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How Would Doctors Want to Die if They Had a Terminal Stage Illness? A Survey Study

Terminal Dönem Bir Hastalıkları Olsa Doktorlar Nasıl Ölmek İsterdi? Bir Anket Çalışması

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Abstract
Objectives: The purpose of this study is to determine the treatments that physicians prefer to receive, if they had a terminal stage illness and to observe whether these preferences are influenced by parameters such as age, work years in the profession or specialty.
Materials and Methods: A survey consisting of 22 questions was delivered to physicians. The physicians were asked if they preferred to die in hospital, home, intensive care unit or palliative care center if they were terminally ill; and they would want invasive procedures performed. They were also asked whether they informed their relatives about those preferences.
Results: A total of 443 physicians participated in the study, 77.42% of them stated that they would prefer to die at home if they had a terminal illness. Regarding invasive procedures; 72.46% of the physicians did not want chest compressions, 75.62 % did not want to be connected to the ventilator, 57.56% did not want a central catheter, 49.88% did not want hemodialysis, and 61.17% did not want a feeding tube placement. Only 17.15% of physicians stated that they had talked with their relatives about end of life decisions.
Conclusion: In this study we found that most physicians want to die at home and do not wish to be treated with invasive interventions in case they had a life limiting illness. However, we also observed that the majority of the physicians do not share these opinions with their close ones.
Key words: Advance care planning, death, palliative care, physician, terminal care

Öz
Amaç: Bu çalışmada amaç hekimlerin terminal dönemde olan bir hastalıkları olması halinde kendilerine uygulanmasını istedikleri ya da istemedikleri tedavileri saptamak ve yaptıkları bu tercihlerinin yaş ve hekimlik yılı ya da branş gibi parametrelerden etkilenip etkilenmediğini gözlemlemektir.
Materyal ve Metot: Hekimlere açık ve kapalı uçlu 22 sorudan oluşan anket uygulandı. Sorularda hayatın son döneminde olan hastalarla hiç görüşme yapıp yapmadıkları ve bu konuda eğitim alıp almadıkları, hayatın son dönemimde olsalar hastanede mi, evde mi, yoğun bakımda mı yoksa palyatif bakım merkezinde mi ölmek istedikleri ve invaziv işlemlerle ilgili fikirleri soruldu. Ayrıca hayatın sonuna dair istekleri konusunda yakınlarına bilgi verip vermedikleri soruldu.
Bulgular: Çalışmaya 443 hekim katıldı. Hekimlerin %77,42'i son dönemde olan bir hastalıkları olması durumunda evde ölmeyi tercih edeceğini belirtti. Kararsız olan ya da hastanede ölmek istediğini belirtenlerin %44'ü de yoğun bakımda ölmek istemediğini belirtmiştir. Bir hastalığın terminal döneminde olsalar çalışmamıza katılan hekimlerin %72,46'sı kendisine göğüs kompresyonu yapılmasını, %75,62'i entübe edilip ventilatöre bağlanmayı istememiştir. %57,56'sı kendisine santral kateter takılmasını istemeyeceğini, %49,88'si diyalize girmek istemeyeceğini, %61,17'i ise PEG takılmasını istemediğini belirtmiştir. Hayatın sonuna dair istekleri konusunda yakınları ile konuşan doktorların oranı sadece %17,15'dir.
Sonuç: Bütün bu cevaplar dikkate alındığında hekimlerin son dönemde olan bir hastalıkları olsa çoğunlukla evde ölmek istediklerini ve invaziv işlemlere maruz kalmak istemedikleri görülmektedir. Ancak hekimlerin çoğunluğunun bu konudaki görüşlerini yakınları ile paylaşmadıkları da gözlenmiştir.
Anahtar kelimeler: İleri tedavi planlama, ölüm, palyatif bakım, doktor, terminal bakım

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Introduction

A fully competent adult patient may refuse any treatment, including life-saving or life-sustaining treatments recommended by the physicians.[1] Advance directives are written documents that specify in advance who will make medical decisions on one's behalf and one's preferences for possible medical procedures to be performed if he/she lacks decision-making capacity.[1, 2]

