**Title page:**

**Title:** NEW DILEMMA IN MEDICAL ETHICS: PEDIATRIC EUTHANASIA AND TURKISH MEDICAL STUDENTS’ PERSPECTIVES ON IT

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**A NEW DILEMMA IN MEDICAL ETHICS:**

**PEDIATRIC EUTHANASIA AND TURKISH MEDICAL STUDENTS’ PERSPECTIVES ON IT**

**Abstract**

**Background**

The legalization of pediatric euthanasia and paradigmatic cases such as Baby Doehave initiated a debate on pediatric euthanasia.This paper examines the historic background, the current extent of implementation, and the main ethical arguments on pediatric euthanasia and analyzes the perceptions of Turkish medical students’ attitude towards pediatric euthanasia.

**Methods**

An online survey was conducted among Turkish medical students. Investigated were responders ’ perceptions of euthanasia, futile treatment, abuse of legalization, any specific requirements and conditions, who should decide, the right of minors to require euthanasia, and the attitudes of physicians to applying lifesaving procedures on pediatric patients.

**Results**

Participants hada negative attitude towards euthanasia and did not agree that physicians should decide not to resuscitate an infant with severe abnormalities and a low chance of survival. They did not consider the economic burden of the treatments to be a determining factor for euthanasia. The majority agreed that the legalization of euthanasia would lead to misuse and would deprive patients of treatments currently available for untreatable conditions.

**Conclusions**

The increase in access to life-sustaining medical interventions, together with insufficient resources, draws attention to end-of-life decisions even for pediatric patients. This survey records the perceptions of young medical students in Turkey about pediatric euthanasia, which may be a bigger issue by the time they start their professional life. More research focusing on the effect of various variables on perceptions and attitudes should be carried out to highlight the issue and empower discussions.

**Key Words**

Euthanasia, end of life, pediatrics, medical students, Turkey

**Introduction**

The term “euthanasia” is composed of two ancient Greek words; *eu*, meaning “good,” and *thanatos*, meaning death. The main argument of euthanasia is that death should occur easily, painlessly, and with respect for human dignity. The vast improvements in modern medical technology have changed death from an instantaneous event to a process that may last for years. Medical interventions provided during this process sometimes hardly contribute to the patient’s lifespan or well-being. Hence concepts of euthanasia come up for discussion more frequently in today’s medical practice.

*How to define euthanasia*

It is hard to identify a consensus on any of the definitions. This is because every definition brings new dimensions to the discussion on the content and possible consequences of euthanasia.1,2

A simplistic definition of euthanasia—“euthanasia is the termination of life of a patient who is suffering from unbearable pain emerging from a disease which is incurable due to current medical knowledge, with the request of the patient or the surrogate who is legally in charge of deciding for the patient”3—provokes several ethical discussions.Some might well object to setting“unbearable pain” as amedical criterion, since it is subjective and relative. The concept of quality of life is offered instead of unbearable pain; however,critiques of subjectivity and relativity can be made for this criterion as well. Furthermore, some progressive diseases such as Alzheimer’s disease or dementia are not characterized by pain. Hence this definition leaves out the sufferers of most prevalent diseases, who might be subject to euthanasia.

Another popular definition rests on the type of action conducted during euthanasia. Committing an action that directly causes the death of the patient is considered active euthanasia. On the other hand, to pave the way to death by omitting some actions is thought to be passive euthanasia.4In this respect, active euthanasia is considered tantamount to “killing,” and passive euthanasia to “letting die.” Despite controversyoverthe analogy between active euthanasia and killing, it was concretelyreflected in medical ethical codes.5,6This linkagehas also shaped legal regulations. For example, the American Medical Association Code of Ethics objects to active euthanasia based on the argument that it is analogous to killing.7,8,9

Today, all types of euthanasia are gathered under the umbrella term “physician-assisted death,” which provides a virtual consensus among scholars. Recently, the discussions regarding euthanasia have turned to the issue of pediatric patients, initiated by the Baby Doe case and intensified by the legalization of pediatric euthanasia in Belgium and the Netherlands.

