

Decision-making and Folklore in the Matter of Life and Death: Brain Death, Organ Donation, and Miracle Narratives

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ABSTRACT: Türkiye and the rest of the world have been experiencing insufficient cadaveric organ donations. Although Turkey laws regulating organ transplantation allow the harvest of organs from the brain-dead who donated their organs while they were alive, Turkish social norms prohibit physicians from applying the written procedures. Therefore, both verbal and written consent of the close relatives of the possible cadaveric donors must be obtained after the brain death is announced. The ambiguity of the concept of brain death, invented in the 50s, and the terminology of modern medicine limit people's ability to comprehend the states of coma, vegetative life, and brain death. Even though cross-cultural studies verify that the most common reasons for reluctance in cadaveric organ donations are religious concerns, interviews with donors and refusers, who are the relatives of brain-death people, revealed that folklore transmitted to generations within the context of beliefs, rituals, social norms, and oral genres also affect the judgment of prospective donors. As will be discussed in this paper, miracle narratives are particularly referenced in rejecting the reality of brain death in the conducted interviews. This paper will explore how such narratives affect decision-making process of refusers concerning the death of one and the survival of another.

KEYWORDS: Culture, folklore, cadaveric organ donation, decision-making, miracle narratives

Introduction

Brain death is an invented form of death due to the advances in resuscitation and intensive care. Before then, medical understanding of death was uniformly acceptable worldwide and defined as irreversible loss of functions of the heart and lungs. When C. Beck successfully defibrillated his patient in 1947, medical practitioners discovered that death was reversible (Beck et al. 1947). If the heart could be resuscitated, lung failure death must have also been reversible. Piston ventilators had been used in operating rooms since 1947, but the possibility of lung resurgence first came true in 1950. A year after the piston ventilator was developed for medical purposes, in 1954, Robert Scwab evaluated a coma patient with brain damage. The patient didn't show any life signs apart from the heart maintaining circulation. He turned the respirator off and announced the patient's death (De Georgia 2014, 673). At the time, practitioners had not known the concept of brain death. The concept of death began to change with the mass production of ventilators.

After ventilators were mass-produced in 1955 and became more accessible to doctors, doctors faced diagnostic and ethical dilemmas, particularly concerning patients in a coma (Feng and Lewis, 2023; Beck, Pritchard, and Feil 1947; De Georgia 2014). While these discussions arose, the first successful organ transplantation was performed in 1954 (Merrill et al. 1956). Parallel breakthroughs in resuscitation and intense care, clinic findings in coma patients regarding nervous integration and consciousness, organ transplantation, and ethics coincided (De Georgia 2014, 674). Ethical concerns regarding end-of-life care shifted from whether patients could have euthanasia to avoid further suffering to whether doctors had to prolong the lives of incurable patients. Afterward, ethical concerns regarding end-of-life care moved from academia to the church. Pope Pius XII responded to these concerns with an ordinance in 1957 declaring that doctors did not have to provide extraordinary treatment if it were hopeless. A few years later, F. Ayd suggested to his colleagues that withdrawing care was their duty when death was inevitable. According to him, physicians must recognize

man's right to live or die peacefully. Otherwise, life-preserving treatment could be a scientific weapon for prolonging agony (Ayd 1962, 1099).

Furthermore, before the developments in immunosuppression, transplants between unrelated donors and recipients failed since recipients' immune systems rejected the transplanted kidney. After using immunosuppressants in organ transplants in 1960, rates of organ rejections between unrelated parties declined. In the course of the conceptualization of brain death, terms such as severe coma, beyond coma, hopelessly unconscious patient, irreversible coma, and brainstem death were used to define brain death and its' medical criteria between 1968 and 1981 (Beecher 1968b; 1968a; 1969; Spoor and Sutherland 1995; Machado 2014; De Georgia 2014). At the beginning of the discussions about whether brain death is irreversible, Dr. R. S. Schwab, the first neurologist who questioned whether his comatose patient was alive or dead in 1954, foresaw the current discussions saying doctors need a definition that would have to be accepted by lawyers, medical examiners, and laypeople in 1968 (De Georgia 2014, 675). Defining and legislating brain death took nearly thirty years for the medical community (1954-1981). Studies show that some medical practitioners have questioned the validity of brain death even today since medicine is open to discoveries (Franklin G. Miller and Truog 2009; Alan Shewmon 2009; Hamdy 2012). The brain death concept meets two functions: ventilated persons with irreversible and permanent loss of brain function are declared dead, and ventilated organs of the person can save patients with organ failure.

