# Assessment of Knowledge and Preferences Regarding Advance Directives Among Patients in University Family Medicine Outpatient Clinics

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# Ismet Koşar, MD, PhD<sup>1</sup>, Melahat Akdeniz, MD, PhD<sup>1</sup>, Ethem Kavukcu, MD, PhD<sup>1</sup>, and Hasan Huseyin Avci, MD, PhD<sup>1</sup>

# Abstract

**Aim:** The aim of this study is to draw attention to the subject of "advanced directives," to create awareness, whether or not they want to investigate to determine the preferences for medical care and applications in the period of end-of-life while individuals can specify their preferences and wishes for medical decisions and take steps for it. **Materials and Methods:** The study was carried out on individuals aged 20 years and older in family medicine outpatient clinics. A questionnaire consisting of 30 questions was applied to 300 people who volunteered to participate in the study by a face-to-face interview. **Results:** Of all participants, 70% had not heard of advance directives (ADs) before this survey. Three quarters of participants thought that advanced directives were necessary. The rate of requesting cardiopulmonary resuscitation (CPR) to prolong survival in the case of end-of-life care was 55%; the rate of requesting the continuation of life-sustaining treatment was 24%. **Conclusion:** Most participants want their own decision to be taken into account in end-of-life care. Family physicians should talk to their patients about ADs via effective communication when people are still healthy.

# Keywords

advance care planning/directives, end of life care, decision-making, adults, family medicine

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# Introduction

Advance directives (ADs) are derived from the ethical principles of patient autonomy and are oral and/or written instructions about the future medical care of patients in the event he or she becomes unable to communicate (Pugno, 2004; Spoelhof & Elliott, 2012; Talebreza & Widera, 2015). ADs provide a formal and legal mechanism for a competent person to specify their preferences for medical treatment in case they become unable to make decisions. ADs are documents signed by a competent person and include living wills, health care proxies, and do-not-resuscitate orders (Kessler & McClellan, 2014; Mahon, 2011).

The aim of AD is to support an individual's decisions and choices regarding end-of-life care and to prevent unnecessary suffering. ADs help ensure that patients receive the care they want, guide the family, and reduce their decision-making burden. Another reason for ADs is to limit the use of expensive, invasive, and useless care (Kessler & McClellan, 2014; Mahon, 2011). Research shows that ADs improve the quality of endof-life care and reduce the burden and cost of health care without increasing mortality (McDaniel et al., 2005; Teno et al., 2007).

Unexpected end-of-life situations can happen anytime and at any age. Therefore, ideally, it is recommended that ADs should be created with adults of all ages during an interview between the person, family, and the physician before an acute illness occurs, and in a less stressful environment. The person may review and revise these documents at any time (Mahon, 2011; Pugno, 2004; Talebreza & Widera, 2015).

<sup>1</sup>Akdeniz University, Antalya, Turkey

**Corresponding Author:** 

Melahat Akdeniz, Faculty of Medicine, Department of Family Medicine, Akdeniz University Hospital, Akdeniz University, Dumlupınar Bulvarı, Dumlupınar Boulevard, 07058 Campus, Antalya, Turkey.

Email: melahatakdeniz@gmail.com

Creative Commons Non Commercial CC BY-NC: This article is distributed under the terms of the Creative Commons Attribution-NonCommercial 4.0 License (https://creativecommons.org/licenses/by-nc/4.0/) which permits non-commercial use, reproduction and distribution of the work without further permission provided the original work is attributed as specified on the SAGE and Open Access pages (https://us.sagepub.com/en-us/nam/open-access-at-sage). Much of the research regarding ADs has been conducted with elders, hospitalized patients, and those with critical or terminal illnesses (Detering et al., 2010; O'Sullivan et al., 2015). There are few studies examining the knowledge, attitudes, and preferences about ADs among adults of all ages (Chan et al., 2019; Emanuel et al., 1991; Jackson et al., 2009).

The Patient Self-Determination Act (PSDA) was adopted in 1991 in the United States and requires the discussion of ADs in most health care institutions. It encourages competent adults to complete the AD forms before they become seriously ill (U.S. Department of Health and Human Services, 2008). Today, legal arrangements have been made in many countries such as New Zealand, England, Germany, Spain, and Australia (Niebrój, 2007).

There are no legal regulations regarding an AD in Turkey. Patient Rights Regulation contains the following statements (www.mevzuat.gov.tr):

The requests of a patient who is not in a position to declare his / her request during a medical intervention must be taken into attention in relation to the medical intervention previously announced. In repetitive diseases where the competence is lost from time to time, patient may be requested to give informed consent for the medical intervention to be made regarding the periods when he lost his competence. However, the Patient Rights Regulation requires physicians or health institutions only to obtain informed consent prior to medical interventions and does not give them a legal obligation to form AD with patients. In cases where the patient is incapable of making decisions, decisions regarding medical treatment and interventions are made by the parents or children of the patients who are legal guardians.

