

ICU Residents' Views On General Ethical Issues Regarding The Opt-In System Of Deceased Organ Donation In Turkey: A Focus Group Study

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ABSTRACT

This descriptive study explores the views of resident physicians working in intensive care units (ICUs) concerning deceased organ donation and examines the various ethical issues surrounding organ donation encountered by residents.

This was a qualitative, descriptive study utilizing solo interviews with participants together with focus group discussions. The participants' experiences and views were elicited via interviews and focus group discussions covering the following topics: ethical thoughts about deceased organ donation, barriers that impede or prevent organ donation, its effect on the next of kin, and its relationship with futile treatment. The discussions were reviewed using qualitative content analysis.

The residents commented that deceased organ donation is a complex and stressful process for the family of the potential donor as well as the transplant team, and still lacks wide acceptance in Turkish society. The opt-in system requires informed consent, thus creating a major barrier for both the patient's family and the ICU team to overcome. The participants stated that new legal, ethical, and medical arrangements are needed to increase organ donation rates in Turkey.

In order to increase rates of deceased organ donation and reduce cases of futile treatment, improved communication between the ICU, transplant team, and patient relatives is critical to ensure that ethical issues are properly managed. On a societal level, the subject of deceased organ donation needs to receive greater attention from public health authorities to increase public awareness. Residents can make valuable contributions to the deceased organ donation process as physicians and as psychosocial support for patients and their families.

Keywords: Intensive care unit, resident, deceased organ donation, medical ethics, focus group discussion

Introduction

Brain death, a concept first described by Mollart and Goulan in 1959, later came under discussion in 1968 by committees at Harvard Medical School and other medical centers, resulting in the determination of criteria for brain and brainstem death¹. Since then, deceased organ donation (DOD) has been the subject of numerous studies.

Developments in DOD were closely monitored in Turkey, and the Organ and Tissue Removal, Preservation, and Transplantation Law was enacted in 1979². The criteria for brain death were published in the official gazette of the Republic of Turkey in 1993³. The first regulation concerning DOD explicitly stated that "if the intensive care unit (ICU) team is not able to obtain informed consent from the next of kin following brain death, at that time, all medical support is to be

discontinued by the medical team". In the Regulation on Organ and Tissue Transplant, from 2000, the above directive was amended to "medical support may only be discontinued with the permission of the patient's next of kin". In Appendix 1 of the Organ and Tissue Transplant Regulation, published in 2012⁴, the rules regarding the diagnosis of brain death were revised according to neurological criteria. According to organ transplantation rules and patients' rights regulations in Turkey,⁵ informed consent must be obtained from the patient or patient's next of kin. The process of organ donation in Turkey involves organ transplant units in hospitals where these procedures are performed, along with transplant coordinators, but does not include the provision of grief counselors.

One of the most important aspects of deceased organ donation is informed consent⁶, which involves both ethical and legal aspects. There are

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two different informed consent practices: in the first, healthcare professionals (HCPs) are obliged to obtain explicit consent from the patient or their next of kin ("opt-in consent"), as specified by Turkish medical regulations⁴. The second practice operates on the assumption that the patient or their next of kin agrees to deceased organ donation unless otherwise stated (presumed consent or "opt-out")⁷. The latter practice has been accepted in more than 15 European Union countries^{5, 6}. Unlike an opt-in system, an opt-out system increases DOD rates (although not enough to meet demand) because it is based on treating every individual in a country as a willing organ donor unless they specify otherwise. Such a system may help to overcome traditional barriers and lack of education/awareness about transplantation as well as aid communication with grieving families^{8, 9}.

The consent practice adopted by a given country affects the rate of deceased organ donation as well as the predicaments faced by ICU donation physician specialists. Despite regulations pertaining to DOD following brain death, the topic remains mostly undiscussed among the Turkish public, rendering the subject of informed consent regarding organ donation largely moot. Establishing legal and ethical guidelines related to organ donation, to delineate the roles and responsibilities of patients, their relatives, medical ethicists, and HCPs, as has been done in Canada¹⁰, would be of immense benefit to all involved in the organ donation process⁶.

