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Attitudes and Awareness Towards Organ Donation Among Parents of Pediatric Brain Death Patients in a Pediatric Intensive Care Unit in Eastern Turkey

Authors' Contribution:

Study Design A
Data Collection B
Statistical Analysis C
Data Interpretation D
Manuscript Preparation E
Literature Search F
Funds Collection G

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Background: The real causes of organ donation refusal decisions of parents after pediatric brain death and the factors that most influence their decisions are not known sufficiently in Turkey. This study aimed to investigate the detailed factors that may be relevant to parents' refusal, including their education level and knowledge about organ donation.

Material/Methods: Between August 2017 and September 2018, parents who had been asked to allow organ donation from their deceased child were included in this study. An appointment for a home visit for administration of a questionnaire was arranged with the families for the purpose of giving their consent to the study. The questionnaire included items on parents' demographic data, education level, knowledge about organ donation, and the underlying causes of donation refusal.

Results: The study included 24 parents (12 mothers and 12 fathers) of 13 pediatric patients because the mother of one patient and the father of another died before their child's brain death. The rate of illiteracy in the parents was 33.3% and only one (4.2%) parent had graduated from university. The rate of knowledge about organ donation was 70.9%, and the most common source of information was television programs (35.9%). All parents remarked on their insufficient information about organ donation. The two most common reasons for organ refusal were unwillingness to allow damage to the child's internal organ integrity (28.7%) and thinking that their child would feel pain at the time of organ donation (21.2%).

Conclusions: The most important reasons relevant to parents' organ donation refusal are the parents' low level of education and insufficient information about brain death and organ donation. The unwillingness to allow impairment of their child's internal organ integrity and thinking that their child would be in pain at the time of organ donation were the most common reasons.

MeSH Keywords: Brain Death • Child • Parents

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Background

Organ transplantation (OT) is a widely accepted lifesaving intervention for patients with end-stage organ failure. Despite organ donation (OD) policies and favorable outcomes, the shortage of donated organs continues to be a leading factor limiting pediatric OT. In addition to the refusal of OD by parents, inadequate size matched brain death (BD) diagnosis in younger children is another important factor limiting OT in pediatrics [1,2]. It is difficult for families to accept OD immediately after the death of their child. Therefore, family interviews must be managed while being aware of the emotional and mental conflict of the family. Hence, supporting them by establishing a conscious communication throughout the process is paramount [3].

Despite Turkey's leading status in worldwide living organ donors, the cadaveric transplant rates remain very low [4–6]. The International Registry in Organ Donation and Transplantation data in 2017 revealed that living donors, in contrast to cadaveric donors, per million population were 47.5 and 7, respectively [6]. The real causes of OD refusal of parents after pediatric BD and the factors that most influence their decisions are not sufficiently known in Turkey.

The primary aim of this study was to investigate the detailed factors that may be relevant to parents' refusal, including their education and knowledge about OD and OT. Information about underlying causes of their refusal and awareness of OD might help to guide the design and implementations of more effective community education and donation request strategies.

Material and Methods

This study was approved by the Ethics Committee of Noninvasive Clinical Research at the University of Health Sciences, Van Research and Training Hospital on 4 October 2018 (Approval No: 2018/14). This study was conducted between 5 October 2018 and 5 November 2018 in the Clinics of Pediatric Intensive Care Unit, which is a referral center in the Eastern region of Turkey. We included parents who had been asked to donate their deceased children's organs between August 2017 and September 2018.

Data collection

The predefined clinical data were obtained from the medical records and institutional databases. The parents were informed about the aim of this study via phone calls. An appointment for a home visit to administer the questionnaire was arranged with the families for the purpose of receiving their consent to participate in the study. In the home visits, before implementing the questionnaire, signed informed consent was obtained

from each parent after explaining the purpose of the study. Parents who could not be contacted via phone calls and those who did not consent to participate in the study were excluded. The questionnaire was designed to collect data on parents' demographics, educational level, knowledge about OD and OT, and the underlying causes of their refusal to allow OD from their children (Table 1).

Statistical analysis

Statistical analyses were performed using SPSS (Chicago, IL, USA), version 20. Data on continuous variables that were normally distributed are presented as mean±standard deviation, and data on non-normally distributed continuous variables are presented as median (minimum–maximum). Categorical variables are presented as frequency and percent.