To the best of our knowledge, no studies have been conducted about ADs among the general population in Turkey. All studies about end-of-life care are related to palliative care (Gultekin et al., 2010). The aims of this study are to draw attention to the subject of ADs, which is not yet sufficiently acknowledged in our country, to raise awareness and to investigate whether individuals who do not yet have a fatal disease and can state their preferences and desires for health care want to set their preferences for medical care and interventions to be performed during the last period of life.

# **Materials and Methods**

The design of this study was a cross-sectional questionnaire survey consisting of face-to-face structured interviews with adults 20 years and older. No sample was selected for the study. Between October 2017 and June 2018, 300 people who visited to family medicine outpatient clinics for any health problems or counseling and gave written consent to participate were included in the study.

Inclusion criteria were as follows: 20 years of age or older, being able to communicate verbally, not having cognitive health problems, and giving informed consent to participate in the study. Persons who did not meet these criteria were excluded from the study. The objectives of the study were explained to each participant, and participants were encouraged to express their point of view freely. They were also informed that there were no right or wrong answers to the questions because their purpose was to explore attitudes and not to promote any particular concept. Informed written consent was obtained from each participant. The interviewer then verbally administered the study questionnaire to each participant individually.

The study questionnaire was not a readily available scale translation and was designed by the researchers after a comprehensive review of studies in the international scientific literature. In the pilot study, draft questionnaire was used, randomly applied to 20 adults and 10 family medicine residents. After the pilot study, the language and comprehensibility of the questionnaire were revised. Pilot study data were not included in the study. Our questionnaire contained 30 questions, and it was conducted in Turkish.

Our study was approved by the Akdeniz University Faculty of Medicine Clinical Research Ethics Committee with the decision dated August 15, 2017 and numbered 2012-KAEK-20 70904504/299. It was deemed scientifically and ethically appropriate.

#### Statistics

Data were analyzed using IBM SPSS Packet version 24.0 (IBM Corporation, Armonk, NY, USA). Descriptive statistics are presented as the mean  $(\pm)$ , standard deviation, median (min–max), and frequency distribution as number and percentage. Continuous variables in the data were first analyzed for normality by the Kolmogorov–Smirnov goodness-of-fit test. Comparisons between two groups were made via *t*-test for the variables that fit a normal distribution and a Mann–Whitney *U* test for those that did not fit a normal distribution. Categorical variables were evaluated by the chi-squared test. All *p* values of <0.05 were considered significant.

#### Results

Three hundred people, 56% of whom were female, participated in the study. Table 1 shows the sociodemographic characteristics of the participants.

In the study, the participants were asked many questions about the concept of AD and preferences for endof-life care. Table 2 gives the answers of the participants to questions regarding their future health status and their preferences about end-of-life care.

#### Statistical Comparisons

No statistically significant relationships were found between considering the possibility of not being able to

Table I.	The Sociodemographic	Characteristics	of the
Participant	ts.		

Sociodemographic characteristics	N	%
Sex		
Female	168	56.0
Male	132	44.0
Age (years)		
20–29	93	31.0
30–39	66	22.0
40–49	56	18.7
50–59	45	15.0
60–69	33	11.0
70–79	7	2.3
Education level		
Illiterate	3	1.0
Literate	11	3.7
Elementary school	37	12.3
Secondary school	17	5.7
High school graduate	81	27.0
Universities	151	50.3
Marital status		
Single	111	37.0
Married	175	58.3
Other	14	4.7
Monthly income		
US\$<300	21	7.0
US\$300–US\$999	104	34.7
US\$1000–US\$1999	111	37.0
>US\$2000	64	21.3
Profession		
Officer	81	27.0
Worker	59	19.7
Farmer	I	0.3
Retired	37	12.3
Self-employment	10	3.3
Housewife	36	12.0
Unemployed	5	1.7
Other	71	23.7
Self-rated health		
Good	165	55.0
Fair	102	34.0
Poor	27	8.0
Very poor	6	2.0
Total	300	100.0

make decisions about their own medical care with gender, age group, education level, marital status, average monthly income, and current health status perception. In the event that the participants were unable to decide on their own medical care, there was no statistically significant relationship between gender, age, educational status, marital status, and poor health in terms of talking to a family member or physician about making decisions on their behalf.