Studies on DOD have indicated that consent is the main issue associated with DOD rates on a global scale. These studies have also shown the opt-out system represents an effective strategy to increase the number of DODs in European Union countries¹¹.

On the other hand, the opt-in system has made the issue of authorization regarding the cessation of medical support controversial, leading to confusion and hesitation in practice, and constituting one of the main reasons why the subject of futile treatment is on the ICU agenda. Given that legal regulations and the concept of informed consent are critical factors in the implementation of DOD, ICU teams need to understand brain death¹² and organ donation from a medical perspective and consider their legal, ethical, psychosocial, and communication implications¹³ to develop a prudent approach when broaching the topic of organ donation. Resident physicians also require special training programs focusing on quality care for dying

patients and their families while at the same time providing and/or improving organ donation services.

In order to propose a new approach to the issue of DOD, it was first necessary to interrogate ICU residents who could thoroughly and competently evaluate ICU workings based on their experiences. HCPs need to be well-versed concerning deceased organ donation, and those attending to cases involving brain death should positively regard the latter, as one cannot work effectively on something that one objects to⁶. The present study was organized to elicit the views of ICU residents because they are an integral part of the HC team and are actively involved in the care of ICU patients. However, since they are not authorized to direct the care of patients, residents are in a position to evaluate procedures implemented in the ICU impartially. The present study, therefore, contributes to an understanding of the issues involved in DOD as it considers the perspectives of residents who closely observe what takes place in the ICU and are also in close communication with patients' next of kin.

Methodology: This study employed descriptive and qualitative methodology, incorporating solo interviews and focus group discussions (FGD), to elicit the medical residents' views regarding deceased organ donation. The study was conducted between 21 January to 21 February 2022. The topics discussed in this research arose during conversations between the hospital ethics committee and the ICU residents, who mentioned issues such as occupied hospital beds, futile treatment, and DOD as among the problems they had encountered. Thus, the sensitive topic of DOD was chosen with the support of both the participants and the researchers.

We determined the criteria for the focus group discussions and content analysis based on the relevance of the topic to ethical issues pertaining to deceased organ donation. The subjects reflected the residents' own ideas concerning DOD, associated medical ethical values and principles, legal procedures, and public approaches to DOD. Exclusion criteria included topics irrelevant to the DOD such as living organ donation, ICU treatment challenges, and ICU working conditions.

In order to recruit participants, we telephoned the ICU medical residents, all of whom accepted our invitation to participate on a voluntary basis. Information on the participants, data collection methods, questions for semi-structured interviews, and data analysis are detailed below.

Focus group discussions were employed because they augment interactions within groups, thus fostering in this case the exchange of information on the medical, ethical, legal, and communication issues that participants have faced concerning DOD in cases of brain death or irreversible brain damage. There has already been much quantitative research in which the participants were comprised of physicians and nurses; however, only a few studies have involved medical residents. Selecting ICU residents who were actively involved in every step of the care of such patients provided us with the additional necessary data concerning DOD and led to delving deeper into DOD issues. Resident physicians are both observers as well as energetic and enthusiastic young healthcare workers who communicate one-on-one with all stakeholders in the DOD process although they are not involved in the relevant decision-making. Their knowledge and skills with respect to deceased organ donation allowed them to critique current practices while suggesting potential solutions and new ideas. Finally, the focus group format provides participants with a non-hierarchical situation in which they can articulate their valuable insights, thoughts, and experiences while ensuring effective interaction between the moderator and group members.

Participants: The study sample consisted of 34 resident physicians educated at various medical schools throughout Turkey. Of the participants, there were 24 men (70.6%) and 10 women (29.4%), ranging from 25 to 42 years, with a mean age of 32.12 ± 4.76 and an average of 10 years of experience working in medicine.

The specialties of the participants were as follows: 21.2% general surgery, 6.1% neurology, 6.1%; chest diseases, 3%; cardiology, 6.1%; emergency medicine, 36.2%; and anesthesiology and intensive care. They expressed the view that working in the ICU is of special importance, given the vulnerability of patients. Nearly 90% of the study participants had previously served as general practitioners upon graduation from medical school and prior to taking the national medical specialty exam.