*The Baby Doe and Baby Jane Doe cases*

Baby Doe was born with Down syndrome and esophageal atresia in the U.S. state of Indiana in 1982. The infant needed surgery to open the esophagus so it could be fed, but the physicians and the parents decided against the surgery. Baby Doe died of starvation and dehydration within six days.

The second case, known as Baby Jane Doe, was born one year after Baby Doe in New York City. She suffered from meningomyelocele, anencephaly, and hydrocephaly. The parents were told that without surgeryshe could not survivefor more than two years, but with surgery she could live up to twenty. The parents decided to forgo surgery and approvedthe administration of antibiotics and palliative care. They stated that their decision was based on doing what was best for the infant. However, the parents’ declaration of good will initiated a wide public debate as well aslawsuits. Finally, three years after the death of Baby Jane Doe, the “Baby Doe” regulation went into effect. This regulation not only defined the withholding of treatment but also stated the conditions under which doing sowas appropriate.

i) The infant is chronically and irreversibly comatose;

ii) The provision of such treatment would merely prolong dying, not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or otherwise be futile in terms of the survival of the infant; or

iii) The provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.11

With this regulation, withholding treatment from infants under certain conditions was legalized for the first time.

*The legalization of pediatric euthanasia in Europe and the United States*

In the first few years of the twenty-first century, attempts to legalize euthanasiaforadults gained momentum. This time, European states were the pioneers. In 2002, euthanasia for adults was legalized in the Netherlands, followed by Belgium and Luxembourg. In the United States,Oregon was the first state to legalize euthanasia for adults. It wasfollowed by four other states: Washington, Vermont, Montana, and New Mexico.

However, the initiatives for the legalization of pediatric euthanasia are far too limited. In 2005 the University Medical Center of Groningen in the Netherlands published the Groningen protocol for conducting active euthanasia on severely disabled newborns. The protocol required four conditions to justify euthanasia for infants:

1. the presenceof hopeless and unbearable suffering
2. the consentof both parents
3. consultation with physicians
4. termination procedures that comport with “medical standards.”12

In 2014 Belgium legalized pediatric euthanasia for chronically ill children whose suffering is constant and unbearable. The law requires the child’s own explicit request, as well as parental consent and careful examination of child’s capacity for discernment by a multidisciplinary team of professionals. The presence of an intellectual disability or mental illness makes children ineligible for euthanasia.13

*The situation in Turkey*

Article 17 of the Constitution of the Republic of Turkey states that “everyone has the right to life to protect and improve his/her corporal and spiritual existence. The corporal integrity of the individual shall not be violated under medical necessity and in cases prescribed by law.” Any attempt to conduct either active or passive euthanasia is addressed under Article 83 of the Turkish Penal Code, which says, “any person causing the death of a person due to failure in performing a legal obligation or requirement, as a basic punishment, is sentenced to imprisonment from twenty years to twenty-five years…” Assisted suicide or any suggestion of euthanasia falls underArticle 84 of the penal code and is subject to imprisonment from two to five years. Article 13 of the Turkish Patient Rights Directive explicitly states that euthanasia is not permitted under any circumstances. Hence it is plausible to say that all euthanasia is strictly banned by law and by the ethical codes of medical professionals. However,new discussions have recentlytaken place. A recent survey showed that despite the legal ban, 43–60% of nurses believed that passive euthanasia was being conducted in Turkish hospitals.14 This survey initiated a debate among media and health professionals about euthanasia and end-of-life issues. Although quite timid, the newly emerging discussions on the issue might potentially be reflectedat the administrative and jurisdictional levels. The aim of this survey is to analyze the perceptions of medical students about euthanasia and their attitude towards pediatric euthanasia, which is a new debate in the field of end-of-life issues.