Approximately 32% of participants who consider the possibility of losing decision-making competence about their own medical care report that they have talked to a family or physician to decide on their behalf if they are

unable to decide on their own medical care. This rate was 15.1% in those who did not consider such a possibility and the difference was statistically significant (p = .002).

Although there was no statistically significant relationship between accepting the necessity of ADs and gender, marital status, and health status (p > .05), there was a statistically significant relationship between age and education level with acceptance of the necessity of ADs (p < .05).

One fifth of the participants stated that if they signed the AD form, they might be concerned that their treatment would not be done adequately. Reporting concern was statistically significantly higher in people over the age of 40 compared with people under the age of 40 and compared with single people versus those who were married (p < .001).

More than 70% of participants reported that they might want to choose a person as a health care proxy to make decisions about their own medical care. There was no statistically significant relationship between educational status, marital status, and income status with the desire to choose a health care proxy (p > .05). As age increases, the proportion of people who want to choose a health care proxy increases (66.7%–100.0%), and this difference was statistically significant (p < .05). Other parameters related to the request to choose a health care proxy are shown in Table 3.

Approximately 43% of women and 42% of men reported that they would like to choose their "spouses as health care proxy" (p > .05). Age, education level, marital status, and health status perception had statistically significant effects on who would be the health care proxy (Table 4).

In end-of-life care, the rate of participants who wanted life-sustaining treatments was statistically higher in male participants (59.1%) than female participants (44%) (p < .05). As age increases, the rate of not wanting life-sustaining treatments increases; however, the difference was not statistically significant. Table 5 presents the status of wanting life-prolonging treatment compared to other variables.

Participants were asked to indicate whether they wanted cardiopulmonary resuscitation (CPR) in the event of cardiac arrest while in the end stage of a fatal disease. Sex, age, marital status, and health status perception had statistically significant effects on who CPR request status, but, as education level increases, the rate of requesting CPR increases significantly (p = .009).

# Discussion

Advances in medical care and technology have prolonged life expectancy globally. The prolongation of life exposes people to living with chronic diseases and requires physicians to plan end-of-life care. Not planning end-of-life care may lead to unnecessary health care expenditures, and too often individuals receive

Questions		Answers	
At any time in your life, your health may deteriorate and you	Yes	No	l'm not sure
may not be conscious enough to make decisions about your	n (%)	n (%)	n (%)
own medical care. Have you ever considered the possibility that such a situation could arise?	207 (69.0%)	93 (31.0%)	0 (0%)
For situations where you may not be able to decide on your	Yes	No	l'm not sure
own medical care in the future, have you talked to a family	n (%)	n (%)	n (%)
member or physician about end-of-life care decision	80 (26.7%)	220 (73.3%)	0 (0%)
Do you have information about ADs that is defined as	Yes	No	l'm not sure
documented verbal and/or written instructions about the	n (%)	n (%)	n (%)
medical care that people want or do not want to take if they lose their ability to specify treatment preferences and	92 (30.7%)	208 (69.3%)	0 (0%)
According to you are A De personner and youful?	Vee	Na	Pro not ours
According to you, are AD's necessary and useful:	n (%)	n (%)	n (%)
	235 (78 3%)	65 (21 7%)	0 (0%)
If you signed such a document, would you be concerned that	200 (70.070) Yos	No.	l'm not suro
your treatment would not be done well enough?	n (%)	n (%)	n (%)
your treatment would not be done wer enough:	63 (21%)	126 (42 0%)	111 (37%)
Whether or not you sign such a form do you know that	Yes	No	I'm not sure
your treatment will continue in the best possible way?	n (%)	n (%)	n (%)
	135 (45%)	48 (16%)	117 (39%)
Do you know that an AD form does not have to be prepared	Yes	No	l'm not sure
by a lawyer and accepted by the court?	n (%)	n (%)	n (%)
-//	50 (16.7%)	250 (83.3%)	0 (0%)
Would you like to choose someone (a relative or friend) as	Yes	No	I want my doctor
a health care proxy to make decisions about your medical	n (%)	n (%)	to decide for me.
care when you are seriously ill or unable to express your wishes after a sudden accident?	221 (73.7%)	23 (7.6%)	n (%) 51 (18.7%)
Who do you want to choose as a health care proxy?	My partner: 102 (34%	()	
, , , , , , , , , , , , , , , , , , , ,	One of my parents: 5	0 (16.7%)	
	One of my children:	46 (15.3%)	
	My brother or sister:	36 (12.0%)	
	My friend: 7 (2.3%)		
	No answer: 59 (19.75	%)	
It is sometimes possible to resuscitate with CPR when people	Yes	No	I'm undecided.
have their heartbeat stopped or failed to breathe. If you	n (%)	n (%)	n (%)
had a deadly disease such as end-stage cancer, would you want CPR to prolong your life when your heartbeat stops?	165 (55%)	91 (30.3%)	44 (14.7%)
If you had irreversibly lost your mental functions and were	Yes	No	l want my doctor
able to live with artificial nutrition and breathing apparatus,	n (%)	n (%)	to decide for me.
would you like to continue life-sustaining treatment?	74 (24.7%)	166 (55.3%)	n (%) 60 (20.0%)
If you were in a late-stage disease or vegetative condition	l want life-	l want artificial	l don't want any
where there was no chance of treatment, what are the life-	sustaining	nutrition and	life-sustaining
sustaining treatments you want done?	treatments that	hydration if	treatment,
	my doctors think	they re going to	
	are best for me.	make me live.	n (%)
	186 (62 0%)	) (/%) )) (7 3%)	92 (30.0 <i>%</i> )
Would you like your life to be as long as possible, even if	Yos	22 (7.5%) No	l'm not suro
life-sustaining treatments do not improve your health or	n (%)	n (%)	n (%)
relieve vour suffering?	74 (24 7%)	152 (50.6%)	74 (24 7%)
If you have a fatal disease, who do you want doctors to tell	I'd like to be told	I'd like my family	It does not matter
first?	first	members to be	who was first
	n (%)	told first.	informed.
	253 (84%-3%)	n (%)	n (%)
		35 (11.7%)	12 (4.0%)
Do you know that you have a legal right to not have your	Yes	No	l'm not sure
illnesses informed to other people, such as family members,	n (%)	n (%)	n (%)
unless you want to do so?	180 (60.0%)	120 (40%)	0 (0%)
Do you want your decision or your family's decision to be	My decision must	It would be more	l'm not sure
taken into consideration in relation to organ donation?	, be taken into	appropriate	n (%)
Ğ	account	for my family's	0 (0%)
	n (%)	decision.	
	240 (80.0%)	n (%)	
		60 (20.0%)	

