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# Experiences of Organ and Tissue Donation Coordinators During COVID-19: A Qualitative Study

Organ ve Doku Bağışı Koordinatörlerinin COVID-19 Döneminde Deneyimleri: Nitel Bir Çalışma

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## ABSTRACT

This study was intended to examine the experiences of Organ and Tissue Donation Coordinators (OTDCs) in Turkey involved in the cadaveric donor process during the COVID-19 pandemic. This was a descriptive qualitative study conducted with 12 OTDCs working in nine different regions in Turkey. Consolidated criteria for reporting qualitative research (COREQ) guidelines were used to ensure transparency. Six themes emerged regarding the experiences of OTDCs: 1) intensity in intensive care units, 2) negative effects of the COVID-19 pandemic on OTDCs, 3) changes in the donor diagnostic process, 4) communication difficulties with family, 5) the reduction in potential donors, and 6) a decrease in organ donation activities of OTDCs. The findings emphasized that there were prolongations and changes in the coordination process due to increased patient density in intensive care units, which negatively affected the OTDCs. In addition, it was emphasized that the changes in the diagnostic process, communication difficulties with family members, and fewer potential donors led to a decrease in the number of cadaveric donors. This study highlights important issues experienced by OTDCs in Turkey during the COVID-19 pandemic. The findings also explain the decrease in organ donors during the pandemic. Our study revealed insufficient action plans, guidelines, and communication tools regarding the cadaveric donation process during this time.

**Keyword:** Brain Death, COVID-19, Health Personnel, Intensive Care Units, Tissue and Organ Procurement.

## ÖZ

Bu çalışmanın amacı, Türkiye'deki Organ ve Doku Bağışı Koordinatörleri (OTDC)'nin, COVID-19 salgını sırasında kadavra donör sürecindeki deneyimlerini incelemektir. Bu, Türkiye'nin dokuz farklı bölgesinde çalışan 12 OTDC ile yürütülen tanımlayıcı nitel bir çalışmadır. Şeffaflığı sağlamak için nitel araştırmaların raporlanmasına yönelik birleştirilmiş kriterler (COREQ) kılavuzları kullanıldı. OTDC'lerin deneyimlerine ilişkin altı tema ortaya çıktı: 1) yoğun bakım ünitelerindeki yoğunluk, 2) COVID-19 salgınının OTDC'ler üzerindeki olumsuz etkileri, 3) donör teşhis sürecindeki değişiklikler, 4) aileyle iletişim zorlukları, 5) potansiyel donörlerin azalması ve 6) OTDC'lerin organ bağışı faaliyetlerinde azalma. Bulgular, yoğun bakım ünitelerinde hasta yoğunluğunun artması nedeniyle koordinasyon sürecinde uzama ve değişikliklerin yaşandığını ve bu durumun OTDC'leri olumsuz etkilediğini gösterdi. Ayrıca tanı sürecindeki değişikliklerin, aile bireyleri ile iletişim zorluklarının ve potansiyel donör sayısının azalmasının kadavra donör sayısında azalmaya yol açtığı vurgulandı. Bu çalışma, Türkiye'deki OTDC'lerin COVID-19 salgını sırasında yaşadığı önemli sorunları vurgulamaktadır. Bulgular aynı zamanda pandemi sırasında organ bağışçılarının azalmasını da açıklamaktadır. Çalışmamız bu dönemde kadavra bağışı sürecine ilişkin eylem planlarının, yönergelerin ve iletişim araçlarının yetersiz olduğunu ortaya çıkardı.

