

# Clinical Ethics, Personal Values, Legal Uncertainties, and Possible Conflicts in Cases of Brain Death in Türkiye: An Applied Study

## Türkiye’de Beyin Ölümü Vakalarında Klinik Etik, Kişisel Değerler, Yasal Belirsizlikler ve Olası Çatışmalar: Bir Uygulamalı Çalışma

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**ABSTRACT** Both clinically and legally, brain death has long been recognized as death. However, many people including patient relatives still equate death with cardiopulmonary death (irreversible cessation of heartbeat and breathing), and thus may oppose withdrawal of life-support technologies and refuse to consider organ donation in brain death. Such reactions may lead to problematic or dilemmatic situations in relation to the norms and practices of justice, beneficence, paternalism, futile care, defensive medicine, due care, consideration of personal beliefs and values and financial and emotional burdens, etc. Although the determination of brain death and procedures of organ donation have been legally regulated in Türkiye since the late twentieth century, there have also been legal uncertainties about the decision to terminate care, particularly the extent to which the decision depends on the agreement of patient relatives. With consideration of historical developments, legal documents, ethical issues, and personal attitudes, the present study aimed to analyze the nature of such conflicts between patient relatives (agents that act with subjective priorities) and health-care providers (agents that should act within certain standards) as the two parties in a typical case of brain death. For particular emphasis on the pivotal role of information and communication in the resolution of potential conflicts in real cases of brain death, the discussion was made with application in a hypothetical case.

**ÖZET** Beyin ölümünün ölüm olduğu, uzun zamandır gerek klinik gerekse yasal olarak tasdik edilmiş bulunmaktadır. Fakat aralarında hasta yakınlarının da olduğu pek çok insan, hâlen ölümü kardiyopulmoner ölüm (kalp atışının ve solunumun geri getirilemez biçimde durması) ile özdeşleştirmekte ve böylece beyin ölümünde teknolojik yaşam desteklerinin sonlandırılmasına karşı çıkabilmekte, organ bağışını düşünmeye yanaşmayabilmektedir. Bu gibi reaksiyonlar adalet, yararlılık, paternalizm, boşuna tedavi, defansif tıp, gereken özeni göstermek, kişisel inanç ve değerleri ve de finansal ve duygusal yükleri gözetmek gibi norm ve pratikler ile ilgili problemlere ya da ikilemlere yol açabilmektedir. Türkiye’de beyin ölümünün tespiti ve organ bağışı prosedürleri XX. yüzyılın sonlarından bu yana kanunî regülasyona tabi olsa da bakımı sonlandırma kararı konusunda, başta kararın ne derece hasta yakınlarının katılımına bağlı olduğu hususu olmak üzere, yasal belirsizlikler de olagelmıştır. Bu çalışmada tarihi gelişmeler, yasal belgeler, etik meseleler ve kişisel tutumlar göz önünde bulundurularak, tipik bir beyin ölümü vakasındaki iki tarafı teşkil eden hasta yakınları (subjektif önceliklerle hareket eden özneler) ve sağlık hizmeti sağlayıcıları (belli standartlar dairesinde hareket etmesi gereken özneler) arasında yaşanan bu türden çatışmaları analiz etmek amaçlanmıştır. Bilgilendirme ve iletişimin gerçek beyin ölümü vakalarında yaşanabilecek çatışmaların çözümünde oynadığı merkezi rolü bilhassa vurgulamak adına, ilgili tartışmalar hipotetik bir vaka üzerinden tatbik ile birlikte gerçekleştirilmiştir.

**Keywords:** Brain death; life support; organ donation; organ transplantation; patient relatives

**Anahtar Kelimeler:** Beyin ölümü; yaşam desteği; organ bağışı; organ nakli; hasta yakınları

“*[Doctors] are only a human trying to fix up a human.*”

Anne Sexton (1928-1974)

When a dead human body is spoken of, most people will associate that body with certain tradi-

tional physical signs of death, such as no bodily movement and an utter absence of heartbeat and breathing. However, these signs that many reasonable people would view as the only possible way in which death can manifest itself are far from amounting to death today. Although the irreversible cessa-

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tion of the cardiac and pulmonary functions had been clinically and legally the most significant indicator of death for centuries, this has not been the case since the mid-20<sup>th</sup> century, due to the clinical introduction of life-sustaining treatments including modern cardiopulmonary resuscitation.