Results

During the study period, the diagnosis of BD was made for a total of 16 patients. The parents of all 16 patients refused OD. Table 2 shows patient demographic data, as well as the methods and the criteria used to diagnose BD. The parents of three patients were excluded from the study; one set of parents could not be contacted via phone calls, and the other two sets of parents stated that did not want to relive their painful experience and refused to be included in the study. The study included 24 parents (12 mothers and 12 fathers) of the 13 patients because the mother of one patient and the father of another patient died before their child's BD. The mean duration of time between diagnosis of BD and implementation of the questionnaire was 7.2±4.2 months (range, 1–15 months). The demographic characteristics, the level of education, and the knowledge about OD/OT, along with the reasons for OD refusal, are presented in Table 3. The rate of illiteracy in the parents was 33.3%, and only one (4.2%) parent had graduated from university. The rate of knowledge about OD was 70.9%, and the most common source of information was television programs (35.9%). All parents mentioned their insufficient knowledge about OD. The two most common reasons for organ refusal were unwillingness to impair their child's internal organ integrity (28.7%), and thinking that their child would feel pain at the time of OD (21.2%). Five (20.8%) parents expressed regret for not giving consent to OD.

Discussion

In the current study, unfortunately, none of the parents gave consent for OD. In our opinion, the low level of education had a considerable impact on this decision. Among the parents included in the study, 33.3% were illiterate, 16.6% had dropped

Table 1. Data on parents' demographics, education level, knowledge about organ donation/transplantation, and underlying causes of organ donation refusal.

| |
|--|
| 1. The name of the child diagnosed with brain death |
| 2. Would you like to participate in this study and answer the questions in the questionnaire? |
| a. Yes |
| b. No |
| i. I don't want to feel that sadness again. |
| ii. I don't have enough time to fill out the questionnaire. |
| iii. I don't give consent to be included in this study. |
| iv. Other: |
| 3. Your relationship to the child |
| 4. Your education level |
| 5. Your age |
| 6. Did you have any knowledge about organ donation before your child's brain death? |
| a. Yes |
| b. No |
| 7. If your answer is "Yes" to question 6, what was the source of information about organ donation? |
| a. Educational establishment |
| b. Television programs (educational programs, movies, series, etc.) |
| c. A public spot between the advertisements on television |
| d. Radio |
| e. Newspapers and/or journals |
| f. Friends, relatives, or neighbors |
| g. Religious official |
| h. Healthcare professionals or brochures in health institutions |
| i. Billboards or brochures of government agencies apart from health institutions |
| j. Friends, relatives, or neighbors who were waiting for organ donation |
| k. Other: |
| 8. Were you given any information about organ donation from your family physician or family practice center? |
| a. Yes |
| b. No |
| 9. Do you believe in benefits of organ donation? |
| a. Yes |
| b. No |
| 10. Do you know any people awaiting organ donation? |
| a. Yes |
| b. No |
| 11. Do you think that you have enough information about organ donation or transplantation? |
| a. Yes |
| b. No |
| 12. What is/are the underlying reason(s) for your refusal of organ donation? (You can choose more than one choice) |
| a. I don't believe that brain death and real death are the same. I thought that there could be a miracle, and my child could get well. |
| b. I couldn't think clearly about organ donation because of my sadness. |
| c. I didn't want the integrity of my child's body to be compromised. |
| d. I thought that my child would have suffered during the donation procedure. |
| e. I thought that donation is a sin according to my faith. |
| f. An elder in our family who I asked for advice has refused organ donation. |
| g. I didn't give consent according to the religious authorities, clerics, or imams. |
| h. I was scared of criticism from society. |
| i. I had a different opinion from my partner. If my partner had accepted the donation, I would have accepted. |

Table 1 continued. Data on parents' demographics, education level, knowledge about organ donation/transplantation, and underlying causes of organ donation refusal.

| |
|--|
| j. If I had known the child patients who needed organ transplantation, I would have donated my child's organs. I thought that my child's organs would have been given to privileged or wealthy people rather than to those who were really in need. I did not trust healthcare professionals about this issue. |
| k. Other: |
| 13. Are you remorseful about your organ refusal decision? |
| a. Yes, explain why?..... |
| b. No |
| 14. Would you consider donating your own organs in the future? |
| a. Yes |
| b. No |

Table 2. The demographic data, the methods, and the criteria used to diagnose brain death.

