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Donation Decision-Making Process and Psychological Experiences of Families of Brain-Dead Donors from Turkey

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ABSTRACT

Purpose: Families play a key role in the decision to donate the organs of people with brain death. However, studies on the factors affecting the decisions of families and possible emotional difficulties they experience afterwards are insufficient. In our study, we aimed to investigate donor families' personal evaluations of the donation approval process and long-term psychological experiences in their families, such as prolonged grief, depression and restructuring of meaning.

Methods: A total of 24 first-degree relatives of donors who had brain death at least 6 months ago and who gave their consent for transplantation were included in the study. Demographic data form, Prolonged Grief Scale(PG-13), Grief and Meaning Reconstruction Inventory(GMRI), and Beck Depression Inventory(BDI) were administered to the participants.

Results: It was found that female gender increased the risk of depression by 13 times(OR=13, $p<0.05$) and the risk of prolonged grief by 5 times(OR=5.57, $p<0.05$). It was observed that the presence of a relative waiting for an organ transplant increased the risk of depression by 17 times(OR=17.0, $p<0.05$). It was determined that the risk of depression increased 1.26 fold by the increase in PG-13 scores($p<0.05$), while GMRI scores were not statistically significant in increasing the risk of depression($p>0.05$).

Conclusion: It is considered that in donor families, especially female gender and witnessing the experience of waiting for organ transplantation before donation may increase the risk of depression and grief. Programs that will facilitate access to psychological counseling services for all donor families in the long term is needed.

Key words: Organ donation, Brain death, Transplantation, Depression, Donor, Family

ÖZET

Amaç: Aileler, beyin ölümü gerçekleşen kişilerin organlarının bağışlanması kararında kilit rol oynamaktadır. Ancak ailelerin kararlarını etkileyen faktörler ve sonrasında yaşadıkları olası duygusal zorluklar üzerine yapılan çalışmalar yetersizdir. Çalışmamızda donör ailelerin, bağış onam süreciyle ilgili kişisel değerlendirmelerini ve uzun vadede ailelerdeki uzamış yas, depresyon ve anlamı yeniden yapılandırma gibi psikolojik deneyimleri araştırmayı amaçladık.

Yöntem: En az 6 ay önce beyin ölümü gerçekleşen kişilerin nakil onamını veren birinci derece yakınlarından toplam 24 gönüllü çalışmaya dahil edildi. Katılımcılara demografik veri formu, Uzamış Yas Ölçeği (UYÖ-13), Yas ve Anlam Yeniden Yapılandırma Envanteri (YAYYE) ve Beck Depresyon Envanteri (BDE) uygulandı.

Bulgular: Çalışmamızda kadın cinsiyetin depresyon tanısı riskini 13 kat (OR=13, $p<0,05$), uzamış yas tanısı alma riskini ise 5 kat arttırdığı (OR=5,57, $p<0,05$), öncesinde organ nakli bekleyen bir arkadaşın varlığının ise depresyon riskini 17 kat artırdığı (OR=17.0, $p<0.05$) bulunmuştur. UYÖ-13 skorlarının artmasıyla depresyon riskinin 1,26 kat arttığı ($p<0,05$), YAYYE skorlarının ise depresyon riskini arttırmada istatistiksel olarak anlamlı olmadığı belirlendi ($p>0,05$).

Sonuç: Olası sonuçlar göz önüne alındığında; donör ailelerinde özellikle kadın cinsiyetin ve bağıştan önce organ nakli beklemeye aşina olmanın depresyon ve yas riskini arttırabileceği düşünülmektedir. Bu sebeple başta bu özellikte olan aileler olmak üzere tüm donör ailelerin uzun vadede psikolojik danışmanlık hizmetlerine erişimini kolaylaştıracak programların geliştirilmesini önermekteyiz.