The participants were all familiar with the different stages of DOD and futile treatment, as they had acquired experience in dealing with futile cases as part of their job responsibilities. Their medical education and work experience prior to their residencies took place in different cities and hospitals throughout Turkey.

Data Collection: Residents were invited in groups of 6-8 to discuss issues relating to DOD in

the format of one and half-hour-long, semi-structured interviews and focus group discussions (FGDs). These discussions were determined to be a useful means of revealing the complex ethical and emotional issues involved in DOD. Each discussion was anchored by the four open-ended questions below, communicated before the start of the session, allowing for variable and detailed responses and sharing of personal as well as group experiences, observations, and opinions. The internal dynamics of each group also directed some of the conversations toward re-evaluations of actual cases that the participants had encountered.

Data Analysis: The answers to the four questions initially posed to the participants were received in writing, and focus group discussions were recorded with their permission. The initial responses were quite limited in scope, but the comments expressed in the focus group discussions were clearer and more detailed and included participants' personal feelings, views, and experiences. These statements were categorized, organized, and evaluated following the removal of comments unrelated to the topic under discussion.

Ethical approval and consent to participate: This study was designed and conducted in accordance with the principles of the Declaration of Helsinki. The study protocol and all study-related materials were approved by the Van Yuzuncu Yıl University Clinical Research Ethics Committee on May 21, 2020 (decision no. 07). All participants gave both verbal and written informed consent, which included a confidentiality agreement.

Results

The answers provided by the ICU residents participating in our study within the framework of four questions were evaluated according to the content themes and these data were presented below in boxes.

Theme 1: Views on DOD and patient safety: Participants in all the focus groups concurred that DOD was less problematic than having a living donor. As organ donation with living donors usually occurs within the family, the altruistic aspects of organ donation may be compromised; hence, the donor may be subjected to social and psychological pressures or influenced by financial considerations. Thus, the participants concluded that DOD was preferable and would lead to an increase in organ transplantation. However, they understood that the next of kin might feel concerned that the patient's safety could

Table 1. Questions For Semi-Structured Interviews

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1. What are your views on deceased organ donation?
 2. What are the barriers impeding or preventing organ donations from the deceased?
 3. How do information and communication regarding organ donation requests affect the next of kin?
 4. What effects do deceased organ donations have on futile treatment, and vice versa?
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conceivably be compromised in cases of DOD. The following comments represent viewpoints widely shared by the participants (Box 1).

Box 1: Participants' views on deceased organ donation (DOD)

Beneficence, autonomy, and decision-making capacity: "Of course, organ donation is a life-saving activity, it changes people's lives." "End-of-life conversations with families are a very emotional process. During this process, I cannot be sure of how rational the family's decision was. I do not know to what extent autonomous decision making takes place."

Nonmaleficence (patient safety) and decision-making capacity: "It bothers me to ask permission for organ donation from a family who just lost their relative." "These people are very sad; how can I broach the subject of organ donation? If I were in the same situation, I would think that bringing up the issue of organ donation at such a time is not at all empathetic, and I would feel saddened."

Duty/responsibility is not clear: "My colleagues and I support organ donation. However, after brain death occurs, I do not want to talk to the next of kin about organ donation. My main focus is on my patient, so it is not suitable for me to speak with their relatives about this issue. I am responsible for the health and safety of my patient first and foremost." "This is really very distressing and disturbing."

Building trust and rapport: "Discussing organ donation with the patient's next of kin may create suspicion in their mind concerning the patient's treatment, whereas my priority is my patient. Talking with the patient's next of kin about organ donation is actually very uncomfortable, because they may think that I have endangered the safety of my patient and even react accordingly."

The participants emphasized their concerns regarding the feelings of the family. The topic of deceased organ donation spurred some participants to begin thinking about existing organ donation practices and the ethics involved, even going so far as to question whether following up on organ donation is or should be part of their job. Moreover, the participants clearly stated that

the DOD process entailed serious emotional and ethical issues for them and their patients' next of kin. These factors may affect a resident's decision-making capacity concerning issues of patient safety, as the next of kin may perceive a connection between the patient's status as an organ donor and the safety of the patient.