Methodology

Regulations regarding cadaveric organ donation allow surgeons to harvest cadaveric organs if the brain-dead filled out a consent form while alive. However, the Turkish Health Ministry wants to get along with social norms to protect the social structure of the family of brain death donors. Therefore, even if the individuals donate their organs, coordinators invite the person's relatives after the brain death is announced to ask them if organ donation can proceed. 63.808 patients receive dialysis treatment, and 24.983 are registered waiting list (WL) for cadaveric kidney donors. 2.414 died because they could not find living or cadaveric kidney donors. 3.886 patients suffering from liver failure were active on the waiting list, and sadly 178 of them died while on the WL in 2021 (Domínguez-Gil 2021). While Turkiye is among the three world countries in live organ donations (kidney and liver), the rates of cadaveric donations are meager (Domínguez-Gil, 2021). Knowing Islam promotes organ donation referencing the 32nd Ayat of Surah Al Maida- "...if anyone saved a life, it would be as if he saved the whole people..." This research project aimed to investigate the socio-cultural reasons for unwillingness to cadaveric organ donation.

Therefore, I designed an ethnographic research project to understand how culture and folklore intercept the decision when one has a chance to make several people live by donating cadaveric organs. Informants were selected from among Muslims adherent to Sunni, Shafiq, or Alevi-Bektashi traditions. Since prior studies regarding Turkiye handled the subject as if all Muslims share common beliefs and values and follow standard norms, I wanted to enlarge the fieldwork with informants from different Muslim subcultures.

Fieldwork was conducted between August 21, 2022, and May 15, 2023. For ten months, I interviewed informants who are transplant surgeons, patients with kidney failure or/and liver failure, living organ recipients and donors, cadaveric organ recipients, relatives of brain death donors, living organ donors, imams, Alevi-Bektashi dedes [dedes are faith leaders of Alevis]. The intention was to continue the fieldwork until October 2023 to enlarge the research as much as possible. The work environment consists of 11 training and research hospitals, 9 of which belong to the state, others to the foundations, and all located in Ankara, the capital of Turkiye. In terms of the national organ transplant system, Ankara is one of the most populated regional organ coordination centers [RCC] (tr. Bölge Koordinasyon Merkezi/BKM), and nine RCCs, including Ankara RCC, are subjected to the National Organ and Tissue

Transplantation Center which is also located in Ankara. This facilitated access to informants involved in organ donation in particular ways.

To uphold ethical responsibilities and ensure the well-being of informants socially, physically, mentally, and economically, complete anonymity was promised to all informants, and pseudonyms, chosen from common Turkish names, were used to replace real names. While interviews were recorded at the moment of interviews, observations regarding the interviews and experiences in fieldwork were noted at the end of the day. Recordings were decoded with the help of the Transcripator, each audio listened to make required corrections on the transcript texts. Before conducting fieldwork, ethics committee approval was obtained from Bartın University Social and Humanities Research Ethics Board, 2022 SBB-0055. Additional official research permissions from each hospital and Ankara RCC were obtained before the fieldwork. All participants were provided with fully informed consent forms, and each participant participated in the research voluntarily.

Data in this paper comes from the interviews conducted with people who refused to donate the cadaveric organs of their brain-dead relatives at the moment of the family meeting held by organ donation coordinators. Participating in these meetings in person, I noted the official reason for rejecting the cadaveric donation that was put forward at the family meeting. Since the mourning period among Sunnis, Shafiq, and Alevis is 40 days, I waited at least forty days after conveying my condolences to relatives of the deceased. After their mourning period passed, I called them, asking if they would interview me. 23 Informants, I will call them from now on as refusers, returned to me. The ages of informants vary from 27 to 68, and interviews were conducted online or face-to-face. Only 4 of the informants are female; the rest are male. Even though female relatives of the brain death were active participants in the meetings, they were passive at the moment of decision-making, withdrawing themselves from the social responsibility and burden of the donation decision. Being present at these meetings, I must add that only dominant female relatives, primarily wives, mothers, and daughters of the brain-dead, could affect other relatives' opinions regarding cadaveric donation.