Anahtar Kelimeler: Organ bağışı, Beyin ölümü, Nakil, Depresyon, Donör, Aile

Although the number of patients waiting for organ transplantation is increasing in the world, the transplantation rates are still insufficient. Socio-economic status, differences in cultural and religious beliefs, level of knowledge about donation and brain death, and the deceased person's preference for organ transplantation may affect donation decisions of families (1,2). It is affirmed that poor communication with family negatively affects the transfer decisions and a clear, understandable, empathetic, informative, supportive communication style with families at the appropriate time and environment is important, and thus it may be beneficial to provide communication training to health professionals working in organ donation coordination team (3,4). On the other hand, it has been shown that the quality of communication established with the healthcare team during this period has a positive effect on the subsequent psychological processes of families who give consent (4).

While most people who mourn the loss of a loved one can return to their daily routines and functions, some may experience psychiatric disorders such as depression, prolonged grief and post-traumatic stress disorder (5). The symptoms observed in the grief process of people diagnosed with prolonged grief disorder(PGD) are more severe and take a longer time. Although 6 months have passed since the loss, the symptoms do not subside and there is clinically significant impairment in social, occupational and other areas of functioning (6). Studies show that grief reactions can vary according to the type of death, the type of relationship with the deceased, and the personality traits of those left behind (7).

Studies have shown that restructuring meaning after bereavement can be a protective factor for prolonged grief (8). Restructuring of meaning enables re-meaning of the world, learning after loss, personal growth, exploring new roles, and adapting. Therefore, the individual searches for answers to various questions and obtain different explanations. Interventions to reconstruct meaning have been shown to have positive effects on the treatment of chronic grief (9).

Considering the lack of literature, in the present study we aimed to evaluate the experiences of the relatives who lost their first-degree family member due to brain death and gave consent for organ donation, in terms of their experiences with the donation process and their subsequent levels of depression, prolonged grief, and restructuring of meaning.

Material and Method

Participants and Procedure

First-degree relatives of brain-dead donors between 2011 and 2021 who gave consent for transplantation were included in the study. According to the criteria for prolonged grief disorder, it was required that at least 6 months have passed since the bereavement. The contact information of the families was obtained through the Bursa Region Organ Donors database of the Ministry of Health Organ Transplantation Institution(OTI). It was observed that there were 96 donors in the 10-year period covered by the study. Fourty six relatives of donors could not be reached because their contact information was not up-to-date. Fifty relatives of donors were contacted by phone and 24 of them agreed to participate in the study. A questionnaire prepared with Google Forms was sent to the relatives of donors who agreed to participate in the study. Ethics committee approval was obtained from Bursa Yüksek İhtisas Training and Research Hospital Clinical Research Ethics Committee.

Measurement Tools

Demographic data form: This form, which includes items to question the sociodemographic variables (such as age, gender, education,etc.) and the experience during decision-making process (such as closeness to the deceased, the age of the deceased, cause of death, beliefs about having sufficient knowledge about brain death and the donation process, environmental support for transplantation, time after transplantation,etc.), was prepared by the researchers and applied to all participants.

Beck Depression Inventory (BDI): It is a self-report scale that evaluates depression from cognitive, emotional and physiological aspects (10). The cut-off score was determined as 17 in the Turkish validity and reliability study (10). An increase in the scores obtained from the scale indicates an increase in depressive symptoms.

Prolonged Grief Scale (PG-13): It is used to diagnose and to measure symptom severity of prolonged grief, and its Turkish validity and reliability study was conducted by Işıklı et al (11). The PG-13 contains 11 Likert type questions and two "yes/no" questions, which evaluate symptoms of separation distress and other cognitive-emotional behaviors specific to PGD. The increase in the total scores obtained from the 11 items of the scale indicates an increase in the severity of the symptoms of prolonged grief (6).

Grief and Meaning Reconstruction Inventory (GMRI): Its Turkish validity and reliability were performed by Keser and Işıklı (12). Exploratory Factor Analysis showed that the Turkish version of the scale has 27 items and 4 sub-dimensions as continuing bonds, personal growth, emptyness-meaninglessness and sense of peace. As the scores obtained from the scale increase, the level of restructuring of meaning increases.