Theme 2. Barriers to deceased organ donation: The participants identified three main barriers to deceased organ donation. First, organ donation is not widely accepted in Turkey; 75% of Turkish families do not consent to donate their deceased relatives' organs¹⁴. Secondly, Turkish health authorities have never implemented campaigns to publicize (and ultimately, increase acceptance of) organ donation; as a result, the subject simply falls outside the scope of most peoples' awareness. Lastly, the participants admitted that they experience difficulty in effectively communicating with grieving relatives. Below are sample comments pertaining to the obstacles mentioned above (Box 2).

Box 2: Participants' views on barriers to deceased organ donation

Donation is not on the public agenda: "This issue is not on the agenda of the public at large; it is only on the agenda of those who have organ failure. Therefore, I do not know how we can broach an issue that most people never pay much attention to."

The shortage of organs for donation is not on the public agenda: "The gap between the number of cadaveric donors and the number of patients on the transplant waiting list is not on the public agenda."

Lack of empathy: The sadness of the patient's relatives prevents the issue of organ donation from coming to the fore. "I agree with my colleague, the main problem here is the worry that the sadness of the family will be exacerbated by broaching the topic of organ donation, and the main concern of residents is that the next of kin may also blame the doctors (us) in this situation." "I think that it is not ethical to ask family members to consent to organ donation while they are grieving."

Lack of information: "The patient relatives don't know what deceased organ donation is. We have only a short time to explain. The relatives must

make this decision under conditions of profound sadness and mourning. In my opinion, this is the main barrier to and reason for the shortage of DODs.”

Dealing with grieving relatives: “It is difficult for me to ask for consent from the next of kin, who does not have much knowledge about DOD, while they are still mourning.” “I agree that DOD concerns both emotions and beliefs/values. Both need to be taken into account.”

The participants’ responses indicated that organ donation and organ shortages are not on the public agenda in Turkey, and thus there is a lack of empathy for patients requiring transplants and information on the subject in general. In the Turkish media environment, there are no discussions, announcements, or regular programs that bring DOD to the agenda. Furthermore, some participants stated that they do not have access to resources (such as courses and guidelines) advising on how to communicate with the next of kin on this subject. Despite this, however, some participants expressed both readiness and willingness to begin such difficult conversations with the next of kin.

Theme 3. How do information and communication regarding organ donation requests affect the next of kin? The participants stated that discussing organ donation requires special communication skills, whether speaking with an educated or uneducated (but almost certainly grieving) next of kin. They suggested that organ transplantation teams also include professionals from other specialties such as psychiatrists, psychologists, and ethicists (**Box 3**).

Box 3: Participants’ views on information, communication, and emotions regarding organ donation requests.

Lack of communication skills: “The main problem stems from communication. When the person discussing organ donation also provides information about its technical or historical basis (e.g., Wilson’s criteria, etc.), the patient’s relative does not show interest in organ donation and refuses.” “Communication should include clear explanations, active listening, and feedback. However, we have never received professional training on this subject. I think this is a problem.”

Lack of knowledge and education of the next of kin: “It would be beneficial for those who provide information about organ donation to receive instruction on ethical and clear communication as well as the necessary technical information. First and foremost, this information

should be delivered in a simple, clear, and compassionate manner. Secondly, the relatives of the patient should also feel that the person discussing this topic empathizes with them and is aware of their pain.”

Lack of understanding on the part of the next of kin: “The patients’ next of kin may have limited education and lack the necessary comprehension. The relatives may not understand what brain death means or what organ donation following brain circulation determination of death involves. We explain the reasons for brain death and tell the patient’s relatives that unfortunately brain death has occurred and the patient cannot return to life. However, oftentimes the relatives of the patient do not understand and they ask us when the patient will open their eyes again.”

“We try to explain technical issues in detail when discussing organ donation. This is legally necessary, but the process of informing the next of kin in this manner distracts their attention.”

Issues with the transplant team: “In fact, I think if psychiatrists, ethics consultants, and psychologists would attend organ donation discussions, the communication would be more effective.”

This question has highlighted the importance of the views of both the next of kin and each member of the medical team. Residents may play the role of facilitator in the organ donation process by actively participating and expressing their thoughts clearly, rather than just silently observing the process.