In most countries, it is not legal for physicians to help or accelerate the death of a patient. However, in some cases, it may be legal to withdraw or withhold some treatment. A competent adult patient or his legal representative can refuse any treatment when it is not in the patient's best interest, if the treatment might be mortal or the potential harms would exceed its potential benefits.[3]

Making decisions about the end of life (such as withholding life sustaining treatment and transition of care to more palliative treatments) have become part of emergency medicine in recent years.[3]

The purpose of this study is to determine the treatments that physicians prefer to receive, if they had a terminal stage illness and to observe whether these preferences are influenced by parameters such as age, work years in the profession or specialty.

Material and Methods

Study Design and Setting

This is an observational cross-sectional study. The XXX Institutional Ethical Review Board approved the study protocol.

The survey was conducted between 20 October 2015 and 20 January 2016 in Ankara city center. At the time of the study, there were 15 education and research hospitals, 11 university hospitals, 30 private sector hospitals and 263 family health centers in Ankara and 16114 medical doctors were registered to work in those centers. Same researcher visited all these centers. Each center was visited 3 times on different days so that all physicians working in that center are offered the survey.

Selection of Participants

The physicians who have been actively practicing medicine and who accepted to answer the questionnaire were included in the study.

Physicians who did not actively practice medicine (e.g. administrative personnel) or did not consent to respond to the questionnaire were excluded.

The physicians were informed about the research, written and verbally, and the questionnaires were filled out after written consent was obtained. Identity information was not gathered in order to preserve anonymity for correct answers on the survey

forms, but names of physicians who participated were listed separately to avoid repeated participation.

Measurements

In order to determine the socio-demographic characteristics of the physicians and their end of life decisions, a questionnaire consisting of 22 open and closed end questions was applied. Questions were original and were not taken from another source. Demographic information was questioned in the first six questions. In questions 7-9 physicians were asked whether they had ever had interviews with patients who were in the last periods of their life, and whether they had received training on this issue. If the answer is yes to the latter question, they were asked where they had received training about the subject. In questions 10-13, the participants were asked whether they wanted to die in a hospital, in an intensive care unit, or in a palliative care center. In questions 14-18, the physicians were asked about their opinions regarding invasive procedures such as chest compressions, endotracheal intubation, invasive mechanical ventilation, placement of central catheter, placement of nutritional tube, and dialysis. In questions 19 and 20, they were asked whether they had informed their relatives about their end of life decisions and whom they want to decide for them in case they lose decision-making capacity, and in questions 21 and 22 they were questioned about their opinions about organ donation.

Statistical Analysis

The appropriateness of normal distribution of age and year variables in the study was evaluated graphically and by the Shapiro-Wilks test. The median (minimum, maximum) was used to represent the descriptive statistics of the variables that were not normally distributed. Additional information was given as mean ± standard deviation. Number (n) and percentage values are given to show the distribution of categorical variables such as gender and responses given to the questions. Pearson square, Mann-Whitney U and Yates corrected Chi square tests were used when appropriate in examining the variance of responses given to the questions. For statistical analysis and calculations, IBM SPSS Statistics 21.0 (IBM Corp. released 2012. IBM SPSS Statistics for Windows, Version21.0, Armonk, NY: IBM Corp.) and MS-Excel 2007 programs were used. A value of $p < 0.05$ was accepted as statistically significant. Sample size was not calculated before the study started. Post hoc power analysis revealed a power of %42-48 depending on the question.

Results

Participants

Out of 16114 physicians registered in healthcare facilities in Ankara during the study period 13512 physicians were offered the survey. A total of 443 physicians participated in the study. The response rate was %3.2.

Descriptive data

The median age of all individuals included in the study was 31.0 (min = 24.0; max= 58.0). The median years in the profession was 6.0 years (min = 1.0; ma = 34.0, mean = 8.41 ± 7.16).

