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Opinions of a group of Turkish patients regarding patients' rights¹

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Abstract

The aim of this descriptive study is to determine a group of patients' awareness of patient rights, significance of patients' rights for them and how they utilize these rights.

The study was carried out with 100 of the patients who were admitted to the blood-taking unit of the outpatient services department of Mersin University Health Research and Application Center between September 1, - October 15, 2009, and agreed to participate in the study. The participants were asked to state whether they were knowledgeable about each of these rights, and whether they had ever benefited from them. Of the participants, 53% were knowledgeable about the 14 patients' rights listed in the data collection form and 28% benefited from these rights.

Although the study participants generally attached importance to patients' rights, they neither were knowledgeable about these rights nor benefited from them sufficiently.

Keywords: Patients' Rights, Health Law, Medical Ethics, Nursing, Public Health

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1. Introduction

9 It is possible to consider patients' rights, a mechanism regulating medical relation, as the alternative
10 and also the complementary of medical ethics. While the aforementioned arrangements are
11 prepared to determine health care professionals' ideal and/or standard behaviors within the
12 framework of medical ethics, the main concern in terms of patients' rights is the patient's needs and
13 expectations. While the conceptual-theoretical dimension of patients' rights is within the scope and

¹This study presented as verbal statement in VI. Medical Ethics Congress organized on 25-26 November 2010 by Turkish Bioethics Association. Istanbul, Turkey.

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14 interest of medical ethics, its practice-related legal-administrative dimension is within the scope and
15 interest of the medical law.

16 The onset and spread of the concept and implementation of patients' rights began in the second
17 half, especially in the last quarter, of the 19th century. In the first years of the Turkish republic,
18 legislation regulating health services included, although not entitled accordingly, some patients'
19 rights within the context of basic human rights. However, developments related to contemporary
20 patients' rights were put into practice later, in parallel with those in the world. Within the context of
21 these developments, discussions regarding patients' rights began in the late 1980s. Recognition of
22 patients' rights within the legislative framework took place at the end of the 1990s when the
23 Patients' Rights Regulations were put into effect. The Regulations which came into effect in August
24 1998 remained the same until they were subjected to a radical revision in May 2014 (Turkey
25 Patients' Rights Regulations 1998; Turkey Regulations Amending the Patients' Rights Regulations
26 2014).

27 One of the determinants indicating to what extent patients' rights would be effective in regulating
28 medical relations is how well they are known and adopted by the community. Determining the
29 patients' rights-related knowledge and opinions of the general population or its specific subgroups
30 has the potential to contribute to practical arrangements of and theoretical debates on these rights.
31 The purpose of this present study based on these assessments and conducted on a limited number
32 of people is to determine and evaluate to what extent patients are aware of patients' rights and
33 benefit from them, and how important these rights are to them. The hypothesis we developed in
34 the initial phase of our study based on general observations and literature review is that 'patients are
35 aware of their rights and they benefit from at a moderate level'.

36 2. Methods

37 The data collection form prepared within the scope of the study consists of two parts. While the
38 first section includes 8 items questioning the socio-demographic characteristics of the participants
39 and their attitudes towards patients' rights, the second part has a list of 14 patients' rights. The
40 participants were asked to state whether they were knowledgeable about each of these rights, and
41 whether they had ever benefited from them. They were also asked to rate each item on a scale
42 ranging from 0 to 10 points to demonstrate the significance of patients' rights from their
43 perspective.

44 Data were collected using a random sampling method. The data collection form was administered
45 to first 100 (50 male, 50 female) of the patients who presented to the blood-taking unit of the

46 outpatient services department of Mersin University Health Research and Application Center
 47 between September 1, 2009 and October 15 and agreed to participate in the study. In the
 48 processing of the data of this descriptive study, the SPSS 11.5 for Windows was used. In the
 49 statistical analysis, while numbers and percentages were calculated for categorical variables, means
 50 and standard deviation were calculated for continuous variables. Approvals to conduct the study
 51 were obtained from the Health Sciences Ethics Committee of Mersin University and the
 52 management of the institution where the study was conducted.

53 3. Results

Table 1. Socio-demographic characteristics of the participants

		Number (n)	Percentage (%)
Age	18-20	8	8
	21-30	21	21
	31-40	31	31
	41-50	21	21
	51-60	14	14
	61 and over	5	5
3 Educational status	Primary school	16	16
	Junior high school	8	8
	Senior high school	36	36
	University	40	40
Employment status	Employed	56	56
	Unemployed	44	44
Health insurance	Yes	95	95
	No	5	5
Place of residence	Village-small town	4	4
	Town	19	19
	City	77	77
Attending training/meeting on patients' rights	Yes	7	7
	No	93	93
The number of health care services received from Mersin University Health Research and Application Center	Three or more times	78	78
	Twice	12	12
	once	10	10
Being informed about patients' rights	Yes	22	22
	No	78	78

54 Responses to the eight questions asked to determine socio-demographic characteristics of the
 55 participants and their attitudes towards patients' rights are listed in Table 1.