Statistical Analysis

Study data were analyzed with the IBM Statistical Package for the Social Sciences for Windows 26.0 package program(SPSS 26.0-IBM, NY, USA). Demographic and clinical characteristics of the participants were evaluated with descriptive statistical analyzes such as number, percentage, and median. The relationship between the BDI, GMRI and PG-13 scores were analyzed by Spearman Correlation Analysis. To investigate the effects of clinical variables about deceased and donation process on the risk of depression and prolonged grief, Univariate Binary Logistics Regression Analysis was performed. The efficiency of PG-13 and GMRI scores in increasing the risk of depression diagnosis, and the efficiency of BDI and GMRI scores in increasing the risk of prolonged grief diagnosis was examined by Multivariate Binary Logistic Regression Analysis. A value of $p<0.05$ was accepted as significant for all analysis.

Results

The sample of our study consists of first-degree relatives of 24 donors who gave transplant approval. Of the participants, 14 were male (58.3%) and 10 were female (41.7%). A total of four participants (16.7%), three women and one man, were diagnosed with prolonged grief. A total of 6 people (25%), five women and one man, and 75% of those diagnosed with prolonged grief received a score of 17 or higher on the BDI. It has been observed that an average of 2,6 years have passed since the loss. Other sociodemographic and clinical data are presented in Table 1. As a result of Chi-Square and Mann Whitney U tests, it was concluded that there was no statistically significant difference($p>0.05$) in terms of regret and demographic and clinical characteristics.

Table 1: Sociodemographic and clinical characteristics of participants

Characteristics (N=24)		n	%
Gender	Male	14	58,3
	Female	10	41,7
Education status	Primary education	14	58,3
	Higher education	10	41,7
Closeness to the person you lost and to whom you gave approval for the transfer	Parents (Mother or Father)	12	50
	Spouse	2	8,3
	Child	3	12,5
	Brother/Sister	7	29,2
Cause of death	Disease resulting in sudden death	15	62,5
	Suicide	1	4,2
	Human caused	1	4,2
	Traffic accident	3	12,5
	Industrial accident	2	8,3
	Other	2	8,3
How death happens	Sudden unexpected death	23	95,8
	Expected death	1	4,2
Did the person you lost have a known preference regarding organ transplantation?	Yes	7	29,2
	No	17	70,8
Did you find the attitude of the hospital staff empathetic, respectful and supportive during the donation process?	Yes	23	95,8
	No	1	4,2
Do you believe you have enough information about brain death and the entire donation process?	Yes	19	79,2
	No	5	20,8
Have you ever regretted your transplant decision?	Yes	4	16,7
	No	20	83,3
Have you ever needed to consult anyone other than healthcare professionals when deciding on donation?	Yes	13	54,2
	No	11	45,8
If you have consulted, please indicate who you consulted (relative, religious official, etc.)	Relative(s)	8	61,5
	Religious official	5	38,5
Having diagnosis of depression	Yes	6	25
	No	18	75
Having diagnosis of prolonged grief	Yes	4	16,7
	No	20	83,3
Age of the participants	18-24	1	4,2
	25-34	8	33,3
	35-44	5	20,8
	45 yaş üstü	10	41,7
Age of deceased	Mean±SD	51,42±16,98	
	Min.-Max.	23-87	

SD: Standart deviation, Min.-Max.: Minimum-Maximum

Univariate Binary Logistic Regression Analysis demonstrated that female gender increases the risk of depression by 13 times (OR=13,p<0.05) and the risk of prolonged grief by 5 times (OR=5.57,p<0.05), while presence of a friend waiting for an organ increased the risk of depression 17 times (OR=17.0, p<0.05). Sociodemographic characteristics were not statistically significant factors in increasing the risk of prolonged grief (p>0.05)(Table 2).