The socio-demographic characteristics of the participants are summarized in **Table I.**

Regarding the distribution among specialties, 219 (49.43%) participants were working in non-surgical specialties and 114 (25.73%) were working in surgical specialties.

Table I. Sociodemographical characteristics of participants

Age groups	**n (%)**	**Position**	**n (%)***
< 29	176 (39.7)	General Practitioner	33 (7.4)
30 – 34	126 (28.4)	Resident	256 (57.9)
35 – 39	65 (14.7)	Specialist	114 (25.7)
40 – 44	37 (8.4)	Professor	4 (0.9)
45 – 49	22 (5.0)	Associate Professor	14 (3.2)
50 – 54	11 (2.4)	Assistant Professor	7 (1.6)
≥ 54	6 (1.4)	Training Supervisor	1 (0.2)
Sex	**n (%)**	Training Officer	5 (1.1)
Female	233 (52.6)	Chief intern	9 (2.0)
Male	210 (47.4)	**Branch**	**n (%)**
Institution	**n (%)**	Emergency medicine	92 (20.8)
Family Physicans office	21 (4.8)	Medical branches	219 (49.4)
State hospital	24 (5.4)	Surgical branches	114 (25.7)
Training and research hospital	295 (66.6)	Basic medicine	18 (4.1)
University	86 (19.4)	**Years in profession**	**n (%)**
Private hospital	13 (2.9)	≤ 5	215 (48.5)
Other	4 (0.9)	6 – 10	107 (24.2)
		11 – 15	56 (12.6)
		16 – 20	29 (6.5)
		21 – 25	20 (4.5)
		26 – 30	10 (2.3)
		>30	6 (1.4)

*One option is marked.

Outcome data

For this study; internal medicine, family medicine, pediatrics, neurology, gastroenterology, nephrology, radiology, radiation oncology, cardiology, chest diseases, physiotherapy and rehabilitation diseases, nuclear medicine, infectious diseases, psychiatry, general practitioner and occupational medicine were treated as medicinal specialties; general surgery, urology, orthopedics and traumatology, otorhinolaryngology, forensic medicine, plastic and reconstructive surgery, brain and neurosurgery, cardiovascular surgery, thoracic surgery, obstetrics and gynecology, pediatric surgery, and ophthalmology were treated as surgical specialties; and pathology, microbiology, and biochemistry were accepted as basic sciences. Emergency medicine was evaluated separately. The distribution of the answers to the questions 7-22 is summarized in Table 2.

Table 2. Summary of the answers to questions 7-22

Question	
Q7: Have you ever talked to your patients who are in the last stage of life with any disease (cancer, SVO, Alzheimer's, heart failure, COPD, etc.) and/or their relatives about wishes of the patient about the end of life?	**n** (%)
Yes	200 (45.14)
No	243 (54.85)
Q8: Have you ever received training about interviewing with patients in the last days of life about their last wishes for life?	**n** (%)
Yes	71 (16.02)
No	372 (83.97)
Q9: If your answer is "Yes" for the 8th question, when have you received that training? n=71	**n** (%)*
During the medical school	54 (76.05)
During residency training	9 (12.67)
During a continuing medical education activity after I become an expert	8 (11.26)
Q10: If you had an end stage disease (cancer, COPD, SVO, heart failure, etc.), would you like your physician to talk to you about your wishes for the end of your life?	**n** (%)
Yes	281 (63.43)
No	73 (16.47)
I am not certain	89 (20.09)
Q11: If you had an end stage disease, would you like to die in a hospital or at home?	**n** (%)
At home	343 (77.5)
In a hospital	40 (9.0)
I am uncertain	60 (13.5)
Q12: If you had an end stage disease, would you like to die in an intensive care unit? (n= 94) **	**n** (%)
Yes	22 (23.40)
No	44 (46.80)
I am not certain	28 (29.78)
Q13: If you had an end stage disease, would you want to die in a hospital clinic or palliative care center instead of your home? (n= 94) **	**n** (%)
Yes	35 (37.23)
No	24 (25.53)
I am not certain	35 (37.23)
Q14: If you had an end stage disease, would you like to receive chest compressions?	**n** (%)
Yes	62 (13.99)
No	321 (72.46)
I am not certain	60 (13.54)
Q15: If you had an end stage disease, would you like to be entubated and mechanically ventilated?	**n** (%)
Yes	54 (12.18)
No	335 (75.62)
I am not certain	54 (12.18)
Q16: If you had an end stage disease, would you like to be placed a central venous catheter?	**n** (%)
Yes	123 (27.76)
No	255 (57.56)
I am not certain	65 (14.67)
Q17: If you had an end stage disease, would you like to undergo hemodialysis?	**n** (%)

