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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

1. Introduction

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

The onset and spread of the concept and implementation of patients' rights began in the second half, especially in the last quarter, of the 19th century. In the first years of the Turkish republic, legislation regulating health services included, although not entitled accordingly, some patients' rights within the context of basic human rights. However, developments related to contemporary patients' rights were put into practice later, in parallel with those in the world. Within the context of

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these developments, discussions regarding patients' rights began in the late 1980s. Recognition of patients' rights within the legislative framework took place at the end of the 1990s when the Patients' Rights Regulations were put into effect. The Regulations which came into effect in August 1998 remained the same until they were subjected to a radical revision in May 2014 (Turkey Patients' Rights Regulations 1998; Turkey Regulations Amending the Patients' Rights Regulations 2014).

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

2. Methods

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

Data were collected using a random sampling method. The data collection form was administered to first 100 (50 male, 50 female) of the patients who presented to the blood-taking unit of the outpatient services department of Mersin University Health Research and Application Center between September 1, 2009 and October 15 and agreed to participate in the study. In the processing of the data of this descriptive study, the SPSS 11.5 for Windows was used. In the statistical analysis, while numbers and percentages were calculated for categorical variables, means and standard deviation were calculated for continuous variables. Approvals to conduct the study were obtained from the Health Sciences Ethics Committee of Mersin University and the management of the institution where the study was conducted.

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
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
Age	18-20	8	8
	21-30	21	21
	31-40	31	31
	41-50	21	21
	51-60	14	14
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Responses to the eight questions asked to determine socio-demographic characteristics of the participants and their attitudes towards patients' rights are listed in Table 1.

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

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

The distribution of the participants in terms of their awareness and utilization of the 14 patients' rights listed in the data collection form, and the mean significance scores from the highest to the 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 can not 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

Of the 14 patients' rights listed in the data collection form, the one known most by the participants was that "If the patient is willing and hospital authorities approve, his/her family members or relatives may accompany him/her" (71%). The second most known right was that "The patient's privacy should be respected; irrelevant people should not view medical procedures he/she undergoes" (65%) followed by that "The patient is informed about his/her medical condition, medical practice options and the expected course of the disease" (64%). The ones known least by the participants were as follows: "Inpatient health care centers are supposed to provide a place of worship in order for patients to observe their religious practices (32%).", "The patient can designate his/her healthcare providers within the bounds of possibilities of the health center (39%)" and "The patient may not be told what his/her diagnosis is if he/she is to be adversely affected (39%)".

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

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

4. Discussion

Awareness of patients' rights is the reflection of health consciousness of the public and is among the determinants of the quality of health services. It is possible to say that the rates of utilization of patients' rights are an indirect indicator of both the level of the delivery of health services and the success of health care professionals in fulfilling their tasks. In line with this assessment, it is just normal to desire and expect that awareness and utilization rates of patients' rights should be high.

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

rights ranged from 12% to 37%. The mean utilization rate of all the rights including the right to “not being euthanized” was 28%.

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

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

During the literature review carried out within the scope of this study, it was observed that there were a number of studies conducted in Turkey aiming to determine general population's, healthcare professionals' and patients' knowledge and opinions of patients' rights. Some of the findings of these studies are consistent with those of our study. The mean rate of awareness of patients' rights (53%) determined in our study is close to those determined in various studies carried out in our country recently. In two studies conducted on hospitalized patients, the rate was determined as 50% (Ozer et al., 2009) and 55% (Zaybak et al., 2012). The other two best known patients' rights in our study that “A patient can have a family member/support person as a companion” and “The patient's privacy should be respected.” were also among the best known patients' rights in several other studies (Kuzu et al., 2006; and Ozer et al., 2009). Although no statistically significant difference was determined between the participants in terms of sub-groups of socio-demographic characteristics in our study, in a study conducted by Eksen et al. (2004), the knowledge levels of patients living in villages were found to be higher than were those of the patients living in cities and towns.

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

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

patients, it is possible to make inferences by evaluating them together with those carried out with patients.

Both our study and Özer et al.'s study (2009) indicate that health professionals remained in the background in terms of providing patients with information on patients' rights (Özer et al., 2009). Low rates determined in several studies conducted on how well patients were informed about patients' rights and their status confirm the fact that health care workers were not sufficiently capable of providing information (Vural 1996; Sarı and Başağaoğlu 1998; Basağaoğlu and Sarı 2005; Kuzu et al., 2006). However, that the rates obtained in more recent studies are higher than those of previous studies is a positive progress since it indicates that patients' rights are put into practice more, and awareness of them is on the rise. On the other hand, the fact that there are studies indicating that tendency to utilize patients' rights is low (Zaybak et al., 2012) or claiming that there are circumstances in which these rights are violated and thus they should be investigated (Kıdak and Keskinoğlu 2008) shows that patients' rights have not yet been thoroughly put into practice.

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

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

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

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

5. Conclusion

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

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