**Anahtar Kelime:** Beyin Ölümü, COVID-19, Sağlık Personeli, Yoğun Bakım Üniteleri, Doku ve Organ Temini.

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## INTRODUCTION

The COVID-19 virus identified in Wuhan, China, in December 2019 soon spread worldwide, becoming a pandemic.[1] The virus affected many fields, including education, the economy, and especially healthcare.[2] Individuals with chronic diseases were reported to be especially at risk during the COVID-19 pandemic.[3] Organ failures constitute an important part of chronic diseases.[4,5] The ideal treatment for organ failure is organ transplantation[6] from either living or cadaveric donors. Liver and kidney transplants can be performed from both living and cadaveric donors, while other vital organs, such as heart and lungs, can only be performed from living donors.[7,8] While living donors face operative risks and the healing process, using cadaveric donors eliminates these hazards.[9] However, the number of cadaveric donors is much less than that of patients waiting for organs. Thus, many patients waiting for organs die before they receive a transplant.[10]

In Europe, cadaveric donors are divided into two groups. These two groups consist of cases diagnosed as brain dead based on neurological evaluations and tests, Donor after Brain Death (DBD), and those with cardiopulmonary death, Donor after Cardiac Death (DCD).[11,12] In Turkey, only DBD organs are used.[8] During the cadaveric donation process (Fig. 1), cases with severe brain damage are identified as potential donors. Patients declared brain dead after appropriate neurological examinations and tests deemed suitable for organ removal are defined as eligible donors. Those with family permission and at least one organ removed for transplantation are defined as actual donors. If at least one removed organ has been transplanted, the case is defined as donor used.[13]

Organ and tissue transplant coordinators (OTDCs) are 'the unsung heroes' of transplantation.[14] They play an essential role in identifying potential donors in the intensive care unit (ICU), identifying and declaring potential donors, and interviewing families of eligible donors.[15-17] The COVID-19 pandemic significantly reduced the number of cadaveric donors in Turkey from 619 in 2019 to 263 in 2020, 305 in 2021, and 289 in 2022.[18] Despite this decrease in possible donors, 22660 patients reportedly were awaiting organs.[8,19] At the same time, that there was a dramatic decrease in the rate of family leaves in 2020.[18]

Our study was conducted to examine the experiences of OTDCs in the cadaveric donor process during the COVID-19 pandemic. The experiences of OTDCs, which have a critical role in this process, are of great importance in determining the reasons for the decrease in donor numbers and preventable causes moving forward. When the literature was examined, no study examined the experiences of OTDCs in the cadaveric donor process during the COVID-19 pandemic. Thus, this study was intended to define the problems in the transplant process during the pandemic with the hope of providing OTDCs guidance in the current pandemic and in future extraordinary situations that may be encountered.

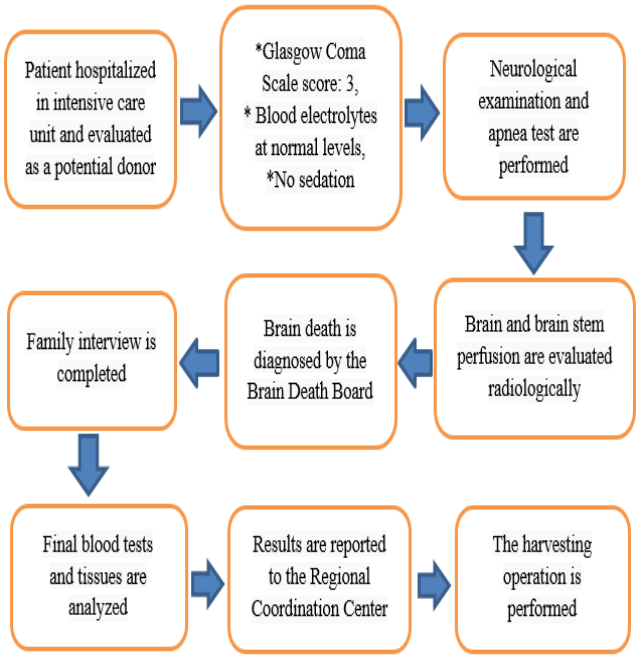


**Figure 1. Cadaveric Donation Process in Turkey**

## MATERIALS AND METHODS

### Study Design

This descriptive qualitative study conducted with OTDCs in Turkey was intended to define the participants' perspectives and understand their experiences in the cadaveric donation process during the pandemic. The purposive sampling method was used in the research.[20]

