

Demographic Characteristics of Brain Death Cases in Our Clinic and Causes of Family Refusal for Organ Donation

Kliniğimizdeki Beyin Ölümü Hastalarının Demografik Özellikleri ve Ailelerin Donör Ret Nedenleri

Ömer Faruk BORAN¹, Hafize ÖKSÜZ¹, Dilek SOYLU², Aykut URFALIOĞLU¹, Bora BİLAL¹, Yavuz ORAK¹, Selma URFALIOĞLU³

¹Kahramanmaraş Sütçü İmam University, School of Medicine, Department of Anesthesiology Kahramanmaraş, Turkey.

²Kahramanmaraş Sütçü İmam University, School of Medicine, Department of Nursing Vocational School Kahramanmaraş, Turkey.

³Kahramanmaraş Sütçü İmam University, School of Medicine, Department of Ophthalmology Kahramanmaraş, Turkey.

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Corresponding Author / Sorumlu Yazar: Ömer Faruk Boran
E mail: ofboran@ksu.edu.tr

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ABSTRACT

Objective: The aim of this study was to investigate the attitudes of patient relatives about organ donation for patients with brain death diagnosis and to identify the cause of negative attitudes related to donation.

Methods: A retrospective examination was made of the archived records of patients with brain death (BD) diagnosis from September 2007 to August 2018 in Anesthesia Reanimation Intensive Care Unit. Demographic factors of the cases with BD such as age, gender, and admission diagnosis were recorded. The patient families were then contacted by telephone and organ donation acceptance or rejection was assessed in terms of reasons.

Results: A total of 86 cases with brain death diagnosis were identified. When cases were assessed in terms of admission diagnoses, post-CPR hypoxic brain was the most common diagnosis (30.2%). The organ donation rate was identified as 12.8% (n=11). The mean age of patients was 31.09±20.98 years in those who donated organs, and 35.62±21.45 years in those whose families rejected donation (p=0.614). When the factors causing brain death of patients with organ donation were assessed, 54.4% died due to traumatic reasons. The two most important factors identified in the study for families rejecting organ donation were religious beliefs (41.3%) and beliefs about not disrupting the integrity of the body after death (37.3%). The most important factor for acceptance was the wish to help other people (91%).

Conclusion: In our study, religious beliefs were found as the main reason for rejection of organ donation. To be able to increase cadaver-sourced donation rates, there is a need for society to be informed by religious leaders, family interviews should be held with an experienced and trained organ donation co-ordinator and families should definitely be fully informed about the sensitivity shown to bodily integrity during the organ donation procedure and surgical procedures.

Key words: brain death, transplantation, tissue and organ procurement, rejection

ÖZ

Amaç: Çalışmanın amacı beyin ölümü tanısı konulan hastaların yakınlarının organ bağıışı ile ilgili tutumunu incelemek ve bağıışla ilgili olumsuz tutumların nedenlerini tespit etmektir.

Gereç ve Yöntemler: Retrospektif desende tasarlanan çalışma kapsamında, Eylül 2007 ve Ağustos 2018 tarihleri arasında Anestezi Yoğun Bakımda beyin ölümü tanısı alan hastaların arşiv kayıtları incelenmiş, beyin ölümü gerçekleşen hastaların yaş, cinsiyet, yatış tanıları gibi demografik özellikleri incelenmiştir. Hastaların ailelerine telefonla ulaşılmış, ailelerin organ nakli kabul ve ret nedenleri değerlendirilmiştir.