**Materials and methods**

The survey was composed of thirteen questions. No personal data was gathered during the survey. The ethics committee’s approval was obtained from TOBB ETU in June 2017. The survey sought the participants’ perceptions on the acceptability of euthanasia, futile treatment, the abuse of legalization of physician-assisted suicide, and the circumstances under which euthanasia is admissible. Apart from queries on euthanasia in general, specific questions on pediatric euthanasia are asked regarding its acceptability, the specific requirements and conditions for it (if any), who should decide on it, the right of minors to direct their owneuthanasia, and the attitudes of physicians to applying lifesaving procedures onpediatric patients.

The survey was conducted online June 9–July 12, 2017.One hundred twenty-five undergraduate medical students participated in the survey.

The data was analyzed by SPSS, and qualitative analysis was made for data to interpret how participants conceptualize the phenomenon of euthanasia in general and pediatric euthanasia in particular.

**Results**

The study has two limitations. The first is that it did not reach medical students who are living and studying in rural parts of Turkey. These results reveal the perceptions of students residing in Ankara, the capital of Turkey. The results might well have beendifferent if students from more conservative cities or more cosmopolitan universities had been involved in the study.

The second limitation is related to the first one: the number of participants and the number of years they had studied medicine. Although there were enough participants to make generalizations about the issue, the accuracy of these generalizations would have improved if more students had participated in the study. The majority of the participants were first- to fourth-year students. These students have limited access to patients. It is possible that their perceptions will change when they have more experience with patients in intensive-care units or clinics such as oncology.

The questions were presentedin two sections. The first section was about euthanasia without reference to the age of the patient. When the participants were asked if they would agree with a physician suggesting euthanasia to a patient with no hope of recovery,32% of participants replied in the affirmative. Most participants (88.7%) did not think the patient had the right to choose to die, and 72.8% of the participants agreed that it was the physician’s dutyto continue a futile treatment at the insistent request of the patient or her surrogate decision-maker.Of the participants,82.4% think that legalizing euthanasia would lead to misuse and misconduct.

**Graph 1**: Medical students’ perceptions of concepts related to pediatric euthanasia

The two leading medical situations in which participants thought euthanasia was acceptablewere a persistent vegetative state (22.6%)and untreatable conditions with severe pain (21.4%). The conditions under which some participantsconsidered euthanasia acceptable included progressive terminal diseases (17.9%),severe physical disabilities (12.7%), chronic degenerative diseases like Alzheimer’s and amyotrophic lateral sclerosis (7.3%),and severe mental disabilities (4.2%). Among participants, 10.5%stated that no medical condition qualifies for euthanasia.Concerning pediatric patients, 25.4% of participants stated that euthanasia would be acceptable for patients with progressive, untreatable, and painful medical conditions, and 24.1% said the same about patients who were in a persistent vegetative state. However,22.3% of participants disapproved of pediatric euthanasia regardless of the conditions, which is significantly higher than the disapproval rate for adult euthanasia.

**Graph 2:** Medical students’ perceptions about situations in which pediatric euthanasia may be acceptable

Only 3.2% of the participants thought that the cost of the treatment should be considered and that any patient who required overly expensive treatments with very little chance of recovery or survival should be eligible for euthanasia. This consensus was sustained when pediatric patients were considered. Of the participants, 80.8% stated they did not think that an untreatable pediatric patient would be violating the rights of other patients even if she were consuming expensive treatments, and 87.17% of them disapproved of withholding or withdrawing treatment from such apatient.Only 4.8% of participants thought that untreatable pediatric patients should be euthanized so that the resources could be reallocated to those patients who would benefit from them.

Most of the participants (68.0%)stated that if euthanasia is permitted by law, then a physician whoeuthanizes a competent patient at the patient’s request would be fulfilling his duty, while 32.0% consider euthanasia equivalent to homicide even if it is legalized in the country and requested by a competent patient.When the participants were asked about their perceptions of a physician who conducts euthanasia on a pediatric patient at the family’s request in a country where euthanasia is legal, only 44% of participants still agreed that the physician was fulfilling her duty, while 56% of them considered it homicide.

