	Indecisive (n) %
There is a probability of living in an individual with brain death	(50) 62.5%	(28) 35.0%	(2) 2.5%
Brain death and coma are synonyms	(61) 76.2%	(16) 20.0%	(3) 3.8%
Brain death means death	(28) 35.0%	(50) 62.5%	(2) 2.5%
Brain death and vegetative life are synonyms	(48) 60.0%	(28) 35.0%	(4) 5.0%
An individual is considered alive if heart is beating despite occurrence of brain death	(60) 75.0%	(16) 20.0%	(4) 5.0%
I feel that I end his/her life if I donate organs of a person with brain death	(70) 87.5%	(10) 12.5%	-
The diagnosis of brain death is made by a single clinician; thus, there is always a possibility of mistake	(44) 55.0%	(31) 38.8%	(5) 6.2%
I don't believe accuracy of test used in the diagnosis of brain death	(48) 60.0%	(28) 35.0%	(4) 5.0%
One should not be despond from God even after brain death	(50) 62.5%	(21) 26.3%	(9) 11.2%

Table 3. Answers of subjects to questions about organ donation

Questions (n=80)	Yes (n) %	No (n) %	Indecisive (n) %
I support organ donation and willing to donate organ	(57) 71.2	(11) 13.8%	(12) 15.0%
I donated my organs	(2) 2.5%	(78) 97.5%	-
I won't donate organs if my relative has brain death (If yes, reason for it. More than one option should be selected)	(19) 23.8%	(44) 55.0%	(17) 21.2%
Religious reasons (n=19)	(3) 15.8%	(10) 52.7%	(6) 31.5%
I don't want to disrupt body integrity (n=19)	(18) 94.8%	(1) 5.2%	-
I don't know his/her decision before death (n=19)	(16) 84.2%	(3) 15.8%	-
Living donor is not possible in liver transplantation because whole liver is procured	(3) 3.8%	(68) 85.0%	(9) 11.2%
They may sell my organs which I donated	(1) 1.2%	(79) 98.8%	-
I cannot waive once I donate my organs	(61) 76.2%	(19) 23.8%	-
My organs can be procured after death without permission of my family if I donate my organs	(47) 58.8%	(29) 36.2%	(4) 5.0%
My other organs can be procured after death if I donate one organ	(32) 40.0%	(42) 52.5%	(6) 7.5%
My organs can be procured even if brain death is established if I donate my organs	(6) 7.5%	(74) 92.5%	-
Organ transplantation is performed only from a living doner to a living recipient	(1) 1.2%	(60) 75.0%	(19) 23.8%

Most subjects think that he/she could not waive once he/she donated organs (76.2%); that organs would be procured after death even if their relatives decline organ donation (58.8%); that other organs could also be procured although he/she donated only one organ (40.0%); and that his/her organs could be procured even if brain death is not established (7.5%) (Table 3).

DISCUSSION

Millions of people die due to organ failure from beginning of life and organ transplantation is a promise for people in waiting lists (3,4,15). Based on data from Turkish Organ Donation Foundation, approximately 29,000 people are on waiting list for organ transplantation in Turkey (4) while there are 113,000 people on waiting list for organ transplantation in USA. A new individual is added to waiting list in every 10 minutes in USA and 20 people die due to failure to find an available organ for donation (3). Although advances in transplantation technology, increased number of transplantation teams and development of novel drugs have contributed to current success in organ transplantation, it is needed to identify and improve level of knowledge and attitudes of society regarding organ transplantation and brain death and to use cadavers as donor in order to save more lives (3,16).