Bulgular: Yapılan arşiv incelemesi sonucunda beyin ölümü tanısı konmuş olan 86 olgu tespit edilmiştir. Olgular yatış tanıları açısından değerlendirildiğinde post CPR hipoksik beyin'in en sık görülen tanı (%30.2) olduğu görülmüştür. Organ bağıışı oranının %12.8 (n=11) olduğu tespit edilmiştir. Organ bağıışında bulunan hastaların ortalama yaşları 31.09±20.98, aileleri tarafından organ bağıışında bulunulmayan hastaların yaş ortalamaları ise 35.62±21.45 olarak belirlenmiştir. Organ bağıışı yapılan hastalarda beyinin ölümüne neden olan faktörler değerlendirildiğinde, %54.5'inin travmaya bağılı sebeplerden beyin ölümü gerçekleştiği görülmüştür. Çalışma sonucunda, beyin ölümü tanısı ile yüzleşen ailelerin organ naklini reddetmesindeki en önemli nedenler; dini inanışlar (%41.3) ve ölümden sonra vücut bütünlüğünün korunması gerekliliğine olan inanç (%37.3) olarak belirlenmiştir. Organ naklini onaylayan ailelerin kararları değerlendirildiğinde, en önemli kabul nedeninin yardım gereksinimi olan başka insanlara faydalı olma arzusu (%91) olduğu görülmüştür.

Sonuç: Çalışmamızda ana ret nedeni olarak dini inanışlar bulunmuştur. Kadavra kaynaklı bağıış oranlarının artırılması amacıyla din adamlarının da desteğiyle toplumun bilinçlendirilmesine yönelik eğitimlerin düzenlenmesi, aile görüşmelerinin deneyimli ve eğitilmiş bir organ nakli koordinatorünün kontrolünde yapılmasıdır. Aile ile yapılan görüşmelerde organ nakli sürecinde ve cerrahi işlem sırasında hastanın vücut bütünlüğünün korunmasına hassasiyet gösterileceği vurgusunun yapılması gerekmektedir.

Anahtar sözcükler: Beyin ölümü, transplantasyon, doku ve organ bağıışı, reddetme

Introduction

Although studies researching public behavior in recent years have found that 95% of the population know about organ donation and 60-70% are willing to donate organs, according to World Health Organization data, donor numbers have remained relatively stable despite an increase in organ donation throughout the world in general. This situation leads to problems that require solutions by professionals dealing with organ donation (1). According to previous studies, the basic problems resulting in the rejection of organ donation by families can be studied under a variety of headings, such as social and cultural beliefs, insufficient information about brain death (BD) and organ donation procedures provided by the transplantation team, fears about disrupting the body integrity of the potential organ donor after death, misunderstandings about the concept of brain death and fear of objection by other family members (1-7). Pivotal variables such as race, ethnicity, and religion make it difficult to maintain a firm strategy to increase family consent based on the patterns of the reasons for refusal (6).

The aim of this study was to examine the attitudes, behavior and knowledge related to organ donation of the families of patients diagnosed with brain death and to determine the reasons for negative attitudes to organ donation.

Material and Methods

Approval for the study was granted by the Clinical Research Ethics Committee of the University (approval dated 10/10/2018, session number 2018/18, decision number: 13). A retrospective review was made of the data of patients in the Anesthesia Reanimation Intensive Care Unit of this tertiary level hospital between September 2007 and August 2018. Data were obtained from patient discharge summaries, intensive care daily monitoring forms and observation papers in patient files and computer records in the hospital archive. Patients with missing data were excluded from the study. The study was planned in two different stages.

The first stage included the demographic features of cases with BD such as age, gender, blood type and admission diagnosis, the duration from clinical suspicion of the onset of BD until the report was finalized, additional tests applied, family organ donation rate, donor rate, number of organs removed and duration from BD diagnosis until cardiac arrest of cases who were not donors. The second stage involved telephone contact with the families of patients with BD to evaluate the families in terms of reasons for avoiding organ donation including views about organ donation, religious beliefs, unstable family mood, expectation of a miracle, worries about organ trade, parental rejection of organ donation, beliefs about bodily integrity after death and fears of objection from other family members.