New Concepts into Old Town: Brain Death and Cadaveric Organ Donation

Turkish national newspapers introduced the international cadaveric transplant operations with headlines such as “patient whose heart was changed”, “a heart transplanted into a dentist is functioning perfectly”, “patients with heart failure are not hopeless anymore”, “patient whose heart changed is getting well”, “patient whose heart changed is going to be discharged in three weeks”, “a heart of a patient, who is fifty-three years old worker, is changed in ABD too” (Hürriyet 1968e; 1968d; 1968c; 1968a; 1968b). At the beginning of the appearance of the news, the authors claimed that donors were dead, referring to the cause of death in detail. Furthermore, the news avoids saying that the vital organs of cadaveric donors, except the brain, were functioning with the help of an artificial life unit at the time of harvesting. To illustrate, Dr. Barnard's criteria for the declaration of brain death were presented as “How do we know a person is dead” on January 31, 1968 (Hürriyet 1968f). News referred to a brain-death person as *living dead* whose brain was crashed, and he was dependent on special machines (artificial life unit) on June 10, 1968 (Hürriyet 1968g). News regarding brain death moved forward, referencing academic discussions in international medicine conventions where Turkish surgeons participated. The first news on this matter introduced that death was not dependent on the functions of the heart and lungs alone but also on the irreversible loss of the brain's functions. However, the news also clearly stated that medical practitioners couldn't decide the medical criteria for the announcement of brain death (Soysal, 1968). The law regulating organ donation was issued on June 3, 1979, claiming that cadaveric organs could be transplanted from dead people. Brain death, as a new form of death, was not included in the law since the concept was complicated to comprehend by the layman. Both the law and news regarding cadaveric organ transplantation stated that all vital organs of cadaveric organ donors, including lung and heart were dead at the time of the

harvesting. Article 11 of the Law on Organ and Tissue Removal, Storage, Vaccination, and Transplantation used the term *medical death* to imply brain death mandating four specialists could announce it (Resmi Gazete, 1979).

Going through national news regarding cadaveric organ donation and brain death, I saw that the term brain death was only mentioned in medically informative news, primarily interviews with pioneer Turkish transplant surgeons. News mentioning the national and international cadaveric transplants preferred to call brain-dead donors cardiac dead even in the nineties, and they included the details of the reason for death, such as cerebral hemorrhage and brain damage. This cautious attitude toward brain death is rooted in the contradiction of the perception of brain death between the West and the East. The declaration of death is related to the biological existence of humans. It relies on collective acceptance and social consensus as well.

Anatolian-Turkish folklore's traditional understanding of death mainly formed around the heart. “Unless soul left the body, personality stays same” [tr. Can çıkmayınca huy çıkmaz], proverb, suggests that the soul lives in the heart. Folklore suggests that the circle of life begins and ends in the heart. The soul enters the heart in the mother’s womb and leaves the hearth at death. The paradox between the traditional understanding of death and brain death relies on the mutual philosophical conceptualization of soul and heart concerning death. Turkish-Islamic understanding of the body's functioning suggests that the soul administers the metabolic systems. It operates not only in a live body but also in a passive or dead body. Islamic philosophy supports the idea that the soul is located in the heart. Avicenna, for example, defines the soul as an elegant substance and notes that the heart is mainly located in the left gap of the heart. The soul must carry the sensual power to the organs. It also prepares the organs to accept to use of this power (Taşcı Yıldırım 2020). According to Islamic philosophy, the death of a person is the separation of the soul from the body, and when it happens, the signs of vitality disappear. The Islamic understanding of life attributes the brain’s abilities to the heart, such as learning, reasoning, and decision-making. Furthermore, the declaration of death requires that soul must leave the body, and it must be visible with physical signs such as skin color and temperature, the stillness of the movement of the chest, and the inactivity of breathing. These signs are strongly related to the communal acceptance of death and make it challenging to embrace brain death for the relatives of the brain-dead person.

Brain Death, Organ Donation, and Miracle Narratives

Brain death concept mess with the Eastern traditional understanding of death. However, it is equivalent to cardiopulmonary death, which is the cessation of adequate heart function and respiration and results in death. “Brain death, in medical terms, results from irreversible loss of brainstem function. It may be announced with advanced tests confirming the absence of neuronal function in the whole brain” (Laureys, Owen, and Schiff 2004, 539). Brain death has been marked as a form of life in the folklore since the ventilated brain-dead person appears to be sleeping with some signs of vitality. This causes the state of brain death to be confused with vegetative life and coma. Coma is the absence of arousal and consciousness. Comatose patients are in a state of unresponsiveness and lie with their eyes closed. They have no awareness of themselves and their surroundings. Patients in a vegetative state are awake, but they are not aware of themselves and their environment. Patients in a vegetative state or coma may entirely or partially recover.