Table 2: Factors that increase the risk of diagnosis of depression and prolonged grief

	Depression		Prolonged grief	
	OR	%95 CI	OR	%95 CI
Age (18-44)	1,60	0,23-11,28	2,46	0,22-27,84
Gender (Female)	13,00*	1,20-140,73	5,57	0,48-64,09
Education status (High school and below)	1,60	0,23-11,08	0,67	0,08-5,75
Relationship (Sibling)	2,50	0,24-2,50	1,29	0,11-15,00
Age of the deceased	0,98	0,92-1,04	0,98	0,92-1,05
Relatives' choice of donation (Yes)	1,30	0,18-9,48	0,78	0,07-9,08
Adequate information about the donation process (Yes)	0,40	0,05-3,27	0,75	0,06-9,27
An acquaintance waiting for an organ (Yes)	17,00*	1,30-223,14	1,89	0,14-24,79
Social support for donation decision(Yes)	2,50	0,36-17,32	1,00	0,12-8,56
Organ donation week participation (Yes)	0,13	0,01-1,33	1,00	0,12-8,56
Time since loss	1,06	0,90-1,25	0,94	0,81-1,08
Having Regret (Yes)	0,99	0,99-1,00	0,99	0,99-1,00

OR: Odds Ratio, Univariate Binary Logistic Regression Analysis, CI: Confidence Interval

According to correlation analysis, a statistically significant positive correlation was found between BDI and PG-13(r=0.672,p<0.001) scores, and a negative correlation between BDI and GMRI meaningless-emptyness subscale(r=-0.480,p=0.018) scores. There was no significant correlation between BDI scores and GMRI scores(r=-0.199,p=0.350). There was a statistically significant negative correlation between PG-13 scores and GMRI total scores(r=-0.410, p=0.046) and sense of peace(r=0.-518,p=0.010) subscale scores.

Multivariate Binary Logistic Regression Analysis revealed that increased PG-13 scores increased the risk of depression diagnosis by 1.26 times (p<0.05,95%CI:1.03-1.54), and that GMRI scores were not a statistically significant variable in increasing the risk of depression (p>0.05)(Table 3). It was found that BDI and GMRI scores were not statistically significant variables in increasing the risk of prolonged grief (p>0.05)(Table 4).

Table 3: The effect of PG-13 and GMRI scores on the risk of depression

	β	OR	%95 CI
PG-13	0,23	1,26*	1,03-1,54
GMRI	0,04	0,37	0,95-1,15

OR: Odds Ratio, Multivariate Binary Logistic Regression Analysis, CI: Confidence Interval, PG-13: Prolonged Grief Scale, GMRI: Grief and Meaning Reconstruction Inventory
** p<0,05statistically significant*

Table 4: The effect of BDI and GMRI scores on the risk of prolonged grief

	β	OR	%95 CI
BDI	0,23	1,26	0,91-1,74
GMRI	-0,18	0,83	0,67-1,04

OR: Odds Ratio, Multivariate Binary Logistic Regression Analysis, CI: Confidence Interval, BDI: Beck Depression Inventory, GMRI: Grief and Meaning Reconstruction Inventory

Discussion

Making the decision to donate organs alone after their loss can be challenging for family members. Previous experiences have suggested that the donation decision is largely determined by the way of mutual interaction between the family of donor and healthcare team, and inadequate communication may be one of the reasons

for negative decisions (3). In our study, 79.2% family members of donors stated that they were adequately informed about brain death and donation process, and 95.8% families found the attitude of the hospital staff to be favorable. Studies show that the concept of brain death can still be confusing for families, less so in families who consent to donation (13). Families who are expected to make quick decisions in the acute period may understand the medical dimension of the concept of brain death better in the following period and tend to view their level of knowledge less in the first period. It has been shown that organ donation volunteerism increases with the training provided (14). We recommend that awareness meetings and training on organ donation be increased throughout society. For this reason, when giving information to families; it is thought that it may be beneficial to use explanatory brochures, offer them to participate in brain death tests, and give them time to ask questions and consider (15). The fact that eight of the volunteers who participated in our study stated that they consulted other family members before making the decision may be related to the need to alleviate the burden of making decisions alone and to be supported. Five participants stated that they consulted religious officials to decide on organ donation. On the other hand, the fact that families who did not consent to transplantation were not included in our study limited the evaluation of the effect of religious beliefs on the decision.