Table 2. Participants' Responses to Questions About AD Concept, End-of-Life Care, and Others.

Note. CPR = cardiopulmonary resuscitation; ADs = advance directives.

	Wants to choose a health care proxy		Does not want to choose a health care proxy		He or she wants his or her physician to make the decision		Total		
Variables	n	%	n	%	n	%	n	%	Þ
Sex									
Female	122	72.6	10	6.0	36	21.4	168	100.0	.214ª
Male	99	75.0	13	9.8	20	15.2	132	100.0	
Age (years)									
20–29	62	66.7	7	7.5	24	25.8	93	100.0	.002 <sup>b</sup>
30–39	48	72.7	3	4.5	15	22.7	66	100.0	
40–49	39	69.6	8	14.3	9	16.1	56	100.0	
50–59	36	80.0	3	6.7	6	13.3	45	100.0	
60–69	29	87.9	2	6.I	2	6. I	33	100.0	
70–79	7	100.0	0	0.0	0	0.0	7	100.0	
The thinking about the possibility of los	ing comp	etence							
Yes	161	77.8	7	3.4	39	18.8	207	100.0	$<.001^{a}$
No	60	64.5	16	17.2	17	18.3	93	100.0	
Self-rated health									
Very poor	20	66.7	4	13.3	6	20.0	30	100.0	.574ª
Fair	73	71.6	10	9.8	19	18.6	102	100.0	
Good	116	75.3	8	5.2	30	19.5	154	100.0	
Very good	12	85.7	I	7.1	I	7.1	14	100.0	
Opinion on AD									
Not familiar with AD, but not	33	63.5	13	25.0	6	11.5	52	100.0	$<.001^{a}$
necessary									
Not familiar with AD, but necessary	125	80.I	4	2.6	27	17.3	156	100.0	
Familiar with AD, not necessary	9	69.2	3	23.1	I	7.7	13	100.0	
Familiar with AD, necessary	54	68.4	3	3.8	22	27.8	79	100.0	
Total	221	73.7	23	7.7	56	18.7	300	100.0	

Table 3. Th	he Status of Opinions /	bout Whether or Not to	Choose a Health	Care Proxy	According to Other	· Variables.
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Note. AD = advance directive.

 $^{\mathrm{a}}\text{Chi-square test.}$   $^{\mathrm{b}}$  Linear by linear association.