Today most terminally ill individuals, as well as victims of fatal accidents, are hospitalized at the end of their lives and receive artificial life support (LS) for the vital functions that their bodies come to fail to maintain. However, in a variety of cases, particularly diseases and injuries involving the brain, there is now the phenomenon of irreversible loss of all brain functions during the use of LS, which inevitably is death, the type of death called brain death. In fact, the LS technologies have become so advanced and widespread that cardiopulmonary function can often be sustained for days to weeks after brain death, with a picture of deceased individuals who appear to be breathing, with their hearts beating. Because of its lack of the traditional, best-known signs, this presentation of death does not match up with what the general public expect to see in a dead body. Even people from communities with clinical knowledge, including physicians and medical students, can equate death with circulatory death.<sup>1-3</sup> Such tendencies not being uncommon, some patient relatives, when told that their loved one has become brain-dead and that medically there is nothing left to do but disconnect the body from the machines, question the truth of such a death and, based on the apparent presence of heartbeat, breathing and spinal reflexes, even deny the fact that the person has died altogether. They ask for empathetic approaches, hope for religious miracles, and request that LS be continued until “the last moment.” Also, sometimes brain death is confused with apparently similar but clinically different, other conditions, such as a coma or vegetative state.

With consideration of historical developments, legal documents, ethical issues, and personal attitudes, the present study aimed to analyze the nature of such conflicts between patient relatives (agents that act with subjective priorities) and health-care providers (agents that should act within certain standards), and emphasize the vital role of adequate in-

formation and communication between these two parties in a typical case of brain death.

## MATERIAL AND METHODS

First, historical research was carried out to set up a factual framework. Beginning with the historical context surrounding the original statements made by the Harvard Medical School (HMS) in 1968, major clinical and legal developments on brain death in the United States (US) and the Republic of Türkiye were reviewed together, with a focus on established definitions and legal uncertainties/inconsistencies. The historical connection between brain death and organ donation was highlighted, and the current LS withdrawal and organ donation procedures in brain death in Türkiye were outlined with regard to the role of patient relatives/families. Then, practical and ethical implications of the facts presented (Results) were discussed using several of the medical ethical norms and considerations (justice, beneficence, paternalism, futile care, defensive medicine, due care, consideration of personal values and beliefs and financial and emotional burdens, etc.) addressed by American philosophers Beauchamp and Childress in *Principles of Biomedical Ethics* since the 1970s.<sup>4</sup> The method of balancing was also used, given the fundamental proposition of Beauchamp and Childress that moral agents (health-care professionals) consider and balance all relevant moral norms (principles, obligations, rights, virtues, etc.) while making a decision that might affect other individuals (patients and patient relatives). *Principles of Biomedical Ethics*, which has become the mainstream paradigm of medical ethics in the Western world, particularly the US, also amounts to an encapsulation of the main principles governing clinical practice and medical ethics and law in Türkiye today.

For particular emphasis on the pivotal role of information and communication in the resolution of potential conflicts in real cases of brain death, the discussion was made together with application in the following hypothetical case:

*Lara, who is 28 years old and lives apart from her parents in southern Türkiye, is bored with the life she has been living lately and says, only to her clos-*

*est friends and without giving details, that she needs to “get away from it all.” She comes to İstanbul (Western Türkiye) for a trip of a few weeks. However, on her way from the airport, she is attacked by a purse-snatcher before she arrives at her hotel; her purse containing her money, phone, and identity card is stolen; and she hits her head on the curb while resisting the attack. The traumatic brain injury results in brain death some time after her hospitalization. The next day when the diagnosis of brain death is clinically confirmed, the attending clinical team discuss the termination of the LS provided to this unidentified woman, although they are hesitant with some questions: “What would the family of the young woman want if they were here?”, “Should we wait some more until perhaps somebody shows up?”*