### Organ and Tissue Donation Coordinators and Sample

OTDCs play a central role in identifying potential donors in hospitals, in the brain death diagnosis process, in the family interview process, in reporting donors to regional and national coordination centers, in public education on organ donation, and in organizing awareness events. Physicians, nurses with ICU experience, midwives, and other health professionals certified by the training programs organized by the Ministry of Health perform OTDC duties.[16,21] The research was conducted with 12 OTDCs working between May and July 2021 in affiliates of nine Regional Coordination Centers (RCCs) established to cover 81 provinces in Turkey, considering geographical location and distance. A communication network was established by connecting RCCs to the National Coordination Center (NCC) in Ankara [16,22,23]

### Data Collection Tools

The data were collected with a semi-structured interview form created by the researchers in line with the literature. This form was converted to an online format using Google Forms. The first page consisted of the research purpose, ethical issues, and confirmation of participation in the study. The next page included an introductory form for demographic data such as the participant's age, gender, and work experience. Finally, there was a semi-structured interview with open-ended questions to collect qualitative data.

### Data Collection Process

The link to Google Forms was sent to the NCC in Ankara via e-mail. In the e-mail, the responsible researcher's contact information, the study's purpose, the criteria for inclusion, the ethics committee approval, and the permission of the Ministry of Health were provided. The data collection form was then requested to be forwarded to the nine RCCs in Turkey. Forms filled out online were confirmed to be up-to-date by the researchers. The collection process was terminated when the data saturation was reached and the data started repeating.

### Data Analysis

The data were transferred directly from the online forms to text. The first and second researchers combined the answers given to the open-ended questions by the participants. Combining the responses, a text was formed, which was analyzed by all researchers. Data analysis was modeled and reported according to the thematic content analysis of Braun and Clarke[24] The data were evaluated by the inductive method using content analysis without using software packages for qualitative data analysis. The data analysis process was carried out in six steps. All researchers first read all documents to become familiar with the data (1), after which the records were divided into sections and coded separately by the researchers (2). The themes were then searched (3), reviewed (4), identified, and named (5) to ensure that the process was consistent and reliable. Finally, the researchers came to a common conclusion by discussing all the results, and the reporting process was performed by four researchers (6).

### Trustworthiness and Rigor

The Consolidated Criteria Guidelines for Reporting Qualitative Research (COREQ) was used in this study to ensure transparency and improve study rigor.[25] The first researcher (PhD Candidate, RN) who participated in our study worked in two different centers as an OTDC and is

experienced in this field. The fourth researcher (Professor, RN) is an experienced researcher in qualitative studies.

At the beginning of the online data collection form, to ensure credibility, the criteria for participating in the research (actively carrying out an OTDC task in any hospital with intensive care), the purpose of the study, how to answer the research questions, and how to contact the researchers in case of any query or opinion, were written in detail. The data collection form was filled in as a pilot application by two OTDCs in Antalya RCC. The average time to complete the form was determined and added to the explanation portion. In addition, it was announced that no personal data was collected, the participants' opinions were valuable, they could express their thoughts freely, and the information collected would only be used for research.

To ensure transferability, all stages of the study were explained in detail in the mail and at the beginning of the online data collection form. In addition, a purposeful sampling method was used in the study. The expressions of the participants were faithfully translated into English with care to preserve the original intent. The identical mail and online form were sent to the OTDCs during data collection to ensure reliability. The researchers checked the data collection forms filled out online for completeness. The collection process was terminated when data saturation was reached and the data started to repeat. A question about comments and suggestions was added at the end of the online data collection form. The researchers gathered for verifiability at each data analysis stage and formed a consensus. In addition, expert opinion was obtained from a professor experienced in qualitative research who lectures at the graduate level on preparing data collection forms, making pilot applications, and communicating with participants.