Theme 4. What effects do deceased organ donations have on futile treatment, and vice versa? Participants noted that one of the main issues encountered in ICUs is futile treatment, as Turkish regulations concerning brain death are not clear regarding who possesses the authority to discontinue treatment. Ideally, ICU medical teams would prefer to obtain informed consent from the patient’s relatives, because if the former were to decide to discontinue treatment, the family may blame and even attack the medical team, believing that their loved one could have been saved (**Box 4**).

Box 4: Participants’ views on whether deceased organ donations would reduce futile treatment

Lack of knowledge on the part of the next of kin regarding futile treatment: “One of the most serious issues is futile treatment. A patient’s relatives cannot accept that the patient is unlikely to recover. For example, patients who develop hypoxic brain injury following cardiopulmonary

resuscitation (CPR) may not yet be brain dead, but these patients are unlikely to recover, and a patient who cannot support their vital bodily functions may remain in intensive care for a long time. Such a scenario leads to futile treatment and the futile use of both human and technical resources.”

“We explain the situation to the patient’s relatives, we tell them that there is no chance of recovery at all, and we express that we would like to discuss organ donation. The next of kin then asks, ‘When will the patient speak and when will they be able to walk?’”

“This situation is very difficult to explain to the patient’s next of kin when they are either not educated or have very limited education, as they often do not understand. In addition, relatives of patients do not accept the information we provide and search for solutions on the internet. For example, they may find stem cell transplantation research on the internet. Stem cell transplants are only available for patients who meet certain criteria. We try to explain this.

Discussion

As mentioned above, legal regulations in Turkey concerning deceased organ donation require explicit informed consent (opt-in) on the part of the patient or next of kin, rather than presumed consent (opt-out). In countries where the latter policy prevails, organ donation is regularly performed when brain death occurs, unless the patient (in their will or medical directive) or their next of kin specifically refuses organ donation¹⁵. This policy can also be applied to euthanasia¹⁶. However, when a country employs an opt-in system for the authorization of deceased organ donation, the patient’s own will or their relative’s sensitivity to DOD comes to the fore. Therefore, countries with an opt-in policy actively include ICU residents during the organ donation process¹⁷. As part of the organ donation team in question, they have the opportunity to evaluate the process both as outsiders (with only limited authority in the ICU while undergoing their specialist training program) and insiders who play an active role in the ICU team. Hence, we conducted a focus group study incorporating four questions related to this research, as the opinions and views expressed by ICU residents may provide useful feedback that could contribute to greater acceptance of organ donation in Turkey. To date, few studies have been published on the perspectives of medical residents in ICUs concerning their experiences of deceased organ donation.

In the present study, we solicited the opinions of the participating resident physicians regarding issues involving DOD and encouraged them to incorporate their views and experiences in the ICU when evaluating this topic. The four main themes identified in this study were determined based on the participants’ observations regarding the primary issues that they encountered. Since brain death represents an unexpected and sensitive situation, decision-making concerning deceased organ donation requires sensitivity on the part of healthcare professionals as well as the family^{13, 18}. Thus this study makes a meaningful contribution to the development of novel solutions and proposals by carefully evaluating the criticisms and suggestions of participating ICU residents who, while not in charge of care, are fully aware of ethical, legal, and medical practices and have demonstrated their concern for the next of kin.

Turkey, which adopted the policy of explicit informed consent (opt-in) in 2012, does not have a high number of deceased organ donations^{21, 22}, unlike other countries that have adopted an opt-out policy. The most recent relevant data from the Turkish Ministry of Health showed that 16,784 cases of brain death were reported in 2019, whereas approval was obtained from only 4,712 families¹⁹. These data serve as evidence that in the majority of cases in Turkey, the next of kin do not consent to organ donation upon the brain death of the patient.