Table 4.	According to the	Variables, tl	he Participants	Want Who	Would Be the	Health	Care Proxy.
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	Health care proxy												
Variables	Par	ent	Sib	ling	Fri	end	Spouse		Child		Total		
	n	%	n	%	n	%	n	%	n	%	n	%	Þ
Sex													
Female	22	16.8	19	14.5	3	2.3	56	42.7	31	23.7	131	100.0	.220ª
Male	28	25.5	17	15.5	4	3.6	46	41.8	15	13.6	I.	100.0	
Age (years)													
20–29	42	60.0	9	12.9	4	5.7	15	21.4	0	0.0	70	100.0	$< .001^{a}$
30–39	5	9.4	14	26.4	2	3.8	31	58.5	Ι	1.9	53	100.0	
40-49	3	6.7	4	8.9	I	2.2	29	64.4	8	17.8	45	100.0	
50–59	0	0.0	8	22.2	0	0.0	13	36. I	15	41.7	36	100.0	
60–69	0	0.0	I	3.3	0	0.0	11	36.7	18	60.0	30	100.0	
70–79	0	0.0	0	0.0	0	0.0	3	42.9	4	57.I	7	100.0	
Education levels													
Illiterate	0	0.0	0	0.0	0	0.0	2	66.7	1	33.3	3	1.0	$< .001^{a}$
Literate	5	71.4	0	0.0	0	0.0	2	28.6	0	0.0	7	3.7	
Elementary school	2	5.7	I	2.9	0	0.0	19	54.3	13	37.1	35	12.3	
Secondary school	2	15.4	2	15.4	0	0.0	5	38.5	4	30.8	13	5.7	
High school	20	34.5	9	15.5	0	0.0	20	34.5	9	15.5	58	27.0	

(continued)

		Health care proxy											
	Par	ent	Sib	ling	Fr	iend	Spo	ouse	Cl	nild	Тс	otal	
Variables	n	%	n	%	n	%	n	%	n	%	n	%	Þ
Universities	21	16.8	24	19.2	7	5.6	54	43.2	19	15.2	125	50.3	
Marital status													
Single	46	53.5	21	24.4	7	8. I	9	10.5	3	3.5	86	100.0	<.001ª
Married	3	2.1	14	9.9	0	0.0	91	64. I	34	23.9	142	100.0	
Other	I	7.7	I	7.7	0	0.0	2	15.4	9	69.2	13	100.0	
Self-rated health													
Very poor	3	13.6	4	18.2	0	0.0	9	40.9	6	27.3	3	100.0	.045 <sup>b</sup>
Fair	17	21.3	9	11.3	I	1.3	34	42.5	19	23.8	17	100.0	
Good	25	19.8	20	15.9	4	3.2	57	45.2	20	15.9	25	100.0	
Very good	5	38.5	3	23.I	2	15.4	2	15.4	1	7.7	5	100.0	
The thinking about th	ne possib	ility of lo	sing cor	mpetence	2								
Yes	31	18.2	26	15.3	7	4.1	73	42.9	33	19.4	31	100.0	.307ª
No	19	26.8	10	14.1	0	0.0	29	40.8	13	18.3	19	100.0	
Total	50	20.7	36	14.9	7	2.9	102	42.3	46	19.1	241	100.0	

# Table 4. (continued)

 $^{\mathrm{a}}\mathrm{Chi}\text{-square test.}$   $^{\mathrm{b}}$  Linear by linear association.

Table 5.	The Status o	of Wanting	Life-Prolonging	Treatment Com	pared With	Other Variables.
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	He o want prolo treat	or she s life- onging ment	He or she does not want life-prolonging treatment		Not sure		Total		
Variables	n	%	n	%	n	%	n	%	Þ
Sex									
Female	42	25.0	74	44.0	52	31.0	168	100.0	.009ª
Male	32	24.2	78	59.I	22	16.7	132	100.0	
Age (years)									
20–29	18	19.4	50	53.8	25	26.9	93	100.0	.128ª
30–39	14	21.2	32	48.5	20	30.3	66	100.0	
4049	21	37.5	24	42.9	11	19.6	56	100.0	
50–59	15	33.3	22	48.9	8	17.8	45	100.0	
60–69	4	12.1	19	57.6	10	30.3	33	100.0	
70–79	2	28.6	5	71.4	0	0.0	7	100.0	
Education levels									
Illiterate	I	33.3	2	66.7	0	0.0	3	1.0	.007ª
Literate	2	18.2	5	45.5	4	36.4	11	3.7	
Elementary school	17	45.9	14	37.8	6	16.2	37	12.3	
Secondary school	9	52.9	7	41.2	I	5.9	17	5.7	
High school	18	22.2	39	48.I	24	29.6	81	27.0	
Universities	27	17.9	85	56.3	39	25.8	151	50.3	
Marital status									
Single	17	15.3	62	55.9	32	28.8	111	100.0	.076ª
Married	53	30.3	83	47.4	39	22.3	175	100.0	
Other	4	28.6	7	50.0	3	21.4	14	100.0	
The thinking about the possibility of losing com	npetence	9							
Yes	50	24.2	105	50.7	52	25.I	207	100.0	.938ª
No	24	25.8	47	50.5	22	23.7	93	100.0	
Do you want to choose a health care proxy									
Yes	52	23.5	118	53.4	51	23.1	221	100.0	. <b>486</b> ª
No	5	21.7	10	43.5	8	34.8	23	100.0	
He wants his doctor to make the decision	17	30.4	24	42.9	15	26.8	56	100.0	