Families may be indecisive about donation, so they may experience regret and even complicated grief afterwards (16). In a comprehensive study, regret was found in 10% of those who gave consent for transplantation and in one third of those who did not (17). In our study, 16.7% of participants stated that they regretted giving their consent for organ donation. Although in the literature regret is associated with sudden loss of a loved one, not knowing the choice of transplantation, not clearly understanding the concept of brain death, and situations where the family is indecisive about consent, in our study, a statistical evaluation could not be made between regret and other variables due to the small size of the population (17). In our study, no relationship was found between regret and sociodemographic characteristics, depression and prolonged grief. This difference may be due to the small sample size of the study group.

Another important finding is that the presence of an acquaintance awaiting an organ transplant beforehand increases the risk of depression in donor families by 17 times, but has no effect on prolonged grief. It is an important finding that waiting in line for organ transplantation makes people and their relatives prone to depression. Witnessing the waiting process for organ transplantation may predispose people and their relatives to depression. On the other hand, establishing a clear causal relationship is difficult due to the nature of depression. However, we recommend not to ignore such past information in donor families and to be cautious about subsequent depression processes.

In our study, the average time since loss was found to be 2.6 years. Although loss-related grief processes and depression are expected to decrease with the time elapsed after the loss, no significant relationship was found between these variables and duration in our study (18). The changes in grief and depression over the course of time can be seen more clearly through longitudinal studies that include acute and chronic period follow-up after transplantation.

Seventy percent of te participants said that the death of their relatives were sudden and unexpected, and they did not know whether they had any preference for organ donation. It has been shown that if the decisions are known in advance, they act in accordance with this decision at a rate of 93%, even if their families do not think alike (19). In cases where the deceased person's preference is unknown, it is thought that the recognition of these people as altruistic and willing to help other people motivates their families in the decision to donate (20). For this reason, although the preferences of the donors in our study are not clearly known, their relatives may have given their consent for donation.

Families of donors may have difficulties in coping with the sudden death of a loved one, the donation decision-making process, and the aftermath and thus, are at risk for many psychiatric problems. Although the participants in our study stated that they did not have a psychiatric disease and did not receive psychological support, 16.7% of them met the diagnostic criteria of PGD. This can be explained by the fact that people culturally meet their mourning processes as usual and tend to ignore their psychological needs. There are culture-specific aspects to the bereaved person's psychological reactions to loss and the way they interpret them (21). Although different rates were found in previous prevalence studies, a recent comprehensive meta-analysis reported the prevalence of PGD as 10.3% (22). In addition to studies reporting that the rate of PGD in families who gave donor consent was similar to those who did not, there are also results showing

that there is a high rate as 46% of donor families with a diagnosis of complicated grief (23). In a study conducted in our country, the PGD rate was found to be 11.4% and differences in prevalence rates may be related to factors such as the variety of measurement tools used and the cultural characteristics of donor families (11).

In our study, it was found that female gender increased the risk of being diagnosed with prolonged grief by 5 times and the risk of being diagnosed with depression by 13 times. It was found that educational status, relationship level, age of the deceased, sufficient information about the donation process, and the time elapsed after the loss were not effective factors in increasing the risk of long-term grief diagnosis. There are studies in the literature showing that female gender, being single, low education level, advanced age and poverty pose risks for PGD (24). The different results in our study may be due to the small sample size.

It is known that the female gender is a risk factor for the development of depression (25). This predisposition is suggested to be related to the biological structure, and socio-cultural characteristics of women. Men's less use of emotion-focused coping strategies after negative life events and less likelihood of being affected by the thoughts and emotions of others may be related to this result (26).