Participants identified several important issues. While noting that deceased organ donation is important for saving lives and, thus benefitting overall public health, it does involve certain emotional and ethical concerns in connection with the very sensitive situation in which the next of kin find themselves under such circumstances^{19,21,22}. For this reason, some participants expressed serious reservations about discussing deceased organ donation with the patient and/or next of kin. The study participants expressed that discussing organ donation creates an additional emotional burden (conscientious issue) for them^{23, 24}, while they preferred to feel confident and professional at work and to be at peace psychologically. The core program in Turkish medical schools does not include instruction in organ transplantation, hence the participants reported only encountering DOD issues after becoming ICU residents. Apart from psychiatric residents, Turkish medical students do not receive psychological training (such as might include the various stages of grief) to communicate effectively with terminal patients and their families in the course of their studies.

Although physicians hesitate to engage in discussions of deceased organ donation with patients' next of kin, which may partially explain the low rates of organ donation in Turkey, the subject is also not on the agenda for Turkish society as a whole, and its acceptance is especially hindered in cases where the next of kin is poorly educated and/or exhibits an overly emotional (e.g., aggressive) response. Such impediments to deceased organ donation suggest that cultural and religious approaches are unlikely to be very effective, although focusing on the next of kin's values and emotions may be useful ²⁰. Accordingly, the educational level of the next of kin is critical in determining the extent to which they may harbor any hope that the patient will somehow recover ¹¹. Clear, direct information and communication are therefore of particular importance when discussing deceased organ donation ^{25,26}. Studies have shown that the following factors affect how the next of kin approaches ²⁷ the organ donation decision-making process: communication ²², timing ²⁸, allowing the next of kin sufficient time to decide ²⁹, use of a private room, satisfaction with the quality of care ¹⁷, educational level ²⁴, treating patients with dignity, broaching the topic with empathy/sensitivity, acknowledging discomfort on the part of the next of kin having to decide for the deceased ^{16, 17}, and the values of the next of kin ^{30,31}.

An important suggestion put forward in this study was the involvement of psychologists, ethicists, and psychiatrists in the organ donation process. The guidelines proposed by Matis et al. ³² under the title "Ethical Guidelines for Organ Transplantation from Deceased Donors" emphasize the importance of having a multidisciplinary team as soon as possible following brain death and during the organ donation decision-making process ⁶.

The study participants recognized brain death as a reason for the provision of futile treatment. Scientific studies have determined that mechanical ventilation is necessary for those diagnosed as brain dead in order to perfuse vital organs while awaiting transplantation ³³. However, following a diagnosis of brain death, if the next of kin does not consent to organ donation, at that time it is considered futile to continue life-sustaining treatment such as mechanical ventilation ³⁴. In Turkey, medical regulations are not clear regarding who possesses the authority to withdraw treatment after a diagnosis of brain death ³⁵. As such, there is a clear need for explicit ethical guidelines on how to proceed in cases of brain

death, not only for healthcare professionals but also for ethicists and lawyers, since the next of kin generally does not wish to discontinue palliative treatment, nor do they look favorably upon organ donation. As a result, many patients continue to receive palliative care in the ICU even when such treatment is medically futile.

Limitations and strengths: The main limitation of the present study was that it was a single-center study, although this is mitigated by the fact that the participants were graduates of more than 30 different medical schools throughout Turkey. The qualitative aspect of the focus group discussions allowed both researchers and participants to delve into fundamental issues involving deceased organ donation. This study is the first to incorporate the views of ICU-resident physicians, thus representing an important contribution to the literature on DOD.

This study revealed the main issues impeding deceased organ donation in cases of futile treatment in Turkey. An overall lack of awareness regarding organ donation among the general public could be rectified by health authorities releasing public statements and initiating a campaign to raise awareness and provide information about organ donation, including the consequences of futile treatment. Lack of communication skills and the emotional and ethical burden on physicians with respect to deceased organ donation also contribute to this problem, as evidenced by residents expressing their discomfort in bringing up such a sensitive topic to a grieving relative. Improved communication skills are also necessary to help less-educated relatives grasp the concept of brain death and obtain informed consent. Residents need to be able to communicate clearly yet empathically in order to convince the next of kin, who often has strong personal/emotional reasons for refusing organ donation, to agree to it. Clarification is necessary regarding legal regulations concerning who has the authority to decide to discontinue treatment. Finally, we recommend that professionals such as ethicists, psychologists, psychiatrists, and social workers be included in the organ transplant teams.

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