## RESULTS

Both clinically and legally, brain death has long been recognized as death. As early as 1968, an *ad hoc* committee consisting of members from the fields of medicine, law, and theology was formed by the HMS in order to define this then-novel clinical condition called “irreversible coma” or “brain death syndrome.” A seminal report by this committee described the clinical characteristics of the condition producing individuals “whose heart continues to beat but whose brain is irreversibly damaged” and becoming increasingly common as a result of improvements in the LS technology and use. In the following years, along with the developments in the US, an internationally growing consensus developed around the nature of brain death as outlined in the HMS statements, with countries (including Türkiye) defining their own official criteria and rules on the subject. The same report also drew attention to issues that are still being discussed today, including the impact of keeping brain-dead individuals on artificial LS on their families, national health systems, and salvageable patients in need of the health-care resources consumed for such futile care.<sup>5,6</sup>

What prompted medical and national authorities to make serious regulations on brain death from the 1970s onward was not a far-reaching stimulation by the influential HMS, but a fact that had previously stimulated the HMS itself; to be exact, two facts: (i)

that the same advanced medical technologies now also enabled the allotransplantation of solid organs (e.g., the first heart transplant was performed in 1967 and this historic event involving the use of a donor diagnosed with brain death fueled the debate on the regulations on organ procurement from these individuals), and (ii) the great need for transplantable organs in medicine worldwide.<sup>7,8</sup> Despite the actual and potential procedures using stem cells and animal and artificial organs/tissues, deceased and living human donors remain the two main sources of organs/tissues in transplantation medicine today; and the category of deceased donors refers mostly to brain-dead individuals, for the use of donation-after-brain-death with better transplant outcomes has long been more common compared with the recent reutilization of donation-after-circulatory-death.<sup>9-11</sup> Accordingly, there have been efforts to make clear and uniform the pertinent legislation in order to prevent the non-recognition of brain death as death in different jurisdictions and the possible confusions due to different approaches. For example, the widely adopted US Uniform Determination of Death Act, aimed at “determining death in all situations”, states as follows: “An individual who has sustained *either* (1) irreversible cessation of circulatory and respiratory functions [circulatory/cardiopulmonary death], *or* (2) irreversible cessation of all functions of the entire brain, including the brain stem, [brain death] is dead.”<sup>12</sup> Similarly, in Türkiye, the criteria and clinical specialty requirements for diagnosis of “brain death” (the term “irreversible coma” was also used) have been regulated by legislation since 1993, while the procedures of organ/tissue procurement, preservation, grafting, and transplantation involving the use of deceased donors have been regulated since 1979.<sup>13-16</sup>

It should also be noted that changes have occurred in the Turkish legislation over the years. For example, while the original 1979 text of the Law on the Organ and Tissue Procurement, Preservation, Grafting, and Transplantation required that the “clinical state of death” be determined “by unanimous agreement of a committee of *four* physicians consisting of a cardiologist, a neurologist, a neurosurgeon, and an anesthesiology and reanimation specialist”,

this requirement was reduced in 2014 to “unanimous, evidence-based medical decision of a committee of two physicians consisting of one neurologist or neurosurgeon and one anesthesiology and reanimation specialist or intensive care specialist.”<sup>17</sup> There have also been textual changes that cause uncertainty and even inconsistency, particularly when they come together with other pieces of legislation. The 1993 Regulations on Organ Transplantation Centers stated as follows: “The medical support provided to the patient is withdrawn when permission for organ donation cannot be obtained after the patient relatives have been informed of the brain death.” In 2000, the Regulations on Organ and Tissue Transplantation Services stipulated that in case of brain death LS could be withdrawn only with the permission of the patient relatives; and this stipulation was not included in the 2012 update of the same Regulations. Accordingly, in the current absence of specification, it is unclear who will decide on the withdrawal of life-sustaining technologies, with the implication that the attending clinician is now given greater discretion in that decision. However, the same legal uncertainty also has the potential to pose a dilemma for the clinician.