(continued)

#### Table 5. (continued)

	He or she wants life- prolonging treatment			or she ot want olonging ment	Not	sure	Total		
Variables	n	%	n	%	n	%	n	%	Þ
Opinion on whether he or she wants CPR									
Yes	64	38.8	58	35.2	43	26.1	165	100.0	<.001ª
No	5	5.5	76	83.5	10	11.0	91	100.0	
Undecided	5	11.4	18	40.9	21	47.7	44	100.0	
Total	74	24.7	152	50.7	74	24.7	300	100.0	

Note. CPR = cardiopulmonary resuscitation.

<sup>a</sup>Chi-square test.

more aggressive care than they desire (McDaniel et al., 2005). In the planning of end-of-life care, physicians negotiate with their patients about their values and wishes or preferences for end-of-life care; they try to provide them with the care they prefer (Pugno, 2004; Talebreza & Widera, 2015). However, patients may not always be competent to communicate their preferences and make their own decisions about health care.

In this study, we evaluated the knowledge and opinions of participants who are still capable of making decisions about ADs which regulate how their care should be performed in case of an inability to make decisions in the future. To our knowledge, this study is one of the first to explore these topics among a healthy outpatient population of adults of all ages in Turkey.

In many studies on ADs, the rate of filling out AD forms was determined. (Detering et al., 2010; Niebrój, 2007; O'Sullivan et al., 2015). In our study, this subject was not asked because there are not legal AD forms in Turkey.

Approximately 70% of the participants reported that they had never heard of ADs before this survey. After being informed of the AD concept, 78.3% stated that ADs were necessary and useful for discussing their wishes or preferences for end-of-life care. Although the rate of those who think that ADs were necessary decreases with age (56.1%-42.9%), the rate increased with education level (6.0%-52.6%).

In previous studies, the rates of participants that had not heard of ADs before the survey were as follows: Thing and Mok (2011) in Hong Kong, 81%; Wong et al. (2017) in 2016, 85.7%; and Chan et al. (2019), 81.4%. In a study conducted by Freer et al. (2006), 86.2% of the participants reported that they did not know the concept of ADs. In the study conducted by Toro-Flores et al. (2017) in Spain, AD awareness and preparation rates were low. In a study conducted by Sam and Singer (1993) in Canada, 16% of the participants reported that they had information about a living will, 11% reported that they had information about a health care proxy, and 4% reported that they had information about ADs. A study by Jackson et al. (2009) examined attitudes, experiences, and preferences about ADs among people aged 20 years and older. In that study, 53% of the 187 participants stated that they heard of a living will, 31% stated that they had heard of a health care proxy, whereas only 22.4% said they had heard of advanced directives (12). In a study conducted by Emanuel et al. (1991), 93% of outpatients and 89% of members of the general public desired AD. Gamble et al. (1991) investigated the knowledge, attitudes, and behaviors of elderly individuals living in North Carolina in the United States. They found that 52% of the participants said that they were familiar with living wills.

In our study, 78.3% of the participants stated that ADs are necessary and useful for discussing their wishes about the end of life. It was found that most of the subjects who consider things such as ADs necessary are better educated and younger (p < .05). These results are also similar to previous studies that demonstrated that people with a higher level of education and those who are younger considered the AD necessary. In the study by Jackson and et al., 48.9% of the participants under the age of 60% and 41.0% of the participants above 60 years of age stated that ADs were necessary. In a study conducted by Dumitraş et al. (2013), 51.4% of participants reported that an AD was a useful document for decisions concerning the end of life.

In this study, only 16.7% of participants knew that an AD form does not have to be prepared by a lawyer to be accepted by the court. In the study by Jackson et al. (2009), almost two thirds of participants were aware that creating an end-of-life care document does not require a lawyer.