On the other hand, patients in a brain-dead state are irreversibly dead even though they show vitality signs by means of an artificial life support unit. After the person is declared brain dead, s/he is dead before the law, regardless of the ventilation of organs. The law mandates that the coordinators must meet and inform the family of the brain dead about organ donation hoping that the family may donate some or all organs of the deceased. If the family consents to donate the organs of the brain dead, coordinators initiate the organ donation

process. If the family does not donate the organs, they may turn the life support off or wait for the organs to fail. It is not uncommon for families to request the termination of life support and the release of the body for burial. Statistics show there are only 305 brain death donors in 2021, which is behind in meeting cadaveric organ needs. Some of those who donated vital cadaveric organs were reluctant to donate heart (221 in 305), lung (275 in 305), pancreas (302 in 305), and small bowel (301 in 305). While Türkiye is a pioneer country in living donation, we are significantly behind in cadaveric organ donation. Numbers in cadaveric organ donations mirror the Eastern philosophical understanding of death. Furthermore, folklore in Eastern societies supports this philosophy with oral tradition, social norms, and rituals.

Miracle Narratives and Reluctancy to Cadaveric Organ Donation

Miracle narratives are a subcategory of urban legends. Experience in these narratives is attributed to “friend of a friend.” Urban legends, according to Brunvand, were formerly termed urban belief tales, contemporary legends, modern legends, urban rumours, and modern urban legends reflecting the social concerns of modern life in cities and suburbs (1996, 1509). Their credibility comes from the events and people mentioned in the plot, which are familiar to us. These narratives reflect contemporary societal concerns, increasing narratives' captivity.

Furthermore, they are told and listened to by individuals regardless of class, age, or gender (Brunvand 2001). They can be formulated and transmitted by mouth-to-mouth conversation and media, accelerating the circulation rate. As de Vos noted, they can be transmitted electronically via e-mails (2008, 479). Urban legends primarily draw attention to the safety of our bodies, minds, and possessions. They use the method of authentication to increase the credibility of the story. The most familiar form of the method is telling the story by attributing the experience to a “friend of a friend”, and the audience may safely suppose that the teller knows the owner of the experience. Urban narratives facilitate the cultural elements, names, and spaces familiar to the listener, which also helps listeners not ask, “How this can be possible?” Tellers, according to de Vos, can tell the urban legends as if they listened, read, or watched them, which increases the credibility of the narrative (2008, 479).

Miracle narratives gain credibility by referencing miracles cited in divine books nurturing the idea that divine powers with a divine plan protect people, touch lives, solve hopeless problems, and heal terminal diseases. They use motifs such as healing miracles (curing disabilities and illnesses), nature miracles (calming storms, making rain, feeding people in famine), and restoration miracles (raising the dead, restoring life). The motifs of resurrection and healing in the miracle narratives confuse the families of the brain-dead person. Since the dead show signs of vitality in appearance, patients assume that s/he is in a coma or vegetative state, and s/he may recover. Since the state of brain death is declared while his/her internal organs live with the artificial life unit, the body's color, warmth, and softness seem as if s/he is sleeping. Furthermore, artificial units' sounds and indicators increase the hope of the relatives of the brain-dead that their beloved ones may wake up. States of brain death and coma are alike in appearance, and differences between the two states can be confirmed by rates and indicators in advanced tests that only medical practitioners can interpret.

The interviews revealed that families refused organ donation because they could not believe their beloved ones were dead. The interviews also show that miracle narratives with healing and resurrection motifs intervene with the decision-making process of the reluctant. “One must not lose hope in God” [tr. Allah'tan ümit kesilmez] and “must not lose hope on someone until his/her soul is taken” [tr. Çıkmamış candan ümit kesilmez] are messages of miracle narratives.

Refusers (n=17) cited these messages while explaining the reasoning for refusal. Moreover, these messages in miracle narratives must have turned into proverbs that we refer to in our conversations to give each other hope in difficult times. During the fieldwork, I

witnessed that even a few intensive care doctors consoled the relatives of the dead by referring to these proverbs while declaring the state of brain death. Even though doctors knew that the state of brain death was irreversible, but their cultural language habits forced them to use these proverbs.