Concerning who should be involved in the decision-making process for pediatric euthanasia,46.4% of participants said it should be family and physicians together, 4.0% said it should be only the parents, and 2.4% said it should be the ethics committee of the hospital; 46.4% stated that no such decision should be made. On the other hand, 44.0% of participants stated that patients under 18 should have the right to request euthanasia for themselves under well-defined circumstances. Of the participants, 79.2% did not agree that physicians should decide not to resuscitate an infant with severe abnormalities, multiple complications, and very little chance of survival, and 15.9% of participants thought that pediatric euthanasia would deprive patients oftreatments available for conditions untreatable today. The majority of participants (94.6%)opposed offering euthanasia as an option to parents of untreatable pediatric patients with no reasonable hope of surviving a normal life span.

**Discussion**

Ethical discussions on euthanasia have been held bythe public, the media, and medical professionals due to vast improvements in life-sustaining health services and medical technology. Most of thesearguments for and against euthanasia are listed in Table 1.

**Table 1:** Arguments for and against euthanasia

|  |  |
| --- | --- |
| Arguments against euthanasia | Arguments foreuthanasia |
| The sanctity of life: This argument counters the quality-of-life argument by claiming that every life, regardless of its quality, is worth living and that it is against God’s will and/or the law of nature to end one’s life due to some artificial criteria. Hence it is among the most widely referenced arguments against physician-assisted death. | The quality of life: This argument suggests that life is not worth living in the absence of some key criteria. These criteria may vary considerably depending on the individual’s definition of a good life. Culture, socioeconomic status, religious beliefs, and other communal values might have an impact on determining what the criteria are of a life worth living. In this perspective, it would be plausible to choose to die if the criteria for a good life were permanently lost. |
| The duties of the physician: The archaic principle rooted in Hippocratic times,*premium non nocere*, is often referred to by the opponents of euthanasia. They argue that regardless of the unique features of the situation, the physician should act for the benefit of the patient and preserve her life. However, it is arguable that acting for the patient’s benefit does not necessarily mean preserving the patient’s life. The supporters of physician-assisted death argue that a decent death causes far less harm to the patient than forcing her to stay alive throughfutile treatments that might cause unnecessary harm. | Human dignity: The Universal Declaration of Human Rights enriched human dignity in itspreamble: “recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world.” Hence it is considered an inalienable asset of human identity that should be respected and protected. The human-dignity concept is widely referred to in euthanasia discourse to support a decent and respectable death for individuals. |
| The lack of certitude in medicine: The vagueness of criteria used in the definition of euthanasia is the basis of this argument. Since there is no consensus on the most essential definitions such as “terminally ill,”“unbearable pain,”and “quality of life,” most decisions on physician-assisted death are subjective and conditional. | Respect for autonomy: The arguments based on respect for autonomy propose that it is the individual’s autonomous decision whether or not to require aphysician-assisted death. Respecting autonomy demands that all parties act in coherence with the individual’s free will. To fulfill this requirement, the setting should not allowthe patient to be coerced or suppressed while making up her mind. |
| Misuse and abuse of euthanasia: Slippery-slope arguments suggesting that opening the door to euthanasia would lead to many unwanted and tragic consequences have been the main grounds of arguments against legalization of euthanasia. The proponents of these arguments say that the historic evolution of euthanasia implementations supports their propositions. At first, passive euthanasia was acceptable only for well-considered terminally ill patients, but over time it has been considered an option for chronic patients, patients with physiological disorders, or people who do not enjoy life anymore. | Just distribution of scarce resources: This argument suggests that life-sustaining medical treatments and other high-tech medical interventions should not be used if they are proven to be futile for the patient. Instead, they should be provided to other patients who have a better chance of getting medical utility from them. This argument also refers to the cost-benefit analysis of medical interventions and holds that using sources without any benefit violatesthe society’s just distribution of resources. |