Statistical analysis

Data obtained in the study were analyzed statistically using the Statistical Package for the Social Sciences 17.0 software (SPSS, Armonk, NY, USA). Variables were stated as mean, minimum-maximum and percentage. In the comparisons of two independent groups, the independent samples T test was applied. Quantitative data are shown in the tables as mean \pm standard deviation (SD) and median-range (minimum-maximum) values. A value of $p < 0.05$ was accepted as statistically significant.

Results

During the study duration, the total number of patients admitted to the anesthesia intensive care unit was 2944 and brain death diagnosis was made for a total of 86 patients. The demographic data of the patients with BD diagnosis are presented in Table 1. When the cases were assessed in terms of admission diagnosis, post-CPR hypoxic brain (30.2%) was the most common diagnosis. The BD diagnosis was made on the basis of clinical findings and the apnea test, which was administered to all except 1 patient. In 5 patients, the apnea test could not be completed. The duration from time of admission to BD tests was 5.52 ± 3.54

Table 1. Demographic features of the participants.

Demographic features	Patients developing BD (total group) n=86		Patients developing BD				p
			Non-donor n=75		Organ donor n=11		
	M \pm SD		M \pm SD		M \pm SD		
Age (Years)	34.11 \pm 21.29		34.62 \pm 24.45		31.09 \pm 20.98		0.614
Duration between clinical suspicion of BD to time of diagnosis (hr)	51.57 \pm 25.92		39.45 \pm 15.34		58.09 \pm 27.07		0.110
Gender (Male)	n	%	N	%	n	%	0.072
	45	52.3	39	52.0	5	45,5	
Admission diagnosis	TBI	15	17.4	9	12.0	6	54.5
	Brain tumor	8	9.3	8	10.7	0	0
	CVD	14	16.3	13	17.3	1	9.1
	Post CPR	26	30.3	22	29.3	4	36.4
	Other	23	26.7	23	30.7	0	0

BD; Brain death, CVD; Cerebrovascular disease, CPR; Cardiopulmonary resuscitation, TBI; Traumatic brain injury, M; Male

Table 2. Demographic data and organ transplant acceptance and rejection reasons for families interviewed about organ donation.

Patient relative characteristics		Rejecting families		Accepting families		p
		N	%	n	%	
Educational status	None	13	15.1	1	9.2	0.7 46
	Primary school	19	22.2	4	35.6	
	Middle school	18	20.1	3	27.6	
	High school	21	24.5	3	27.6	
	University	4	4.7	0	0	
Reason for rejecting organ donation	Religious beliefs	31	40.4			
	Expectation of a miracle	6	8.8			
	Parental denial of organ donation	3	3.9			
	Misinformation about brain death	2	2.6			
	Belief about the integrity of the body after death	29	38.7			
	Fear of objections from other family members	4	5.6			
Reason for accepting organ donation	The desire to keep other families' children alive			1	9.0	
	To help people			10	91.0	

days. The duration to completion of the brain death tests was 51.57 ± 25.92 hours. When patients were grouped as those patients whose families accepted and rejected organ donation, the duration to completion of BD tests for patients whose families gave permission (39.45 ± 15.34) was shorter compared to patients whose families rejected donation (58.09 ± 27.07), with no statistically significant difference determined ($p=0.110$). Of the 86 patients with BD diagnosis, 12.8% ($n=11$) of the families accepted organ donation. The mean age of patients was 31.09 ± 20.98 years in those whose families donated organs, and 35.62 ± 21.45 years in those whose families rejected donation ($p=0.614$). The patients whose families donated organs comprised 45.5% males and the non-donor patients were 48% males ($p>0.05$). When the organ donor patients were examined in respect of cause of brain death, trauma was determined in 54.5%. In the non-donor patients, the leading cause of death was BD developing following cardiopulmonary resuscitation (CPR) (Table 1).