56

57 Of the respondents, 50% were female. Their ages ranged between 18 and 88 with a mean age of
 58 38.58. Of the participants, 40% were university, 36% were senior high school, 8% were junior high
 59 school, 16% were primary school graduates, 56% were employed, 95% had health insurance, 77%
 60 lived in a city, 19% lived in a town and 4% lived in a small town or village. Of the participants,
 61 while 78% presented to the health center where the study was conducted three or more times, 12%
 62 presented twice and 10% presented once.

63 While 7% of them attended training or meeting held on patients' rights, 78% of them did not
64 receive any information regarding patients' rights at all. Of the 22 participants who had received
65 information, 9 obtained the information only from physicians, 6 from nurses and physicians, 2 only
66 from nurses, 2 from the secretary and 3 from other sources.

67 The distribution of the participants in terms of their awareness and utilization of the 14 patients'
68 rights listed in the data collection form, and the mean significance scores from the highest to the
69 lowest are given in Table 2.

Table 2. Distribution of the participants in terms of their awareness and utilization of patients' rights and the mean significance scores

Right	Those who are aware of the right (%)	Those who benefit from the right (%)	Mean significance scores \pm Standard deviation
Health care facilities should have a special unit providing information to patients continuously.	41 (41.00)	12 (12.00)	9.19 \pm 2.14
Patients or family members/support persons should be informed about all the medical interventions patients are to undergo and their consents should be obtained.	60 (60.00)	32 (32.00)	9.07 \pm 2.19
The patient can designate his/her healthcare providers within the bounds of possibilities of the health center.	39 (39.00)	14 (14.00)	9.05 \pm 2.02
If the patient is willing and hospital authorities approve, his/her family members or relatives may accompany him/her.	71 (71.00)	34 (34.00)	8.85 \pm 2.08
The patient is informed about his/her medical condition, medical practice options and the expected course of the disease.	64 (64.00)	32 (32.00)	8.80 \pm 2.47
The patient's privacy should be respected; irrelevant people should not view medical procedures he/she undergoes.	65 (65.00)	37 (37.00)	8.76 \pm 2.37
The patient's life cannot be terminated even if the aim is to relieve pain or despair.	63 (63.00)	58 (58.00)	8.70 \pm 2.65
Health staff should inform the patient that he/she provides care about his/her identity and task.	46 (46.00)	18 (18.00)	8.69 \pm 2.53
The patient can review or obtain a copy of the hospital records related to his/her care/treatment.	55 (55.00)	37 (37.00)	8.64 \pm 2.67
If the patient is to be referred to another health center, the patient or the relatives are informed.	59 (59.00)	29 (29.00)	8.64 \pm 2.41
The patient may require that he/she or the relatives be or not be informed about his/her medical condition	49 (63.00)	26 (26.00)	8.38 \pm 2.48
The patient may not be told what his/her diagnosis is if he/she is to be adversely affected.	39 (39.00)	18 (18.00)	8.38 \pm 2.71
The patient can refuse the current or recommended treatment	56 (56.00)	29 (29.00)	7.78 \pm 2.92
Inpatient health care centers are supposed to provide a place of worship in order for patients to observe their religious practices.	32 (32.00)	16 (16.00)	6.41 \pm 3.46

70

71 Of the 14 patients' rights listed in the data collection form, the one known most by the participants
72 was that "If the patient is willing and hospital authorities approve, his/her family members or
73 relatives may accompany him/her" (71%). The second most known right was that "The patient's
74 privacy should be respected; irrelevant people should not view medical procedures he/she

75 undergoes” (65%) followed by that “The patient is informed about his/her medical condition,
76 medical practice options and the expected course of the disease” (64%). The ones known least by
77 the participants were as follows: “Inpatient health care centers are supposed to provide a place of
78 worship in order for patients to observe their religious practices (32%).”, “The patient can
79 designate his/her healthcare providers within the bounds of possibilities of the health center
80 (39%)” and “The patient may not be told what his/her diagnosis is if he/she is to be adversely
81 affected (39%)”.