Yes	147 (33.18)
No	221 (49.88)
I am not certain	75 (16.93)
Q18: If you had an end stage disease, would you like to be placed a PEG (percutaneous endoscopic gastrostomy tube)?	**n** (%)
Yes	106 (23.92)
No	271 (61.17)
I am not certain	66 (14.89)
Q19: Have you ever talked to your first-degree relatives, who would decide for you, when you cannot decide for yourself, about your wishes about the end of life?	**n** (%)
Yes	76 (17.15)
No	367 (82.84)
Q20: Who would you like to decide for you, when you cannot decide for yourself, about your wishes about the end of life?	**n** (%)
Mother	55 (12.41)
Father	34 (7.67)
Spouse	251 (56.65)
Sibling	31 (6.99)
Child	21 (4.74)
My Lawyer	4 (0.90)
My Doctor	44 (9.93)
Other	3 (0.67)
Q21: Would you like to donate your organs if you were diagnosed with brain death?	**n** (%)
Yes	373 (84.19)
No	70 (15.80)
Q22: Have you informed your intimates about your wish regarding organ donation?	**n** (%)
Yes	262 (59.14)
No	181 (40.85)

*One option is marked.
**94% (n=94) of the participants (n=100) who wish to die in a hospital or uncertain about that, answered questions 12 and 13.

Among those who stated that they wanted to donate their organs, the rate of the physicians who had informed their relatives about this wish was 63.53% (n = 237) compared to 36.23% (n = 25) among physicians who stated that they did not want to donate their organs ($\chi^2 = 17.987$; $p < 0.001$).

The rate of the physicians stating their positive or negative decision regarding organ donation to relatives was 73.23% (n = 52) in the group who received training about interviewing with patients with terminal disease in terminal period versus 56.60% (n = 210) among physicians who hadn't received any training in this subject ($\chi^2 = 6.832$; $p = 0.009$).

The rate of those who did not want chest compressions or endotracheal intubation or invasive mechanical ventilation was not statistically different between the internal medicine, surgical, basic science, and emergency medicine branches. (P = 0.963).

When comparison was made for question 11-22 according to age groups shown in Table 1, there was no statistically significant difference between younger and older physicians (p>0,05; Chi-Square test).

Discussion

The Australian Medical Association suggests that good medical practice involves knowing boundaries of medicine and realizing when the efforts to extend life are not in the best interest of the patient.[3]

Emergency physicians may occasionally encounter situations in which patients and their relatives do not know the outcome of treatments to be administered or are unaware that their illness will lead to death. Nearly 35% of deaths in emergency services cover terminally ill patients with an existing chronic illness.[4] Emergency departments have become places where decisions of withholding or termination of treatments are made since they had become a frequent site of death.[3] In our study, 45% of all physicians, not only the emergency physicians, talked with their patients about end of life decisions.

The primary purpose of talking about the end of life and palliative care is to understand what acceptable outcomes the patient expects from recommended treatments, therefore, to make early and rational decisions about the necessity and appropriateness of treatments and provide patient-centered care by enhancing the dialogue with patients and relatives.[5]

Although such conversations are difficult for physicians, they are generally well received by patients and their relatives, whereas ignorance of the condition of a dying person causes futile treatment.[3] The medical care providers lack information on their legal obligations.[6, 7] Similar to the literature, we also found in this study that most of the physicians (84%) did not receive any education about conversations involving the end of life.

