

Update on Causes of Family Refusal for Organ Donation and the Related Factors: Reporting the Changes Over 6 Years

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ABSTRACT

Introduction. After significant improvement of the family consent rate to organ donation (OD) in recent years, owing to an increase in cultural activities and social awareness, a plateau has been reached. This study was performed to detect the causes for this plateau.

Methods. We reviewed exact causes of family refusal after providing a list of failed potential donors from July 2015 to December 2016. The expert coordinators responsible for handling the failed cases chose the cause of refusal from the previously prepared list. The list was rechecked by contacting the nondonating families by phone. The results were compared with those obtained from a similar group of families in 2009.

Results. In an 18-month period of OD practice, 353 potential brain dead organ donors were referred to our organ procurement unit. The mean age of the cases was 42.6, and 62% were male. The main causes of brain death were cerebrovascular accident and trauma (41.2% and 32.6%, respectively). The family consent rate was 84.4%, and 55 families rejected the request for OD. The leading cause for family refusal was religious beliefs, mainly from Sunni families (43.6% vs 8.6% in 2009). Brain death denial reduced significantly from 44.4% in 2009 to 12.7% in 2015 and 2016 ($P < .001$ for both causes). Opposite donor wishes, unstable family mood, the belief in body integrity, and expectation of a miracle were the other causes of no reportable changes.

Conclusions. After massive social activities in the media designed to enhance social awareness regarding brain death and OD, people currently do not doubt the irreversibility of death, as in the past. However, the noticeable increase in the consent rate has made the religious cause of family refusal prominent. Therefore, this cause seems to be the next barrier to fight against, requiring a careful approach to religious leaders and societies.

DESPITE advances in the field of regenerative medicine, organ transplantation from cadaveric donors is the best rescue therapeutic option for solid organ failure yet. However, to overcome the remaining organ shortage, improvement in the organ donation (OD) rate is required. Therefore, to increase the OD rate, a scientific approach to family consent as the main obstacle has made this field a point of focus [1,2].

Many organ procurement organizations have designed special programs to investigate and increase the rate of consent in their community [3,4]. Different strategies have been adopted, including training the family interviewers and public awareness enhancement programs through media or

social activities. Subsequently, identifying factors corresponding with family refusal and emotions are crucial to

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cover consideration points for the both target groups, interviewer, and relatives [5–7].

Several factors have been proven to influence the consent rate. Donor-related factors include gender, age, race/ethnicity, and previous wishes. Non-donor-related factors, such as the process of OD itself, interviewers' characteristics, the structure of the interview, the timing of the request for donation, and interactions between hospital staff and family members have also been introduced [1,2].

Overall, causes of family refusal vary by region [8–10]. 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 refusal causes [11].

Based on the previous study performed in our organ procurement unit in 2009, some causes of family refusal were evaluated [12]. The causes of family refusal are classified in Table 1. Accordingly, a big proportion of brain death denial (44%) and concern about organ trading, resulted in an enormous effort made to increase society's knowledge about brain death and donation process from donor detection to transplantation. Hoping to change the society's attitude toward brain death and organ trading, we designed this study to compare a new pattern of family refusal causes among our society. We also searched for the impact of donor age and number of influential family members on consent status.

METHODS

In 2009, our research group prepared a list of families with potential organ donors referred to our organ procurement unit who had refused OD and performed a retrospective study to assess the causes of refusal. In continuation of the previous study, we analyzed all cases referred for donation during an 18-month period between April 2015 and December 2016.

For each potential donor whose family declined OD, a pre-designed data form was completed by the expert coordinator responsible for handling the family interview process. Primary perception of the coordinator upon the cause of family refusal was among the considered data. After a period of 1 month, trained researchers with acceptable communication skills, contacted key members of each family by phone to confirm the causes using a semistructured interview method. If the reasons for refusal were

incompatible with the coordinators' perception, those cases were discussed in a session between all researchers and family interviewers, and a final decision was made.

Statistical Analysis

Upon collection, data were analyzed by SPSS/21 software (SPSS, Inc, Chicago, IL). Quantitative data were expressed as mean values \pm standard deviations, and qualitative variables were expressed in percent. The Kolmogorov-Smirnov test was conducted to verify adherence to the normal curve (normal distribution was not confirmed). Accordingly, the data were analyzed using the Mann-Whitney *U* test, considering a significance level of 0.05.

We stratified donors by age into 3 clusters: 0 to 20, 21 to 55, and >56 years of age. To compare family consent rate among different age clusters, the χ^2 test was used. Kendall's tau-b test was used to examine any correlation between the number of family members and consent status owing to lack of normality of the variable. The entire statistical tests were performed in 2 ranges at a 5% significance level.

RESULTS

A total of 612 brain-dead cases were assessed for donation during the 18-month analysis period. In this regard, a total of 360 (58.8%) were eligible for donation, and the family was approached in all of these cases. In 7 cases (1.9%), the family approach was excluded from the analysis owing to unclear ethnicity or data missing. Among all family interviews, 55 families rejected the request. In other words, in 2015 and 2016, the overall consent rate was 84.4%, in comparison with 52% in 2009 ($P < .05$). Among these cases, 4 were ineligible to become organ donors after family consent owing to organ failure. Overall, 294 ODs occurred during this period.

The mean age of the cases was 37.8 ± 13 and 62% were male; in 2009, the mean age of candidates was 32 ± 8 years and 72% were male. Neither significant differences were noted for the average age or for the gender ($P > .05$).

In refusal group, the gender mode and the mean age were the same as of the donors or consent group (57.7% vs 60% male, respectively; $P = .3$) as well as the mean age (39.3 ± 13.3 years vs 36.9 ± 11.1 years, respectively; $P = .2$). However, when broken down into 3 age clusters, middle-aged potential donors were less likely to be actual donors in comparison to the 2 edges of the age spectrum ($P < .001$; Fig 1).

Causes of brain death were mainly cerebrovascular accident (41.2%) and trauma (32.6%). There were no differences regarding the cause of brain death (medical or surgical) concerning family consent by the χ^2 test ($P = .08$). The leading cause of family refusal was religious beliefs, whereas brain death denial reduced significantly. Table 1 describes causes of family refusal and their comparison with those obtained in 2009.

The Number of Family Members

Besides overall difference of number of family members in the consent and refusal groups, it was higher in the middle aged potential donors ($P < .001$) using the Kruskal-Wallis

Table 1. Causes of Family Refusal in 2 Eras: 2009 and 2015–2016

Cause	2009	2015–2016	<i>P</i>
Religious believes	7 (8.6)	24 (43.6)	<.001
Unstable family mood	5 (6.2)	8 (14.5)	<.001
Expectation of a miracle	11 (13.6)	6 (10.9)	NS
Concern about organ trade	8 (9.9)	3 (5.4)	.03
Brain death denial	36 (44.4)	7 (12.7)	<.001
Opposite donor wishes	4 (4.9)	3 (5.4)	NS
Belief in body integrity after death	3 (3.7)	2 (3.6)	NS
Fear of objection by other family members	2 (2.5)	2 (3.6)	NS
Total	81	55	–

Abbreviation: NS, not significant. Values are n (%).

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