Knowing the will of the patient facilitates decisionmaking at the end of life for both family members and health providers. In our study, 26.7% of the participants reported that they spoke to one of their family members or their physician to decide on their behalf if they were unable to decide on their own medical care. In a study conducted by Jackson et al. (2009), 44% of the participants reported that they were talking to someone about their wishes. In our study, the reason why this rate was lower may be the dislike of talking about death between family members in Turkey.

After the participants were informed about the health care proxy, they were asked whether they would like to choose a health care proxy as a decision maker on their behalf in case they lost their decision-making ability. Seventy-three percent of the respondents stated that they wanted to choose a health care proxy; 18.7% wanted their physicians to make end-of-life care decision on their behalf. In the study by Emanuel et al. (1991), 78% of the participants stated that they wanted to be a health care proxy, and 44% wanted to discuss end-of-life care with their physician. In the study of Tink and Mok (2011), 39% of the respondents stated that they would like to discuss these issues with others. Among those who wanted to discuss the concept, most wanted to talk to relatives (92%) and only 9% wanted to have discussions with a physician. In the context of decision-making, 55% of elderly patients agreed that the patient alone should make the decision regarding end-of-life care if he or she was competent; 44% of participants thought that the family should make the decision if the patient was not competent, and 31% agreed that family and the physician should make decisions together.

In our study, as age increases, the ratio of people who want to choose a health care proxy increases as well. As a health care proxy, parents in the younger age group (20-29 years), spouses in the middle age group (30-60 years), and children in the advanced age group (50-79 years) were more preferred. In the Wisconsin Longitudinal Study conducted by Carr et al. (2013), it was found that people with happy marriages were more likely to appoint their spouses as a health care proxy, whereas those who receive emotional support from their children tend to appoint an adult child as a health care proxy (26). In the study by Gamble et al. (1991), 93% of the participants requested that one of their family members or spouses decide on end-of-life care if they themselves were unable to make such a decision.

In our study, if they signed an AD form, the rates of worry about whether the treatment should be done well enough were found to be statistically higher in married participants and those over 40 years old compared with single participants and those under 40 years old. It is important for health care professionals involved in endof-life care to be aware of these patients' concerns and to communicate with them to address concerns, together which may reduce end-of-life care concerns for patients.

The final questions investigated the participant's preferences regarding life-sustaining treatments. In this study, the rate of requesting CPR to prolong survival in case of end-of-life care was 55%; the rate of requesting continuation of life-sustaining treatment was 24%. The rates of requesting continuation of life-sustaining treatment and CPR decreased significantly

with increasing educational status. This may be because educated people do not want to increase the care burden of their family by extending life in case of an incurable disease.

In the study by Emanuel et al. (1991), 74% of the participants stated that they did not want dialysis and artificial nutrition; 73% did not want mechanical respiration, CPR, or blood transfusion; 71% declined intravenous fluids; and 68% did not want antibiotics. In the study by Gamble et al. (1991), it was found that 86% of the participants wanted to receive only basic medical or comfort care and did not want life-sustaining treatment for medical care in the setting of a terminal illness. In the study by Wong et al. (2017), 87.5% of the participants reported that they preferred palliative care rather than life-prolonging treatment.

# **Conclusion and Suggestions**

Seventy percent of participants had not heard of ADs before this survey. The rate of requesting CPR to prolong survival in the case of end-of-life care was 55%; the rate of requesting continuation of life-sustaining treatment was 24%. Although there is no legal regulation about ADs in Turkey, our findings indicated that most participants want their own decision to be taken into account in end-of-life care. Studies have shown that family physicians are in a good position to create ADs because they have long-term and trust-based relationships with their patients.

In Turkey, it is assumed that people will not like to talk about end-of-life care or ADs. The results of this study show that this is not exactly true. Patients also prefer that family physicians initiate the discussion with them about end-of-life care. For this season, family physicians should talk to their patients about ADs via effective communication when people are still healthy.

The strength of this study is that it was conducted through face-to-face interviews with adults of all ages in the community. The limitations of this study are that our sample size was small, and the study was from only one center, which may lead to selection bias. Larger samples are needed to validate the conclusion, and multicenter studies are needed to validate the preference of ADs.