| Patients | Age (year) | Gender | Diagnoses for PICU hospitalization | Day of the BD after hospitalization | The test for the diagnosis of BD |
|----------|------------|--------|---|-------------------------------------|----------------------------------|
| 1 | 4 | M | CA secondary to LRTI (after CPR) | 7 | AT |
| 2 | 8 | F | Vomiting secondary to ileus. Respiratory and CA secondary to aspiration pneumonia (after CPR) | 3 | AT |
| 3 | 7 | F | Respiratory and CA secondary to SE (after CPR) | 3 | AT |
| 4 | 1 | M | CA secondary to respiratory insufficiency (after CPR) | 7 | AT |
| 5 | 0.5 | F | Hydrocephalus, respiratory and CA secondary to aspiration pneumonia (after CPR) | 3 | BCTA |
| 6 | 9 | F | Meningomyelocele, unexplained sudden CA (after CPR) | 2 | AT |
| 7 | 14 | F | STBI (after CPR) | 2 | AT |
| 8 | 1 | F | Fulminant myocarditis | 4 | AT |
| 9 | 18 | F | Suicide by hanging (after CPR) | 2 | AT |
| 10 | 4 | F | STBI | 3 | AT |
| 11 | 3 | F | Respiratory and CA secondary to SE (after CPR) | 3 | BCTA |
| 12 | 4 | F | Respiratory and CA secondary to severe croup (after CPR) | 3 | AT |
| 13 | 1 | M | Hydrocephalus, respiratory and CA secondary to aspiration pneumonia (after CPR) | 3 | AT |
| 14 | 9 | M | Intracranial hemorrhage | 2 | AT |
| 15 | 4 | M | STBI (after CPR) | 2 | AT |
| 16 | 6 | F | CA secondary to LRTI (after CPR) | 3 | AT |

AT – apnea test; BCTA – brain computed tomography angiography; CA – cardiac arrest; CPR – cardiopulmonary resuscitation; F – Female; LRTI – lower respiratory tract infection; M – Male; PICU: –Pediatric Intensive Care Unit; SE – status epilepticus; STBI – severe traumatic brain injury.

Table 3. Demographic data, education level, knowledge about organ donation/transplantation, and underlying causes of the refusal of organ donation.

| | | |
|---|----------------------|---------|
| Number of participants | 24 | |
| Number of mothers | 12 | (50%) |
| Mean age (year) | 34.7±9.3 (21.3–52.6) | |
| Level of education | | |
| Illiterate | 8 | (33.3%) |
| Early drop out from elementary school | 4 | (16.6%) |
| Elementary school graduate | 6 | (25%) |
| Secondary school graduate | 1 | (4.2%) |
| High school graduate | 4 | (16.6%) |
| University graduate | 1 | (4.2%) |
| Parents having knowledge about organ donation | 17 | (70.9%) |
| Source of information in parents who had knowledge about organ donation | | |
| Educational establishment | 0 | (0%) |
| On television programs (educational programs, movies, series, etc.) | 14 | (35.9%) |
| A public spot between the advertisements on television | 4 | (10.2%) |
| On radio | 0 | (0%) |
| Newspapers or journals | 3 | (7.7%) |
| Friends, relatives, or neighbors | 5 | (12.8%) |
| Religious official | 1 | (2.5%) |
| Healthcare professionals or brochures in health institutions | 6 | (15.4%) |
| Billboards or brochures in government agencies apart from health institutions | 6 | (15.4%) |
| Friends, relatives, or neighbors who are waiting for an organ donation | 0 | (0%) |
| Internet | 0 | (0%) |
| Parents who had had information from family practice centers | 0 | (0%) |
| Parents who favor organ donation | 20 | (83.3%) |
| Parents who had relatives on a transplantation waiting list | 0 | (0%) |
| Parents who thinks that their knowledge about organ donation is adequate | 0 | (0%) |
| The reasons for the parents' refusal to donate their child's organ | | |
| – I don't believe that brain death and real death are the same. I thought that there could be a miracle, and my child could get well. | 13 | (16.2%) |
| – I couldn't think clearly about organ donation because of my sadness. | 11 | (13.7%) |
| – I didn't want my child's bodily integrity to be compromised. | 23 | (28.7%) |
| – I thought that my child would have suffered during the donation procedure. | 17 | (21.2%) |
| – I thought that donation is a sin according to my faith. | 4 | (5%) |
| – An elder of our family who I asked for an advice has refused. | 3 | (3.7%) |
| – I didn't give consent due to the religious authorities, clerics, or imams. | 0 | (0%) |
| – I was scared of criticism from society. | 2 | (2.5%) |
| – I had a different opinion from my partner. If my partner had accepted the donation, I would have accepted. | 1 | (1.2%) |
| – If I had known the child patients who needed organ transplantation, I would have donated my child's organs. I thought that my child's organs would have been given to privileged or wealthy people rather than to those who were really in need. I did not trust healthcare professionals about this issue. | 6 | (7.5%) |
| Parents who regret refusal to donate their child's organ | 5 | (20.8%) |
| Parents who wish to donate their own organs in the future | 15 | (62.5%) |