The two most important factors determined in the study as the reasons for families rejecting organ donation were religious beliefs (41.3%) and beliefs about not disrupting bodily integrity after death (37.3%). Other reasons for the rejection of organ donation reported by the families were parental rejection of organ donation, misinformation about brain death and fear of objections from other family members (Table 2).

When the decisions of relatives of cases consenting to organ donation were assessed, the most important acceptance factor was to be of benefit to other people (91%) (Table 2). One of the important elements noted in the study was that four families who consented to organ donation had initially rejected donation. Of these families, two changed their decision in 24 hours, one in 16 hours and one 3 hours later, and accepted donation.

Discussion

As throughout the whole world, in spite of an increasing number of patients waiting for transplants in Turkey, patients on waiting lists are negatively affected due to the scarcity of cadaver-sourced organs (8,9). The success of the organ transplant process depends on the balanced maintenance of two different processes by organ transplant professionals. The first is the appropriate medical management of potential donor candidates and the second is the good preparation of family members about the process at the point of decision, with accurate and sufficient information given in a short time ensuring the transplant process will not be interrupted once initiated (4,5,10,11). Consequently, this study was conducted in two parts. In the first stage, cases with BD were briefly evaluated. In the second stage, the families of the patients were assessed in terms of the organ transplant process and the reasons for families rejecting donation were investigated.

In our clinic, a total of 86 patients received a BD diagnosis between September 2007 and August 2018. The families of only 12.8% ($n=11$) patients with BD diagnosis consented to organ donation. A study by Karasu et al. (7) found that BD developed in a total of 79 cases in the adult and pediatric intensive care unit (ICU) during a 7-year period and the families of 27 (32.4%) of these patients accepted organ donation. Battal et al. (10) reported 62 BD diagnoses during a 5-year period and 29% ($n=18$) were organ donors. A study by Güzeldag et al. (11) found a total of 93 patients developed BD during a 7-year period, but the data of 33 patients was not available or due to the study conditions, 60 patients were included in that study. It was reported that 40% of families accepted organ donation. These studies were conducted in industrialised regions of Turkey (Ege and Marmara) with a high sociocultural level, but studies by Halitoğlu et al. (8) in a region similar to that of the current study in terms of distance and sociocultural levels, found transplant acceptance rates (11.9%) similar

to those of the current study. Compared with other reports in literature, the organ transplant acceptance rate in the current study appears very low. The above-mentioned studies were conducted in regions of Turkey that are economically developed with a high educational level, so the situation can be considered to be linked to regional differences and the experience of hospital personnel shows an awareness that it cannot be explained by a single reason. Thus, in the family section of the discussion, families were assessed in terms of educational level, and humanitarian and religious views about the transplant process.

When patients developing BD were assessed in terms of diagnoses, different classifications and very different reasons have been identified in literature (6-11). Karasu et al. (7) stated that the most important etiological factor was intracranial hemorrhage (47%) while Battal et al. (10) reported traumatic reasons (58%). In the current study, the most important etiological factor was post-CPR hypoxic brain development. When the organ donor patients were assessed in terms of etiological factors, patients developing BD due to traumatic causes (54.5%) were the most common donors. Results in literature have shown that patients with brain death due to trauma are reported to have high organ donation rates, while Güzeldağ et al. (11) reported that organ transplant acceptance rates were high among patients with BD developing due to trauma (48.3%). The current study results are consistent with the literature.

In spite of the statement by the Organ and Tissue Transplant Services of Turkey Directive dated 20 August 1993 that "if organ donation permission is not obtained after BD is declared to patient relatives, medical support of the patient will be withdrawn", this item was suspended from the directive dated 1 February 2012 and it was not stated who would make the decision that medical support treatment should be withdrawn from cases rejecting organ donation (12). Halitoğlu et al. (8) reported that patients developing BD with organ donation rejected by the families were supported until cardio-circulatory arrest developed and emphasized that due to the limited number of beds in intensive care and the expense of intensive care treatment, the authority to withdraw support treatment should be given to doctors. In our clinic, the families of 4 patients developing BD (36.3%) initially decided against organ donation but changed their minds within the first 24 hours and consented to donation. While agreeing with the interpretation of Halitoğlu et al. (8) on this topic, even if patient relatives make a negative decision initially, it should be considered that they may change their minds so we believe that even if clinicians decide to withdraw support they should be flexible about making the decision.