The overlap of some of the symptoms of PGD and major depression and the high comorbidity rates between the two disorders pose a diagnostic challenge (27). It is thought that accepting complicated grief as a subset of major depression and trying to treat it may lead to underdiagnosis of prolonged grief, being untreated, or misdiagnosed and treated as depression and anxiety (23). Therefore, in our study, symptoms of depression and PGD were evaluated with two different scales. In consistent with the literature, a good linear correlation was observed between the PGS and the BDI scores. In multiple regression analysis, it was found that the increase in the PGS scores increased the risk of depression diagnosis by 1.26 times but the increase in the BDI scores did not increase the risk of prolonged grief. This supports that although both diagnoses can be comorbid, they are two different clinical conditions and clinicians should carefully question the comorbidity of depression in the follow-up of donor families diagnosed with prolonged grief.

One of the factors that play an important role in the resolution or chronicity of the grieving process is restructuring the meaning after loss (12). In the literature, studies on the restructuring processes of the meaning of donor families are rare. Communication with healthcare professionals and positive hospital experience have been shown to be positively and significantly correlated with post-traumatic growth (28). In our study, a negative correlation was found between PGD and sense of peace subdimensions of reconstructing of meaning in donor families. The thought that death relieves the pain of the loved one and puts her at peace, as well as the preparedness of both the deceased and the person who gave consent for the death, may reduce the risk of prolonged grief. For this reason, informing the relatives of the patient in advance about the patient's medical condition and the risk of death and the possibility of organ donation, and thus giving the families more time to discuss the donor decision, may reduce the risk of prolonged grief of donor family members. However, in Regression Analysis, reconstructing of meaning was not found to be a statistically significant variable in increasing the risk of both PGD and depression. In the light of the previous literature on the positive relationship between prolonged grief and restructuring of meaning, there is a need for more comprehensive studies investigating the effect of restructuring of meaning in assessing the risk of prolonged grief and depression in donor families.

While some studies report that organ donation has a positive effect on the grieving process, others do not support this relationship (29,30). In addition, it has been stated that the effects of the organ donation decision on the psychological well-being of the family individuals are affected by the nature of the social, cultural, and spiritual factors and the qualification of the bereavement (30). It is known that there are many families who describe themselves as happy and peaceful because of their decision to donate, although thinking that their relatives' organs are living with other people can sometimes cause emotional turmoil for families. Donating the organs of their loved ones can make donor family members feel that they are continuing their legacy through the organ recipient. Furthermore, the feeling that help and favors are given to those in need can increase families' ability to cope with bereavement.

Limitations

Due to the pandemic conditions, our study was planned as an online survey study. The limitations of our study are the lack of face-to-face interviews, the small sample size, and the inability to compare the findings with families

who did not give consent for transplantation. Another limitation of our study is that there is a wide time interval from six months to ten years between the donation decision and the evaluation.

Conclusion

Our results revealed that female gender and being familiar with awaiting organ transplantation before donation are important variables in terms of depression risk in donor families, and reconstructing of meaning is not an effective factor in increasing the risk of both PGD and depression. It can be argued that comprehensive studies involving participants from different religions and cultures, and comparing families who accept and do not accept to be a donor will make significant contributions to the field. It can be recommended to evaluate donor families in terms of depression risk, especially those who are female and have an acquaintance who is waiting for an organ transplant, to develop programs that will facilitate the access of risky individuals to psychological counseling services, and to train health professionals who provide information transfer to use strategic communication methods.

Declarations

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There is no specific funding related to this research.

Conflicts of interests

The authors declare no conflict of interest.

Ethical Approval

The ethics committee approval date 08.09.2021 and protocole number: 2011-KAEK-25 2021/09-06.

Data Availability Statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

Author's contributions

EMA, HAK, IC study concept and design; FT, MA data collection, EMA, IC data analysis and draft the manuscript; HAK, EMA, IC contributed to the data analysis/ interpretation and prepare the table; HAK, EMA, IC, KÖ, SO contributed to writing the manuscript. All authors read and approved the manuscript.

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