out of elementary school, and 25% had graduated from elementary school. In the literature, the relationship between parents' level of education and acceptance of OD is conflicting. While one study revealed a direct correlation [7], another showed an indirect correlation [1], and others showed no influence [8,9]. We did not have an opportunity to evaluate this relationship in the present study because none of the parents gave consent to OD. A questionnaire administered to 414 citizens in Turkey showed that, the rate of volunteering to allow pediatric OD was higher in people with a high level of education compared to people with low educational levels [10].

Many of the parents (70.9%) in the present study were aware of OD before their child's BD, but all the parents indicated they felt they had insufficient information about OD. Previous Turkish studies have found that the level of information about OD is insufficient, even among healthcare professionals [11–13]. Television programs are the first-line source of information (35.9%) regarding OD and OT. Additionally, it was also shown that the rates of acquiring information from public service ads on television, family practice centers, religious officials, radio programs, and the internet are very low.

Due to the participants' relatively low level of education, the low rate of information given by the educational establishment could not objectively indicate the reality. The results of the current study may help increase the rate of cadaveric OT, which was promoted by the Ministry of Health of Turkey. We think that encouraging and emphasizing this subject through mass media, particularly television series, is of utmost importance. Öztürk et al. [4] reported that the parents of two of 10 patients with BD gave consent for OD. One of these two families emphasized that they were encouraged by a television series in which transplantation was performed using an organ from a patient with BD [4]. It will be possible, that along with the difficulties of life and living conditions of the children who are listed in transplantation, the number of television programs regarding BD and OD would be increased. In this regard, it could even lead to the production of cinema films. Organ donation is approved and promoted by the religious council in Turkey [14]. In addition, initiating an education program for Muslim religious officials this matter might increase willingness to allow OD.

In the current study, the unwillingness to impair a child's internal organ integrity (28.7%) and being afraid that their child would feel pain at the time of OD (21.2%) were the two most common reasons given by parents for their OD refusal. The important reasons for refusal of OD found in the current study were as follows: parents were unaware that BD is real death (16.2%), the inability to make appropriate decisions (13.7%), the anonymousness of the patient that will be transplanted, and thinking their child's organ will be given to

a privileged child instead of a patient who is in real need. A recent Turkish national study [15] administered a questionnaire to 202 non-medical academicians and found that 92.6% did not plan to be organ donors, and 25.7% of them stated that this was due to their lack of information about OD. Interestingly, among these academicians, 60.4% believed that OD was done for a financial gain, 52.5% believed that there is a partiality in transplantation lists, and 81.2% had a concern about illegal trading of organs and tissues [15]. Where possible, especially by the Ministry of Health of Turkey and other authorized organizations, the processes should be more transparent, and they should raise public awareness and make the transplantation list open-access to the public. The patients in the transplantation lists should be announced on television programs and, accordingly, a brief public disclosure should be made. Constant education on BD, OD, and its place in our religion for children in public schools at the appropriate time and syllabus would increase the rate of OD in the long-term. As shown in our study, this issue should come to the fore in media organizations, family practice centers, and mosques in order to increase the frequency of OD in the immediate future. In our study, 20.8% of the parents expressed regret regarding not donating their child's organs. Additionally, 62.5% stated that they would donate their own organs in the future. These outcomes showed that, in comparison to adults, it is more difficult to increase the rate of OD in pediatric patients.

The main limitation of our study is that the number of participants was low. Moreover, the low educational and socio-economic levels of our participants prevent generalization of our results to the country as a whole. We believe that multi-center studies with larger sample sizes are warranted. However, due to the methods and the subject of the present study, we believe that it is extremely valuable because it is a preliminary study in our country.

Conclusions

The rate of consent for OD given by the parents of BD children is very low. The most important reasons are the parents' low level of education and insufficient information on BD and OD. The unwillingness to allow impairment of their child's internal organ integrity and their consideration that their child will be in pain at the time of OD were the most common reasons. To increase the rate of OD in pediatric patients in the short-term and long-term, the state authority should set a deliberate course for public disclosure.

Conflict of interest

None.

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