Studies assessing organ transplant consent of families after BD in recent years have focused on the early placement of BD diagnosis (4,9,12,13). A study by Kıraklı et al. (9) found the BD definite diagnosis was made significantly earlier in cases where families accepted organ donation. Halitoğlu et al. (8) also reported a short duration for cases accepting organ donation, although the difference was not statistically significant. Studies by Lustbader et al. (14) reported that the donor rate fell from 57% to 45% for patients with a prolonged BD diagnosis process. In the current study, although the BD diagnosis duration was short for patients

with family consent, this difference was not significant, similar to the findings of Halitoğlu et al (8). It can be considered that this situation may be linked to the low numbers of patients accepting organ transplant.

Studies investigating organ transplant rejection by families include differences related to the nationality, religion and educational level of donor families (1-6). The results of studies performed in the same country may be affected by many variables based on developed (5,9,11) or undeveloped regions (4). The current study was conducted in a region that may be classified as moderate-low in terms of development rates. Interviews with primary relatives in the position to decide about organ transplants from patients developing BD assessed the family educational level. It was determined that 14.3% were illiterate, 24.7% had a primary school level of education and only 4 responsible relatives were university graduates. Martinez et al. (15) emphasized that family educational level was an effective factor on organ donation by potential donor families. It can be understood from the study results that the educational level of the patient families was very low and this can be considered to have had a significant effect on the transplant rates being below the average for Turkey.

Ghorbani et al. (5), in their study on 81 families who refused organ transplantation, stated that the most important reason for refusal was rejection and denial of brain death of their patient.

Another important point emphasized in that study was the difficulty of the general population in understanding BD. In fact, Ghorbani et al. (5) emphasized that this situation was not even fully understood by health workers. Studies in the Middle East have emphasized that religious beliefs and fatwa against organ donation are the most important obstacles to organ donation (15-17). In their study, Aldawood et al. (16) emphasized that the concept of brain-death and organ transplantation received a real impetus in the year 1982 with the approval given by Islamic scholars, but there has been a decline in the rate of organ donations in Saudi Arabia in early 2000 compared to the 1990s, because of a local fatwa from few scholars in Saudi Arabia that discouraged organ donation.

In a study by Mojtabae et al. (18) that evaluated the reasons for rejection of organ donation before 2009 (n:81) and in the period 2015-2016 (n:55), although the rejection rates were lower compared to 2009 (44.4% vs 12.7%), the rate of rejection due to religious beliefs increased significantly in the period 2015-2016 (8.6% vs 43.6%). It was discussed that this rate could be decreased if religious groups were integrated in the process and especially the clerics in close contact participated effectively in the process.

In the current study, the most significant reason for rejection of organ donation stated by the families was religious beliefs. This subject was evaluated in detail by the Muslim Legal Council of the United Kingdom at a meeting in 1996, and on the basis of the verse in the Koran that states "Whosoever saves the life of one person, it would be as if he saved the life of all mankind.", it was decided that organ transplantation was fully compatible with Islam. However, in societies where the vast majority are Muslim, the rates of cadaver-sourced organ transplantation are still not at

the desired level (19).

However, in eastern societies with different beliefs, religious teachings seem to be important in the organ transplantation process. For example, in Japan where Shinto is predominant, it is believed that as the body is pure and foreign bodies are accumulated throughout life, intervention to a cadaver will bring bad fortune. For all these reasons, the harvesting of organs from BD donors was only legalized in 1997 and the first heart transplant was performed 2 years later in 1999 (20).