It was demonstrated that concepts of death, brain death and coma hasn't been fully understood (17-20). In a population-based study from Cuba, it was shown that 57% does not know brain death and 12% does not accept brain death as death of an individual or they have false perceptions; that individuals with knowledge of brain death have more positive attitude towards organ donation (17). Previous studies showed clinicians or even medical

students have limited knowledge about brain death (1,21,22). In a study on university students from Saudi Arabia, 93% of participants reported that they have heard about brain death and 85% reported that they have got information about brain death from media while 73% reported that there is no difference between brain death and natural death (18). In a study on Bolivians living in Spain, it was found that only 27% understand notion of brain death (19). In a study on Latin Americans (n=1237), it was found that 25% of participants know notion of brain death while 56% don't know the term and 19% don't know that brain death does not necessarily means death (20). In the study, majority of participants reported that brain death is synonym for coma or vegetative life; that individual is considered as alive if heart beats despite brain death and that he/she will feel to end life if they donate organs of their relatives. In addition, the study revealed distrust to diagnosis of brain death. It has been seen that 95% of adults support organ donation but only 58% are registered organ donors in USA (5). Milaniak et al. reported that majority of the group including students, teachers and nurses have positive attitude toward organ donation (23). In the study, it was seen that rate of participants supporting organ donation was high but minority donated their organs.

In the literature, it is observed that people are unwilling to donate organs due to several reasons (10,24,25). In a study conducted through social media in Saudi Arabia, 46.4% of participants know that Islamic rules permit organ donation while 51% reported they don't want to donate their organs. Of the participants, 46.5% consider brain death as death of an individual and 37.7% consider as coma while 33.3% don't know that the individual with brain

death will never awake again and 35.4% suggest that they can awake (25). In the study, it was revealed that majority of participants had false beliefs about organ donation such as that he/she could not waive once he/she donated organs; that organs would be procured after death even if their relatives decline organ donation; and that other organs could also be procured although he/she donated only one organ. In a retrospective study, it was reported that 30.8% of 227 organ donors declined organ donation within one year. The most common cause for refusal was desire to protect integrity of body (46.3%); followed by religious beliefs (16.4%), distrust to healthcare community (13.4%) and willing to maintain rising against society (6%) (10). In a review including 15 studies, the reasons for not being donor include religion, medical distrust, anxiety, emotional status, deficiency of knowledge, insufficient time for grieve, possibility of delaying funeral, attempt to protect physical integrity of body, lack of knowledge about registration process for organ donation and social status (24). In agreement with literature, subjects unwilling to donate organs of their relatives proposed similar reasons including religious beliefs (15.8%), desire to protect integrity of body (94.8%) and lack of knowledge about decision of the deceased (84.2%) in our study. Based on our results, it is apparent that society hasn't been informed sufficiently regarding organ donation.

Organ donation is a multifaceted process with medical, ethic, religious, social, economic, psychological and legal aspects, all of which should be addressed separately (15). Thus, each aspect should be addressed meticulously and appropriate strategies should be developed. Educating society and increasing awareness are needed in a regular and persistent manner.

CONCLUSION

Despite small sample size, it was shown that majority of individual have no sufficient information about brain death and organ transplantation and that organ donation rates are extremely in our society. It was also found that reasons such as disruption of body integrity, lack of knowledge about decision of the deceased and religious causes have negative influence on organ donation. The organ donation is an important issue that should be overemphasized. We think that education, increased awareness and providing information are major factors in organ donation. It is important to improve level of education and awareness in order to achieve success in coordination of organ transplantation. However, one of the major drawbacks is that the education provided are insufficient and cannot be understood by public adequately in Turkey. Given that lack of communication and false facts are major causes of insufficiency in cadaveric organ transplantation and negative attitudes towards organ transplantation among families, it can be suggested that there is a need for education about communication which aims to improve organ donation. It is highly important to improve awareness about organ transplantation. We believe that education, improved awareness and enlightenment are important factors in organ donation.

Conflict of interest: The authors declare that they have no competing interest.

Financial Disclosure: There are no financial supports.

Ethical approval: Izmir Katip Celebi University Faculty of Medicine Ethics Committee (Institution Review Board: 2019 / 501).

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