82 Of the 14 patients' rights listed in the data collection form, the ones the participants benefited from
83 most were as follows: “The patient's life cannot be terminated even if the aim is to relieve pain or
84 despair (58%).”, “The patient's privacy should be respected; irrelevant people should not view
85 medical procedures he/she undergoes (37%).”, “The patient can review or obtain a copy of the
86 hospital records related to his/her care (37%). The rights the participants benefited from least were
87 as follows: “Health care facilities should have a special unit providing information to patients
88 continuously (12%).”, “The patient can designate his/her healthcare providers within the bounds of
89 possibilities of the health center (14%)” and “Inpatient health care centers are supposed to provide
90 a place of worship in order for patients to observe their religious practices (16%).”.

91 When the 14 patients' rights listed in the data collection form were classified in terms of the
92 significance scores based on the participants' rating ranging from 0 to 10, the first three ones or in
93 other words the ones considered the most significant were as follows: “Health care facilities should
94 have a special unit providing information to patients continuously (9.19).”, “Patients or family
95 members/support persons should be informed about all the medical interventions patients are to
96 undergo and their consents should be obtained (9.07).” and “The patient can designate his/her
97 healthcare providers within the bounds of possibilities of the health center (9,05). The participants
98 gave the lowest scores to the following items: “Inpatient health care centers are supposed to
99 provide a place of worship in order for patients to observe their religious practices (6.41).”, “The
100 patient can refuse the current or recommended treatment (7.78) and “The patient may require that
101 he/she or the relatives be or not be informed about his/her medical condition (8.38).”.

102

103 **4. Discussion**

104 Awareness of patients' rights is the reflection of health consciousness of the public and is among
105 the determinants of the quality of health services. It is possible to say that the rates of utilization of
106 patients' rights are an indirect indicator of both the level of the delivery of health services and the

107 success of health care professionals in fulfilling their tasks. In line with this assessment, it is just
108 normal to desire and expect that awareness and utilization rates of patients' rights should be high.

109 According to our study results, awareness rates of patients' rights range between 32% and 71%.
110 The average rate is 53%. Although higher rates are favored, these rates are not too low. This low
111 level of awareness of patients' rights can be explained by the public's indifference and lack of
112 publicity. The rate of the patients stating that they were informed by health workers about patients'
113 rights was 22%, which indicates that the aforementioned inadequacy is experienced in medical
114 relations between patients and health staff. That the participants' utilization of patients' rights was
115 significantly lower than their awareness of those rights is a significant indicator of inaccurate
116 functioning of the health system. That even the rate of the only right to not being euthanized which
117 more than half of the respondents utilized was 58% is striking. Utilization rates of the remaining 13
118 rights ranged from 12% to 37%. The mean utilization rate of all the rights including the right to
119 "not being euthanized" was 28%.

120 It is quite unlikely to explain the patients' relatively high levels of awareness and low levels of
121 utilization of patients' rights by saying that they were aware of their rights but reluctant to utilize
122 them for some reason. However, the high significance scores given to patients' rights indicate that
123 the case is not so. The scores range between 6.41 and 9.19. The significance scores given to all but
124 two rights are over eight. The overall mean score is 8.52. Given the limitations of the study, the
125 participants can be said either to be deprived of patients' rights or to have the perception of
126 deprivation of patients' rights which they knew at a moderate level but considered significant at a
127 high level. In order to determine to what extent this inference reflects the general population's
128 attitude, the issue should be investigated with larger-scale studies, and it would be appropriate to
129 seek solutions, whether restricted or widespread, to problems.

130 A new legal arrangement was made regarding patients' right which was considered the most
131 significant by the participants of our study, and it was proposed to establish "patient
132 communication units" in health care institutions within the framework of Regulations Amending
133 the Patients' Rights Regulations 2014 (Regulations Amending the Patients' Rights Regulations
134 2014). This arrangement is of importance because it will not only ease the functionality of
135 institutions but also meet social expectations.

136 During the literature review carried out within the scope of this study, it was observed that there
137 were a number of studies conducted in Turkey aiming to determine general population's, healthcare
138 professionals' and patients' knowledge and opinions of patients' rights. Some of the findings of
139 these studies are consistent with those of our study. The mean rate of awareness of patients' rights

140 (53%) determined in our study is close to those determined in various studies carried out in our
141 country recently. In two studies conducted on hospitalized patients, the rate was determined as
142 50% (Ozer et al., 2009) and 55% (Zaybak et al., 2012). The other two best known patients' rights in
143 our study that "A patient can have a family member/support person as a companion" and "The
144 patient's privacy should be respected." were also among the best known patients' rights in several
145 other studies (Kuzu et al., 2006; and Ozer et al., 2009). Although no statistically significant
146 difference was determined between the participants in terms of sub-groups of socio-demographic
147 characteristics in our study, in a study conducted by Eksen et al. (2004), the knowledge levels of
148 patients living in villages were found to be higher than were those of the patients living in cities and
149 towns.