In the scope of classical death, condolence expressions in Turkish-Anatolian oral traditions, such as “May Allah rest his/her soul peace” [tr. Allah rahmet eylesin, “May Allah give strength and patience” [tr. Allah sabır ve güç versin] “May Allah let him in his paradise” [tr. mekânı cennet olsun], and “May Allah let his/her soul be forever” [tr. Devri daim olsun] are comforting and acceptable for the relatives of the deceased. However, relatives of the brain death had trouble accepting condolences from intense care doctors who declared the state of brain death. Most of my informants (n=18) said they refused to accept condolences since they believed their beloved one was still alive. İrem, the daughter of the brain-dead, told me that she was angry with doctors and refused to believe in them. Because his father seemed to be sleeping at the moment of declaration: “According to his appearance, he was sleeping. I held and kissed his warm hands. I listened to his breathing. I could not give up on him. I waited for a miracle. I let Allah decide what was right to do. I would not let him die myself” (Personal communication, İrem, November 17, 2022).

Miracle narratives hindering cadaveric organ donations are narrated by attributing healing or resurrection experiences to third parties. Experiences of friends of friends, friends of relatives, and neighbors of acquaintances are presented as witnesses of healing or resurrection motifs. Actors in miracle narratives are doctors who lose hope in patients suffering from terminal diseases such as advanced cancer or organ failure. During my interview with refusers, I compiled 12 miracle narratives employing the resurrection motif. Respondents (n=12) referenced these narratives as one of the reasons Why they refused cadaveric organ donation. The resurrection motif in miracle narratives was experienced in morgues. After cardiac arrest, the individual is taken to the morgue, where resurrection happens. Imams whose duty is to give the body ghusl, Islamic ritual purification, are also presented as witnesses of the resurrection. Since imams are practitioners of religion, the narrator presents them as credible witnesses to increase the narrative's credibility. Miracle narratives' plots have four parts. In the first part, a patient with a terminal disease is declared dead, followed by being taken into the morgue. The second part of the narrative may differ in two ways. The dead is resurrected by God after staying dead for a while, a day at most. He is resurrected while the imam was giving him/her a ghusl in several narratives (n=5). In two ways, resurrection happens at night. Third, the resurrected quietly waits, lying down or sitting in the box of the morgue, for someone who releases him from the morgue. S/he calls for help in several narratives (n=6), and S/he manages to exit the morgue on him/herself in a few narratives (n=3) too. The last part of the plot ties narratives with the message: Doctors are not God, and even advanced tests may fail to declare death.

Hüseyin, who is 54 years old male informant, had trouble comprehending the brain death of his father, whose brain stem died after three days he spent in intensive care. He refused to donate his fathers' cadaveric organs. He did not let intense care doctors unplug the artificial life unit. After his refusal was approved, his father's lung and heart ceased in 4 days. Hüseyin told me the story that his imam friend experienced:

...My friend, who is an imam, told me a story. He saw with his eyes. After doctors declared a young man dead, his body was taken to the morgue. His heart stopped for a while. Doctors assumed that he was dead. After he was taken into the morgue, his heart started beating. He woke up in a box, wondering if he was dead. He slapped himself to make sure. Then he understood that he was resurrected. Allah let him have a second chance. He called for help, but no one heard his voice. İmam friend of my friend was on duty. He woke up for morning salah. He came to the morgue to prepare the bodies for burial. When he opened the box, he saw him sitting on the tray. Since he was familiar

with these cases, he took him to the doctor, who sent him morgue. Doctors ran tests that came back good...

Eighteen informants, including the twelve mentioned above, referenced miracle narratives in which healing miracles were plotted as one reason they did not donate the cadaveric organs of their relatives who were in a brain-dead state. During my interviews with refusers (n=18), I compiled miracle narratives (n=24) which include healing miracles. A common message of the plots of these narratives is that doctors, in particular and Western medicine, in general, might fail to define if their patients' diseases are terminal. In this sense, miracle narratives mirror the mistrust of refusers toward Western medicine. These narratives also reflect the confusion of refusers who mixed the state of brain dead with coma. Since an individual whose brain stem is dead cannot recover, miracle narratives report the story of the patient returning from a coma or vegetative state. However, the teller presents his story stating that the patient in his story is in a state of brain death.