Concerning organ/tissue donation after brain death in Türkiye, if the deceased individual had expressed a wish not to be a posthumous donor, the wish is fulfilled in all cases. If the individual had not expressed any wish about posthumous donation, familial consent is mandatory before any attempt at organ/tissue procurement. However, even if the deceased individual had registered (opted in) to be a donor, familial consent is still sought. In clinics operating with due care, brain deaths are diagnosed, and once the diagnosis is clinically confirmed it is ensured that the patient relatives receive further information (from officials from the National Organ and Tissue Transplantation Coordination System) about the meaning of brain death and the option of organ donation. Nevertheless, it has been reported that in a significant number of cases families do not approve their relative’s previous decision to be a donor or reject the idea of organ donation altogether, often due to a refusal of communication or a persistent lack of information.<sup>18-21</sup>

## DISCUSSION

Given the findings presented above, in Türkiye there is no legal barrier to health-care providers’ termination of artificial LS in brain-dead patients; however, since the human is a multidimensional being, there are still additional factors that need to be considered, including the sociocultural, emotional, and religious factors.<sup>22-25</sup> Sometimes the cause of the hesitancy is the reactions of patient relatives that can vary widely. As mentioned earlier, families may not see the clinical presentation of brain death as “true death”, may for various reasons request that LS be continued, and may threaten legal action in case of a contrary attempt or omission that they perceive will “kill” their relatives. For most hospitals and health-care professionals, the risk of being accused of such malpractice/negligence is one that cannot be taken. In 2014, the financial costs associated with non-medically indicated procedures performed to avoid similar accusations, i.e., “defensive medicine” performed merely for usable evidence of sound medical practice, exceeded 45 billion dollars in the US alone.<sup>26</sup> Similarly, depending on country, the cost of one-day hospitalization in the intensive care unit can be considerably high; and the cumulative costs of the medical procedures that become futile in cases of brain death are a burden on national health systems that can be clinically and socially justified only when organ donation has been intended, as well as the individual costs are expenses in private health insurance that companies are reluctant to cover.<sup>27,28</sup> Unless there is at least justification based on the necessity that organs must be kept alive with LS and other interventions until their procurement for transplantation, these consumptions and costs are characterized by the medical ethical phenomena of “defensive medicine” and “futile care” and are inconsistent with the fundamental medical ethical principle of “justice.” This is so simply because the resources unduly allocated to these deceased individuals can instead be effectively used in the critical/intensive care of salvageable patients.

On the opposite end of the scale, the bereaved patient relatives whose disagreement is in fact due to the influences of grief and related emotions are con-

trusted by families that could consent to the termination of artificial LS and, when the deceased member had opted in, procurement of transplantable organs as a result of their information through communication with them. The hypothetical case presented in the section Methods was devised to highlight the importance of the presence of mutual information and communication between patient relatives and clinical teams (or more broadly, health-care providers) as the two parties in a typical case of brain death. When unable to communicate with the patient relatives, the clinical team has two options neither of which may initially be certain enough: continued LS for some additional time or until cardiopulmonary function can no longer be sustained, or immediate discontinuation of the LS technologies being used. Similarly, the patient relatives could make a request in line with either of these options: that “treatment” be continued, or discontinued. Depending on the extent to which the clinical team is determined to act within the clinical limits and to which the patient relatives understand the clinical facts, four combinations of the choices of continued (CLS) and discontinued life support (DLS), with different professional (primarily ethical) and personal (primarily moral, emotional and financial) consequences, are possible:

*When both parties choose CLS:* Because of their disappointing experiences in many previous cases, the clinical team assumes that Lara’s parents (the patient relatives) would request CLS and thus do not withdraw LS although they know that the use of LS is clinically futile. In this situation there is a professional loss because they go against the bioethical principle of justice and waste resources that could be used effectively in salvageable patients. Lara’s parents, when they do insist on CLS despite its futility, also act against principles of social justice and, as another loss, the expenditures associated with the futile interventions they demand could (private health insurance) and should (national health insurance) be imposed on them for out-of-pocket payment.