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# ORCID iD

Melahat Akdeniz (D) https://orcid.org/0000-0003-0792-8701

#### References

- Carr, D., Moorman, S. M., & Boerner, K. (2013). End-of-life planning in a family context: Does relationship quality affect whether (and with whom) older adults plan? *The Journals of Gerontology, Series B: Psychological Sciences* & Social Sciences, 68, 586–592.
- Chan, C. W. H., Wong, M. M. H., Choi, K. C., Chan, H. Y. L., Chow, A. Y. M., Lo, R. S. K., & Sham, M. M. K. (2019). Prevalence, perception, and predictors of advance directives among Hong Kong Chinese: A population-based survey. *International Journal of Environmental Research and Public Health*, 16, 365. https://doi.org/10.3390/ijerph16030365
- Detering, K. M., Hancock, A. D., Reade, M. C., & Silvester, W. (2010). The impact of advance care planning on end of life care in elderly patients: Randomised controlled trial. *British Medical Journal*, 340, c1345.
- Dumitras, S., Enache, M., Pârvu, A., Moisa, S. M., Iov, C., & Ioan, B. (2013). Advance directive from the Romanian social cultural perspective. *Postmodern Openings*, 4, 87–101.
- Emanuel, L. L., Barry, M. J., Stoeckle, J. D., Ettelson, L. M., & Emanuel, E. J. (1991). Advance directives for medical care: A case for greater use. *The New England Journal of Medicine*, 324, 889–895.
- Freer, J. P., Eubanks, M., Parker, B., & Hershey, C. O. (2006). Advance directives: Ambulatory patients' knowledge and perspectives. *The American Journal of Medicine*, 119, 1088.e9–1088.e13.
- Gamble, E. R., McDonald, P. J., & Lichstein, P. (1991). Knowledge, attitudes and behavior of elderly persons regarding living wills. *Archives of Internal Medicine*, 151, 277–280.
- Gultekin, M., Ozgul, N., & Olcayto, E. T. M. (2010). Current Status of Palliative Care in Turkey. *Turkish Journal of Gynecological Oncology*, 13, 1–6.
- Jackson, J. M., Rolnick, S. J., Asche, S. E., & Heinrich, R. L. (2009). Knowledge, attitudes, and preferences regarding advance directives among patients of a managed care organization. *The American Journal of Managed Care*, 15, 177–186.
- Kessler, D. P., & McClellan, M. B. (2004). Advance directives and medical treatment at the end of life. *Journal of Health Economics*, 23, 111–127.
- Mahon, M. M. (2011). An advance directive in two questions. Journal of Pain and Symptom Management, 41, 801–807.
- McDaniel, S., Campbell, T., Hepworth, J., & Lorenz, A. (2005). Looking death in the eye: Facilitating end-of-life

care and the grieving process. In *Family-oriented primary* care (2nd ed., pp. 261–284). Springer.

- Niebrój, L. T. (2007). Advance directives and the concept of competence: Are they a moral barrier to resuscitation? *Journal of Physiology and Pharmacology*, 58, 477–484.
- O'Sullivan, R., Mailo, K., Angeles, R., & Agarwal, G. (2015). Advance directives: Survey of primary care patients. *Canadian Family Physician*, *61*, 353–356.
- Pugno, P. A. (2004). Advance directives in the primary care setting. *Wien Klin Wochenschr*, 116, 417–419.
- Sam, M., & Singer, P. A. (1993). Canadian outpatients and advance directives: Poor knowledge and little experience but positive attitudes. *Canadian Medical Association Journal*, 148, 1497–1502.
- Spoelhof, G. D., & Elliott, B. (2012). Implementing advance directives in office practice. *American Family Physician*, 85, 461–466.
- Talebreza, S., & Widera, E. (2015). Advance directives: Navigating conflicts between expressed wishes and best interests. *American Family Physician*, 91, 481–483.
- Teno, J. M., Gruneir, A., Schwartz, Z., Nanda, A., & Wetle, T. (2007). Association between advance directives and quality of end-of-life care: A national study. *Journal of the American Geriatrics Society*, 55, 189–194.
- Thing, F. H., & Mok, E. (2011). Advance directives and lifesustaining treatment: Attitudes of Hong Kong Chinese elders with chronic disease. *Hong Kong Medical Journal*, 17, 105–111.
- Toro-Flores, R., Lopez-Gonzales, R., & Lopez-Munoz, J. A. (2017). Knowledge and attitudes of critically ill patients and their families on advance directives and the decision making process at the end of life. *Enfermería Intensiva*, 28, 21–30.
- U.S. Department of Health and Human Services. (2008). Assistant secretary for planning and evaluation office of disability, aging and long-term care policy advance directives and advance care planning: Report to congress. http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt. pdf
- Wong, S. Y., Wong, E. L., Kiang, N., Chau, P. Y., Lau, J. Y. C., Yeoh, E., Chung, N. Y., & Woo, J. W. (2017). Knowledge, attitudes, and preferences of advance decisions, end-of-life care, and place of care and death in Hong Kong. A population-based telephone survey of 1067 adults. *Journal of the American Medical Directors Association*, 18, 367.e19–367.e27.