Aylin, who is 47 years old female informant, refused to donate her mother's cadaveric organs after waiting for a healing miracle. Then her mother's ventilated organs failed. I interviewed her after 54 days of her mother's funeral. She had not mentioned sub-reasons for her refusal at the family meeting in the hospital, stating that she was scared that her mother wouldn't be resurrected as a whole body in the afterlife. Indeed, one of the most common reasons for the refusal of cadaveric organ donation is related to the resurrection of the body in the afterlife (De Moraes and Massarollo 2008; Pessoa et al. 2013; Elsafi et al. 2017; Bruzzone 2008; Le Nobin et al. 2014; Ghorbani et al. 2011; Ugur 2018; Şenyuva 2022; Rumsey, Hurford, and Cole 2003; Özbolat 2017; Hamdy 2012; N. et al. 2017; Akbulut et al. 2020). I witnessed families of the brain dead first question if the deceased would be resurrected in the whole body in their afterlife. Well-trained coordinators ease the decision-maker's anxiety by referencing the 27th Ayat of Sural ar-Rum: "...and He is the one who originates the creation then will resurrect it, which is even easier for him". Aylin told me that she confused the state of brain death with coma, regretting not donating cadaveric organs: "At the moment of the family meeting, I could not believe my mother was dead. People around me kept telling me stories of which people with terminal diseases recovered. I could not lose hope until her organs started failing. I could not tell the coordinator I did not believe she was dead" (Personal communication, Aylin, May 12, 2023). Mustafa, 56 years old male informant, refused to donate his wife's cadaveric organs believing that his wife could recover too. At the family meeting, He told coordinators he did not want her wife's body cut open. Even though coordinators tried to ease his anxiety by explaining harvesting procedures, He disagreed. Interviewing him two months after her wife's funeral, he told me he did not convince his wife was dead, assuming she was in a coma. He was not regretful for not donating her cadaveric organs. He waited for a miracle until the last moment: "A day after she was admitted to intensive care, a doctor told us that Satı was brain dead. She seemed like she was sleeping. My relatives kept telling stories to comfort me. Knowing her body was strong, I kept waiting for her healing. After ten days, her organs failed." (Personal communication, Mustafa, April 27, 2023).

Doctors show the results of tests and visual reports to relatives of the brain dead to explain what brain death is. Then they lead relatives of the brain dead to organ donation coordinators who must inform them about cadaveric organ donation. I did not witness any refusers referencing miracle narratives during family meetings. The most prevalent reasons for refusing to donate cadaveric organs were related to the resurrection in the afterlife and reluctance to decide the destiny of the brain dead. For the first, organ donation coordinators present the verses and hadiths declaring that humans will be resurrected with their organs to relieve the concerns of families whose beloved ones are brain dead.

In-depth interviews with cadaveric organ donation refusers (n=23) revealed that miracle narratives are one of the sub-reasons for reluctance to cadaveric organ donation. The relatives

of the dead, who cannot define brain death as death, believe that the deceased is in a coma and vegetative state, deceived by her appearance in the artificial life unit. Cadaveric organ donation refusers reported they could not comprehend that their relatives were dead even though doctors told them so. Since the deceased was being ventilated at the moment of declaration, decision-makers doubted if their relative was dead. Moreover, miracle narratives were being told to ease the anxiety of families by visitors, remote relatives, and neighbors, which only gave false hope. Knowing brain death, coma, and vegetative state is difficult to comprehend; one can easily lean on miracle narratives plotting resurrection and healing motifs.

Conclusion

Studies show that culture has an enormous impact on unwillingness to cadaveric organ donation (Rumsey et al. 2003; Hamdy 2012; Ohnuki-Tierney 1994; NicholsI 1997; Janssen et al. 2017; Bruzzone 2008; Özbolat 2017; Oğuz Güner and Cicerali 2021). Since qualitative studies are limited, folkloric reasons for the inadequacy of cadaveric organ donations are resolved within religious ones. Witnessing numerous family meetings, I indeed believe that religious concerns are strong excuses that refusers first put forward to reject to be part of organ donation. Many refusers (n=18) did not change their mind after coordinators informed them about religious aspects according to Islam. In several cases, coordinators even advised refusers to consult with clergy members whom decision-makers trusted. Only a few agreed but did not donate either.

Even though the concept of death is closely linked to religion, insufficient cadaveric organ donations cannot be solely explained through religion. Folklore, including oral tradition, rituals, social norms, and folk beliefs, intervenes with the decision-making processes of the relatives of prospective donors. The effect of folklore is visible through the social-cultural definition of death. Folk beliefs locate the soul in the heart, ignoring the brain's functions. Moreover, Islamic mysticism over the relationship between soul and heart supports folk belief. According to Islamic philosophy, the heart may commune with itself, reason, and think. Miracle narratives are reflections of the elusiveness of the state of brain death among laymen. They also mirror the mistrust toward Western medicine. According to the message in miracle narratives, death is still primarily related to the heart.

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