*When the patient relatives choose DLS and the clinical team chooses CLS:* This is the situation when clinical teams, who fail to consider that the patient relatives they are dealing with may be individuals that would consent to DLS after adequate information,

continue futile medical interventions. (This is close to the attitude of a prejudiced physician thinking that patient relatives, hoping for miracles, tend to insist on CLS or to an approach of defensive medicine where all available medical resources are used to avoid accusations of malpractice, and is far from clinical practice in line with the principle of beneficence.) When the bereaved individuals are ones that would prefer that their relative be interred without delay, continued medical intervention risks provoking feelings of intensified sorrow because of the possible view that the body of the deceased was instead kept connected to some medical machines, exposed to needless interventions. For the clinical team who are now deprived even of an excuse based on familial wishes, there is the risk of a more consequential fault of futile intervention.

*When the clinical team chooses DLS and the patient relatives choose CLS:* This is the situation where the clinical team terminates the artificial LS that legally and clinically they do not have to provide after brain death and Lara’s parents are individuals that would insist on CLS in any case as long as there is cardiac pulsation. For example, a Roman Catholic family with a traditional religious approach might interpret brain death as the failure of only one of the organs found in the body and, given that the human body does not consist only of the brain, might judge that the death of the brain does not mean “the separation of the soul from the body” which results in “the total disintegration of the integrated whole that was the person.”<sup>29,30</sup> An Orthodox Jewish family might maintain that death should occur only “naturally” as manifested by the irreversible cessation of heartbeat and breathing and demand that until that point LS be continued by applying all possible medical technologies (and out-of-pocket payments if necessary).<sup>31</sup> There is the risk that a contrary clinical decision may be perceived as an act of killing, with its outcome being experienced as a devastating loss. As reported in the literature, in such a case there is also the possibility that health-care providers may face grave accusations and have to fight legal battles. Thus, compared with a mutually agreed-upon end, the termination of LS despite contradictory demands of patient relatives is always a more difficult decision to

make for clinicians (and is close to the approach of a paternalistic physician acting exclusively on clinical data and his own opinions without considering the personal values and non-clinical wishes of patients or patient relatives).

*When both parties choose DLS:* This is the situation when there is communication with patient relatives and familial consent to the withdrawal of artificial LS following the information processes or when the patient relatives are individuals that are already knowledgeable about brain death and futile care. When there is agreement on what is rational, no to little professional (ethical) and personal (moral and financial) losses are possible. Moreover, in the case that the deceased individual had opted in, a family honoring that decision could receive consolation from knowing that other individuals will benefit substantially from this “gift of life.”

## CONCLUSION

In cases of brain death, it is not uncommon that the idea of withdrawing life-support technologies/life-sustaining treatments be perceived as not doing everything that could be done and met with opposition by patient relatives. Also, it is not rare that the termination of the interventions be delayed by health-care providers in sympathy with deeply upset patient relatives or in avoidance of problematic reactions, sometimes by not making an official diagnosis of brain death.<sup>32,33</sup> However, it is also a fact that on the other hand there are many families that can agree on DLS in brain death, with cases where families also honor their deceased member’s wishes for posthumous organ donation or consent to offered donation in the absence of any expressed/documentated wishes. As illustrated in the present study, information through mutual communication is essential for eliminating preconceptions and misassumptions of both patient relatives and health-care professionals as well as effects of legal uncertainties and possible ethical

dilemmas. It is also essentially instrumental in reducing the burden of futile/defensive procedures on national health systems, contributing to cost-savings with the superior cost-effectiveness of organ transplants among other treatments such as dialysis, and improving the survival and quality of life of patients suffering from organ failure.<sup>34,35</sup>

The approach of a clinician may not always be based on clinical data and facts, since it can also be influenced by -actual or perceived- rights, requests, and facts of the patient or those representing the patient. In the first scenario above where futile care is continued despite the diagnosis of brain death and in the absence of consent to organ donation, it was shown that such cooperation is characterized by denial and avoidance, and is not based on rational thinking and ethical action. Furthermore, even when the use of LS is to be continued for the non-clinical reasons, this should occur only after thorough information about the lost benefits and multifaceted consequences, the disclosure of all relevant information remaining central to the well-established principle of informed decision-making.

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### *Conflict of Interest*

*No conflicts of interest between the authors and / or family members of the scientific and medical committee members or members of the potential conflicts of interest, counseling, expertise, working conditions, share holding and similar situations in any firm.*

### *Authorship Contributions*

*This study is entirely author's own work and no other author contribution.*

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