150 In two studies conducted in the first years after the Patients' Rights Regulation took effect, 37% of
151 the participants in Tengilimoğlu et al.'s (2000) study and 68% of the participants in Zülfikar and
152 Ulusoy's study (2001) stated that they were aware the patients' rights (Tengilimoğlu et al. 2000;
153 Zülfikar and Ulusoy 2001). Due to the difference between being aware of and being knowledgeable
154 about something, it would be inappropriate to compare these two studies with ours. However, it is
155 hard to understand this striking difference between the findings of these two studies. In two studies
156 investigating the nature of awareness, one-fourth of the inpatients and outpatients were
157 knowledgeable about patients' rights superficially, and only 5% of them read the pertinent
158 regulations (Deveciler et al., 2005; Günay et al., 2007).

159 There are several studies showing that even health care workers are not knowledgeable enough
160 about patients' rights. Three studies conducted with various healthcare professionals in a very long
161 period of time indicate that only half of them were aware of their tasks related to patients' rights
162 such as introducing themselves to the patient (Hakan-Özdemir et al., 2006) and informing the
163 patient about his/her disease and diagnosis-treatment process (Avcı 1990; Hakan-Özdemir et al.,
164 2006), or read relevant regulations (Hakan-Özdemir et al., 2009). Although these studies are not
165 directly comparable with our study since they were conducted with health care workers not with
166 patients, it is possible to make inferences by evaluating them together with those carried out with
167 patients.

168 Both our study and Özer et al.'s study (2009) indicate that health professionals remained in the
169 background in terms of providing patients with information on patients' rights (Özer et al., 2009).
170 Low rates determined in several studies conducted on how well patients were informed about
171 patients' rights and their status confirm the fact that health care workers were not sufficiently
172 capable of providing information (Vural 1996; Sarı and Başağaoğlu 1998; Basağaoğlu and Sarı 2005;

173 Kuzu et al., 2006). However, that the rates obtained in more recent studies are higher than those of
174 previous studies is a positive progress since it indicates that patients' rights are put into practice
175 more, and awareness of them is on the rise. On the other hand, the fact that there are studies
176 indicating that tendency to utilize patients' rights is low (Zaybak et al., 2012) or claiming that there
177 are circumstances in which these rights are violated and thus they should be investigated (Kıdık
178 and Keskinoğlu 2008) shows that patients' rights have not yet been thoroughly put into practice.

179 Since social, cultural, political and legal factors are the powerful determinants of awareness,
180 utilization and significance of patients' rights, the probability of drawing inferences by comparing
181 different studies conducted in different countries is quite low. However, two studies conducted in
182 Iran obtained results similar to those of ours. According to these two studies one of which was
183 conducted both with patients and health care workers (Parsapoor et al., 2012) and the other of
184 which was conducted only with health care workers (Nejad et al., 2011), of the two most widely
185 known and significant patients' rights, one is the right to the protection of privacy which is also
186 well-known and put into practice in Turkey whereas the other one is the right to the provision of
187 information which is relatively less known and has not been into practice sufficiently in Turkey.

188 Patients' rights are an issue with its several dimensions each of which is worth reviewing and
189 interpreting. At the end of the discussion based on the matters directly related to our findings, it
190 would also be appropriate to briefly mention these dimensions of the issue which are indirectly
191 related to our study.

192 Patients' rights are an issue which can be addressed under two headings: health legislation and
193 health policies. That how important and functional the role of this issue is in the arrangement of
194 health care services within the framework of current medical-social conditions and that how much
195 effort health authorities make to put these rights into practice should be constantly kept on the
196 agenda. Comprehensive reviews to be obtained from the pertinent studies conducted with patients
197 and health professionals are of importance, since they may create resources to be used to constantly
198 keep the issue on the agenda or to revise it.

199 Medical ethics and patients' rights are the two instruments that can be used to organize medical
200 relations together or separately. Medical ethics makes this organization via arranging health care
201 workers' behaviors, and patients' rights via defining legitimate expectation of patients. How these
202 two instruments can be integrated so that their combination can be used most effectively is a
203 subject worth studying in the field or at the conceptual level.

204

205 **5. Conclusion**

206 The participants of our study are aware of the patients' rights at a moderate level but cannot benefit
207 from them adequately. They have the opinion that in general, all of the patients' rights and in
208 particular, the one about being informed, are of importance. These determinations that are
209 consistent with the findings of other studies carried out in Turkey and available in the literature
210 indicate that the whole society should be made more familiar with patients' rights, and more
211 importantly, health care workers' sensitivity to the issue should be increased and the conditions in
212 health care institutions should be improved so that these rights can be used effectively.

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ORIJINALLIK RAPORU

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Alıntılarını çıkart Kapat

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Eşleşmeleri çıkar Kapat