The surveys regarding the perceptions of society and medical professionals in Turkey are far more limited than those of Western countries. Nevertheless, the limited amount of literature suggests that euthanasia is not well received in Turkey.15 A survey of 47 countries in Europe showed that public acceptance of euthanasia varies considerably depending on age, sex, income, and education level, urbanization, degree of religiosity, and religious belief. Euthanasia acceptance is lower among young people, women, and the highly religious. On the other hand, it is considered more acceptable among people with higher education and income levels and having urban lifestyle. Furthermore, the survey showed that there was an association between euthanasia acceptance and communitarian values and social attitudes like respecting personal autonomy and tolerance towards personal choices. According to this study, public acceptance is highest in Denmark, France, Sweden, and Spain and lowest in Turkey, Cyprus, and Kosovo.16

The perceptions and attitudes of medical professionals have been at the center of interest in debates on euthanasia. Literature reveals that physicians’ attitudes towards euthanasia vary considerably depending on the diagnosis and the curability and treatability of the diseases. The approval rate increases with the severity and low expectation of recovery.17,18,19The results of our survey correspond with existing literature. The majority of survey participating students did not approve of euthanasia and did not agree that the patients or their surrogate decision-makers had the right to ask for euthanasia, and the approval rates were higher for untreatable, progressive, and terminal cases.

Pediatric euthanasia has been researched much less extensively than euthanasia in general. Research on how medical students perceive pediatric euthanasia in particular is also very limited. In a survey of 400 medical students at the University of Malayain Kuala Lumpur, Malaysia, the majority of respondents supported the withdrawal of active therapy in a patient suffering from a terminal painful disease and were against the idea of active euthanasia, while 61% of them would not practice euthanasia as a doctor or have it performed on themselves even if it became legal.20Another survey, conducted in the U.S. state of Oregon, where physician-assisted suicide was legalized in 1994, found that the majority of medical students favored legalizingphysician-assisted suicide, and 50% reported that they would be willing to prescribe a lethal injection.21A survey of Korean medical students foundthat 73.1% of the respondents opposed active euthanasia, while 74.4% of them supported the legalization of passive euthanasia, and 63.0% revealed that they would perform this if it were legal.22 A survey conducted in the Netherlands in 2007 revealed that about half of Dutch pediatricians, other clinical specialists, and general practitioners approved of pediatric euthanasia as described in the Euthanasia Act.23Another research in 2017 showed that support for pediatric euthanasia is increasing. Most Dutch pediatricians who participated in the surveysaid they felt physician-assisted death was conceivable, even for patients under the age of 12 if requested by the parents.24

The results of our surveyshow that Turkish medical students have a negative attitude towards euthanasia. Moreover, withdrawal of treatment, even if treatment is proven to be futile, is not approved. The request and demand of the patient or the surrogate decision-maker for the patient overrides the objective information that the resources are being wasted and that the medical condition of the patient would not improve. Turkish medical students did not consider the economic burden of the treatments as a determining factor for euthanasia, including withdrawing futile treatment. This is quite unexpected, since a solid base for arguments about withholding or withdrawing futile treatment is the just distribution of scarce resources in medicine. If a costly medical intervention using scarce resources provides no benefit for a patient, and if there are other patients whose medical conditionsmight improve with that intervention, then withdrawing treatment from the first patient and providing it to others in line is considered an appropriate choice. Although many ethical perspectives would agree with this,the utilitarian ethical perspective is the one that would advocate for it simply by calculating the net social and economic benefit. In this case,utilitariansargue that the physician has a duty to withdraw futile treatment, since creating the most benefit for the most people is an ethical duty. However, medical students did not take economic or utility consequences into consideration.