### Ethical Aspect of Research

Approval numbered 14.04.2021 2021/3 from Gümüşhane University Ethics Committee, and research permission dated 23.05.2021 from the Ministry of Health were obtained. No personal data was used in the research. Participation was dependent on the consent of the participants.

## RESULTS AND DISCUSSION

Of the OTDCs participating in the study, 83.3% were nurses (n: 10), 16.7% were doctors (n: 2). As reported, 75% (n: 9) of the OTDCs worked in public hospitals and 25% (n: 2) in private hospitals.

As a result of the meeting with the OTDCs, themes of density in ICUs, negative effects of the COVID-19 pandemic on OTDCs, changes in the diagnosis process, communication difficulties with family, decrease in the number of potential donors, and a decrease in organ donation activities emerged as themes (Table 1).

**Table 1. Main Themes and Sub-Themes**

| Main themes | Sub-themes |
|---|---|
| Occupancy in intensive care | • Extended treatment period for COVID-19 patients<br>• Reservation of intensive care beds for COVID-19<br>• Isolation due to COVID-19 |
| Adverse effects of the COVID-19 pandemic on coordinators | • Burnout<br>• Workload increase<br>• Worry about getting infected |
| Changes in the diagnosis process | • Difficulty in ruling out COVID-19 pneumonia<br>• Requesting additional examinations and consultations from potential returnees |

**Table 1. (Continued)**

| | |
|---|---|
| | • Guidance deficiencies in the diagnosis process |
| Communication difficulties with the families | • Inability to conduct face-to-face family interviews at the desired level<br>• Ineffective remote calling methods<br>• Failure to provide effective communication due to masks and distance |
| Reduction in the number of potential donors | • Active life slowing down due to restrictions<br>• Brain death notification remains in the background |
| Decreased organ donation activities | • Inability to perform mass organ transplant activities due to restrictions<br>• COVID-19 becoming the main agenda<br>• Increasing staff workload |

## Occupancy in İntensive Care

Participants stated that there were no empty beds in the ICU compared to the pre-pandemic period and that most of the beds were occupied by COVID-19 patients hospitalized for an extended time. It was stated that due to this COVID-19 density, space for potential donors was lacking. In addition, study participants stated that the COVID-19-induced density in the ICU was also due to the separation of devices in the ICU for COVID-19 patients, the extra isolation measures, and the prolongation of patient hospitalization.

*"Since intensive care beds were reserved for COVID-19 patients, it was difficult to find a place for brain death cases. We had to refer many patients." P9*

## Adverse Effects of the COVID-19 Pandemic on Coordinators

Participants frequently stated that they were negatively affected by the pandemic process professionally. They indicated that they experienced burnout due to busy working hours, increased workload due to a lack of personnel and patient density in ICUs, and prolonged coordination processes. The OTDCs stated that their motivation decreased because they were working outside their units during the pandemic and were afraid of being infected while working in high-risk areas.

*"Coordinators and intensive care workers were frightened by everything in this process. Fear of illness changed priorities." P3*

## Changes in the Diagnosis Process

The participants in our study stated that with the pandemic, additional tests and consultations were requested to ensure the exclusion of COVID-19, prolonging the coordination process. They also noted that organ perfusion was adversely affected due to the prolonged diagnosis process. Difficulties were experienced in distinguishing between COVID-19 pneumonia and other types of pneumonia, and indecision occurred due to the lack of helpful diagnosis guides.