In this study, conducted in a majority Muslim population, 40.4% (belirtilmeli) rejected organ transplantation for religious reasons in particular, and almost half of the families did not even wish to discuss their reasons for rejection. One of the points on which those who believe that organ transplantation is not appropriate is based on the rule in some religions, such as Islam, Judaism and Shintoism, that violation of the human body is absolutely forbidden. In many studies conducted in different societies, this has emerged at a low or high frequency among the reasons for rejection of organ transplantation (19-21). In the current study, the thought of not disturbing the integrity of the body after death was observed at as high a rate as religious beliefs in the reasons for rejecting organ donation.

Studies in literature have generally focused on the reasons for rejecting organ donation. However, another point which is just as important as the reasons for rejection is the reasons of families who consent to organ donation. At this point it should be considered that the organ transplantation process is better understood by families who accept the process and the factors should be examined that facilitate the acceptance of transplantation. The primary of these is humanistic traits. Family members in this emotional situation empathise with others who are waiting for organs and

wish to make them happy by removing the problems that they are experiencing (21). In the current study, when the families who consented to organ donation were evaluated, it was seen that the predominant thought was to be of help to other people. In a study by Yousef et al, other factors emphasized as important were reported to be the desire for the deceased person to continue living in another person and the belief that the deceased would reach spiritual fulfillment (21).

Conclusion

In this study, conducted in a majority Muslim population, evaluation was made of a total of 86 families of patients who developed brain death in the Anaesthesia Intensive Care Unit of Kahramanmaraş Sütçü İmam University Medical Faculty Hospital between 2007 and 2018. Of this group, only 11 families accepted organ transplantation and a total of 75 families rejected organ transplantation for religious reasons in particular, and almost half of the families did not even wish to discuss their reasons for rejection.

There is no single reason at the basis of rejecting organ donation and it should be remembered that it is affected by many national and regional variables. Considering organ waiting lists in the world in general, to increase the relatively low cadaver-sourced donation rates, social media should be used, with society informed by religious leaders and religious beliefs should be corrected. In addition, after rapidly and consistently establishing a BD diagnosis, family interviews should be held with an experienced and trained organ transplant coordinator and families should be sufficiently informed about the sensitivity to bodily integrity during the organ transplant process and during surgical procedures. If all these steps can be ensured, even if the problem is not fully solved, important steps will have been taken on the path to solutions.

AUTHOR CONTRIBUTIONS:

Concept: ÖFB; HÖ; DS; **Design:** AU; BB; YO; SU; **Supervision:** ÖFB; HÖ; AU; BB; **Resources:** ÖFB; HÖ; DS; AU; BB; YO; SU; **Materials:** ÖFB; HÖ; DS; BB **Data Collection and/or Processing:** ÖFB; HÖ; DS; AU; SU; **Analysis and/or Interpretation:** HÖ; BB; YO; SU; **Literature Search:** ÖFB; DS; AU; YO; SU; **Writing Manuscript:** ÖFB; DS; AU; SU; **Critical Review:** HÖ; BB; YO.

YAZAR KATKILARI:

Fikir: ÖFB; HÖ; DS; **Tasarım:** AU; BB; YO; SU; **Denetleme:** ÖFB; HÖ; AU; BB; **Kaynaklar:** ÖFB; HÖ; DS; AU; BB; YO; SU; **Malzemeler:** ÖFB; HÖ; DS; BB; **Veri Toplanması ve/veya İşlemesi:** ÖFB; HÖ; DS; AU; SU; **Analiz ve/veya Yorum:** HÖ; BB; YO; SU; **Literatür Taraması:** ÖFB; DS; AU; YO; SU; **Yazıyı Yazan:** ÖFB; DS; AU; SU; **Eleştirel İnceleme:** HÖ; BB; YO.

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Informed Consent: Written informed consent was obtained from relatives of patients or patients who participated in this study.

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