Our study showed that 77.42% of physicians stated that they would prefer to die at home if they had a terminal stage illness and 44% of those who were indecisive or who stated that they wanted to die in hospital stated that they did not want to die in an intensive care unit.

Cardiopulmonary resuscitation (CPR) is sometimes performed even in cases where the patient would not return to a previous health status or where death is an unavoidable result.[8] The culture of Western medicine is characterized by medical optimism and patients choose treatments that are really compelling and eventually result in death, and unrealistic results have been expected from CPR.[9,10] For these reasons, it seems that if the patient hasn't requested the opposite, CPR should be performed.[8] Do Not Resuscitate (DNR) decisions are pre-signed by patients in various countries to state decisions that are against this assumption but are not yet valid legally for Turkey. Although, starting and continuing CPR is legally required, when this document is not available, there are many ethical reasons for not starting resuscitation, including respect for the patient's autonomy and preferences, ensuring a quality death, and comparing the advantages and disadvantages of CPR.[11]

As a matter of fact, 72.46% of physicians stated that they would not want to have chest compression and 75.62% of them stated that they would not want to be intubated and receive invasive mechanical ventilation, if they were terminally ill. In addition, 57.56% stated that they would not want to have a central catheter, 49.88% stated that they would not want to undergo hemodialysis, and 61.17% stated that they would not want

percutaneous endoscopic gastrostomy insertion. When all these answers are taken into consideration, it is seen that physicians mostly prefer to die in the home by not being exposed to the invasive interventions and even if they would prefer to die in a hospital, they would not want to die in an intensive care unit, if they had a terminal disease. The physicians' knowledge and experiences about the end of life is higher than that of any other member of society. These may have affected their preferences for dying in a hospital.

Although, we know that, advance directives improve care and patient and family satisfaction at the end of life, and most health care professionals support this idea, the proportion of those who plan for the future is still low.[2] Despite the increasing knowledge and awareness of advance directives, the majority of patients with chronic illnesses who present to emergency departments do not share their decisions regarding the end of life with their families.[13] In our study, only 17.15% of physicians talked with relatives about end of life decisions. The physicians' hesitancy to make these conversations suggests that the rate of these conversations may be even lower in overall society. The reason for this hesitation may be physicians desire to preserve culture of endless hope in the fight of disease for their loved ones but this was not asked in our survey.

In the report of medical will workshop that was held in 2015, authors stated that balance between DNR orders and the most important human right of living should be kept at all times. [12]

The participants in our study stated that they want medical decisions to be made by their spouses, if they lose decision-making capacity. These results are consistent with the literature. [14]

Of the physicians participating in the study, 84.19% wanted their organs to be donated in case of brain death, while the ratio of those who told their negative or positive wishes in this regard with their relatives is 59.14%. The physician's positive opinions about organ donation may be due to their reliance on the medical system and their knowledge of the benefits of organ donation. The proportion of physicians who have talked with their relatives about their wishes about donating organs is higher than those who have talked about the end of life. This may be because organ donation is a more popular subject.

In case of brain death, 63.53% of physicians who want to donate their organs and 36.23% of those who do not want to donate stated that they have talked with their families in this regard, and the difference was statistically significant. This may be because those who want to donate their organs have talked with relatives to make sure that their wishes would be respected.

We grouped the physicians participating in the study as emergency medicine, internal medicine, surgical and basic sciences. When we analyzed the answers of these four groups,the only difference was found in terms of talking about the end of life decisions with patients or their relatives.

Limitations

Since the return rate of survey is low and participants were selected from only one city, our results may not be generalized. There may be a response bias since physicians

who are more interested in the subject may have preferred to join the study. Because the number of participants working on emergency medicine was high, it was evaluated separately.

Conclusion

Currently, being exposed to some interventions and dying in a hospital in the last days of life has become almost a standard. In this study, the opinions of physicians working in various specialties were investigated and it was determined that most of the physicians wanted to die at home and did not want to have CPR performed if they had a life limiting illness. It has also been observed that most physicians do not share these end of life decisions with their relatives.

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