*"The difficulty in excluding COVID-19 infection and COVID-19 tests performed at 24-hour intervals caused the perfusion of unstable patients to deteriorate, as it prolonged the coordination process. Even before this process was completed, donor loss occurred many times." P11*

## Communication Difficulties with Families

The OTDCs indicated that they had problems with family meetings. They stated that family visits were either completely removed or severely restricted due to the pandemic. Families that could not see their sick relatives became closed to communication during the donation process. Due to the pandemic measures, face-to-face information could not be provided, family conversations over the phone were insufficient, and face-to-face meetings were ineffective due to masks and distance. In addition, families were unwilling to meet face-to-face due to the fear of contagion, not enough family members attended meetings, and those who came to the interview were primarily negative about organ donation. They wanted to take their relative's bodies and leave the hospital as soon as possible.

*"The uneasiness of the families to come to the hospital negatively affected the family interview. Most of the time, we were informed by phone. That wasn't enough either." P2*

**Reduction in the Number of Potential Donors**

The OTDCs stated that due to the restrictions in the pandemic and the slowdown in active life, the number of trauma patients and potential donors who were hospitalized decreased, and potential donors were referred because there was no room in the ICU. It has been stated that there has been a decrease in the detection of potential donors due to the reluctance of personnel to enter the ICU environment due to the fear of infection and the increased isolation measures. Our participants also stated that the anxiety experienced with the pandemic put brain death notifications on the back burner.

*"Decreasing traffic and other accidents, leading a quieter life, and a subsequent reduction in injuries naturally reduced potential organ resources." P12*

**Decreased Organ Donation Activities**

Participants stated that the measures taken due to the pandemic prevented organ transplant activities from being carried out. They stated that planned awareness training and organization were postponed or could not be realized due to the COVID-19 pandemic. The changes in the workplace and the increasing density of participants also led to the inability to organize event planning during this process.

*"Motivation has dropped, events have been removed because everyone is afraid of COVID-19, and training has stopped. Organ donation lost its importance and remained in the background." P4*

It is known that DBD numbers reported throughout the world and in Turkey decreased dramatically during the COVID-19 pandemic.[26-32] The findings of our study have clearly revealed the reasons for the decrease in the number of donors in Turkey based on the experiences of OTDCs. Our results are very important for planning solutions that can prevent the reduction in the number of donors that may occur during pandemics and other extraordinary situations. In addition, it is foreseen that our study will make significant contributions to the literature, as it is the first to reveal the experiences of OTDCs during the pandemic.

The first of the themes identified in our study was 'intensity in intensive care.' The vast majority of participants agreed on the density in ICUs. The rapid increase in COVID-19 patients, the inadequacy of personnel, the isolation measures taken, and the long treatment period caused the density. Similar studies stated that patients' average length of stay in the ICU during the pandemic was prolonged and increased by up to 28 days. It has been reported that the increase in COVID-19 cases and the prolongation of treatment processes are important reasons for the increase in ICU density.[33] Cheung et al.[34] stated that most of the beds in ICUs where brain death cases occur were reserved for patients with COVID-19, and the number of donors decreased accordingly. This decrease in the number of donors is to be expected during pandemic conditions where the hospitalization and evaluation of potential donors in ICUs cannot be adequately performed.

Our study, which reveals the pandemic process's effect on OTDCs, contributes to an important issue that needs to be included in the literature. It was determined that OTDCs are exhausted professionally and adversely affected by intense working conditions outside of the pandemic.[35-37] In addition to the normal intensive working conditions during the pandemic, OTDCs in our study experienced negative effects and burnout. Working in clinical areas where the risk of being infected by workplace changes is high may have brought new stressors for the OTDCs. Feeling that personal health is under threat with the increased workload may have increased the anxiety of the OTDCs and decreased their willingness to work. For

healthcare workers, studies have determined that negative effects such as depression, anxiety, burnout, and post-traumatic stress disorder occurred during the COVID-19 pandemic.[38,39] These negative effects may have decreased the work efficiency of the OTDCs and reduced donor notification.