This attitude of participatingstudentsis sustainedwhen pediatric euthanasia is at stake. The results of our surveyshow that the participating students do not approve ofwithholding or withdrawing treatment from a pediatric patient even if it is futile and costly. The participant students obviously do not see this issue as a matter of distributing scarce medical resources fairly.

One of the most striking results of the survey is that a majority of the students agree that legalization of euthanasia would lead to misuse. This perception is linked with the slippery-slope arguments suggesting that opening the door for euthanasia would lead to many unwanted and tragic consequences. On the other hand,amajority of the participant students think that if euthanasia were legalized, the physician would have aduty to euthanizea competent patient who requested it. However, the approval rate fell when the request was made by the parents of a pediatric patient. This leads us to another dilemma on euthanasia. Who should decide for the patient if the patient cannot decide for herself, and what criteria should be considered when deciding?

The main criterionin determiningwho is responsible and authorized to decide on the appropriateness of physician-assisted death in a particular case is the level of competency of the patient. If the patient is competent enough to make the decision on euthanasia, then she is the oneto decide. In the case of pediatric patients, the situation is more complex. For newborns and babies, surrogate decision-makers are inevitably responsible for this decision, since the patient has no competency. However, for older children, the debate is sharper, since there is some competency, but its level varies due to the child’s age and intellectual capacity.

Surrogate decision-making is an ethically complex procedure. The main ethical discussion emerges from the criteria to be used while deciding on behalf of the patient. Beauchamp and Childress state that if the surrogate decision-maker considers what the patient would want, by referring to the patient’s own concept of a good life, her values and expectations, then the surrogate would be deciding in the way that most respects the patient’s autonomy.This criterion would apply for adults and older children, but it cannot be used for babies and newborns.

To overcome this obstacle, some other criteria have recentlybeen offered. One of them is “the best interests standard.” This standard requires the surrogate to decide from an objective standpoint to promote the patient’s good. The consequences of the decision should reasonably lead to the good of the patient.

However, the “patient’s good” concept is far too vague to guide a standard decision-making process. It could be argued that withdrawing a life-sustaining treatment or withholding a lifesaving operation in circumstances where the child has very little chance to have a normal life is *for the good of the child*. The parents of Baby Jane Doe claimed they were acting for the good of the child when they decided to forgo surgery.25Other criteria would includethe expected medical utility of the proposed treatment. These criteria dependon objective and scientific evaluation of physicians regarding the medical status of the patient. The physicians are considered to have access to the most accurate and up-to-date information as they consider individual cases.26

It is hard to say that medical-utility criteriawould provide an objective standard for end-of-life decisions on children. Rhoden showed that medical professionals’ decisions vary significantly in different countries: “Swedish doctors tend to withhold treatment from the beginning from infants for whom statistical data suggest a grim prognosis. The British are more likely to initiate treatment but withdraw it if the infant appears likely to die or suffer severe brain damage. The trend in the U.S. is to start treating any baby who is potentially viable and continue until it is virtually certain that the infant will die.”27The participant medical students’ hesitation regardingparent‑approved and ‑requested euthanasia may be interpreted as a reflection of the subjectivity and relativity of all the above criteria.

**Conclusion**

Although Turkish legislation strictly bans euthanasia under any conditions, the concept has been among the subjects discussed by medical professionals in Turkey. The considerableaging of the population, together with the increase in access to life-sustaining medical interventions and theinsufficient resources for all needy patients, inevitably draws attention to concepts related to end of life, such as futile treatment, withholding andwithdrawing treatment, advance directives, surrogate decision-making, and euthanasia. Recently some voices have been raised, albeit timidly, stating that legislation does not match current medical practice and that euthanasia has been performed undercover in medical facilities. However, the research in this area is still very limited in both amount and content. This survey, despite its limitations, providesa brief glance atthe current situation among young medical students. More research focusing on the effect of socio-cultural background, religious and communitarian values, gender, and other variables such as area of specialty in medicine should be carried out to highlight the issue and empower discussions.

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