The pandemic has brought with it many uncertainties. One of our study's prominent findings is that there were issues in diagnosing possible donors during the pandemic. The inadequacy of the guidelines covering the pandemic increased the uncertainties, and the additional tests required to clarify diagnoses extended the process. When the literature was examined, it was found that new flow charts and guidelines have been developed and implemented to standardize the diagnoses process for potential donors during the COVID-19 pandemic and to make diagnoses in the optimum time. According to the renewed schemes, the patient's COVID-19 test result, signs and symptoms, and imaging examination influence the process.[26,40] In Turkey, we acted by waiting for the COVID-19 test results, and it was observed that organ perfusions were affected by the time lost in this process, and the number of possible donors decreased.

Within the scope of the measures taken during the pandemic, families were removed from hospitals, and patient-family communication was prevented. Families, important decision-makers in organ transplantation, were also kept away from the hospital environment due to precautions, and visits were limited.[32] Accordingly, the interaction between OTDCs and families decreased. Effective communication and persuasion processes are key in obtaining the family's consent regarding organ transplantation. Based on our study results, the inability to maintain effective communication with the family was among the primary reasons for the decreased number of donors. Our study demonstrated that remote communication techniques are not optimal for obtaining the consent of families who do not want to meet face-to-face due to the fear of being infected. The fact that some family members could not see their relatives or control the disease process caused the acceptance of loss to be prolonged and a negative decision about donation. Masks and distance measures have emerged as new obstacles where face-to-face communication is possible. It is known that body language is an integral part of effective communication, and family members receiving effective communication have higher donor acceptance.[40] Our study revealed that pandemic conditions negatively affect communication in this respect. Cheung et al.[34] stated that family interviews were conducted face-to-face during the pandemic, and thus, possible off-putting effects on family approval were eliminated. The difference in study outputs has also demonstrated the necessity of face-to-face communication for family acceptance under pandemic conditions and in all extraordinary situations.

With the pandemic, curfews due to contagion measures and the reduction of crowded environments led to a decrease in activity, which in turn led to a considerable reduction in traffic accidents, traumas, and injuries. It is known that trauma patients constitute the majority of potential organ transplantation donors.[31,32] In our study, it was observed that potential donors decreased, and the reduced number of trauma patients admitted to the hospital was an important reason for this. In addition, the decrease in brain death reports also reduced the number of potential donors. The chaotic work environment and the anxiety of being infected may affect the occupational motivation of health professionals and, as a result, reduce the detection of brain death. The presence of unknown conditions for COVID-19 is also thought to be a factor that complicates the detection of brain death.

The prohibition of mass events due to the pandemic and the fact that the fight against the epidemic became the main agenda led to a decrease in organ donation activities and a decrease in interest in organ donation awareness. Prioritizing the developments

related to the pandemic in the media overshadowed public awareness of organ donation campaigns. As a result, individuals in the community could not raise awareness of organ donation.[40] Our study supports the findings that awareness and donations have decreased. The OTDCs were also motivationally affected by the overshadowing of the issue of organ donation. Working conditions became more difficult for OTDCs to organize new activities, and activities decreased quantitatively.

### Limitation and Strength

The limitation of our study is that the data cannot be collected face to face due to the pandemic. However, a strength of the study is the inclusion of OTDCs from all regions of Turkey.

## CONCLUSION AND RECOMMENDATIONS

In our study, six main themes emerged regarding the experiences of OTDCs during the pandemic process. These themes provide important clarification as to the reasons for the decrease in organ donors during the pandemic. Our study revealed insufficient action plans, guidelines, and communication tools regarding the cadaveric donation process during the pandemic. Developing new guidelines regarding the donor identification process and integrating telemedicine practices into family interviews for pandemics and all extraordinary situations is recommended. With the institution of such practices, it is predicted that both the acceptance of the family and the motivation of the OTDCs will increase. Although new workflows and guidelines are being introduced in accordance with pandemic conditions to prevent clinical backlogs in hospitals, it is recommended to include the cadaveric donor process in these guidelines.

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