The views of cancer patients on patient rights in the context of information and autonomy

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Received 13 February 2007
Revised 5 June 2007
Accepted 18 June 2007

ABSTRACT

Objectives: The aim of this study is to evaluate the views of cancer patients on patient rights in the context of the right to information and autonomy according to articles related to the issue in the ''Patient Rights Regulation''.

Methods: The research was conducted among cancer patients in the medical oncology department of a research and practice hospital using a random sampling method between June and September 2005. Data were collected during face-to-face interviews using a questionnaire.

Results: There was a high rate of positive response to the items that the patients have the right to be informed (86.5%), that the physician should inform the patient on the diagnosis and the treatment (92.3%) and that the physician is obliged to inform the patient (76.9%). Only 43.3% of the patients stated that the patient has the right to refuse the treatment recommended by the physician. The participants mostly agreed that the patient should participate in decisions about the treatment and that patient consent should be given (78.8%).

Conclusions: There are extensive efforts in Turkey towards making patient rights a significant supportive component of health services. For patient rights to become a natural part of medical practice it is necessary to give priority to education of both patients and physicians about patient rights and to lay emphasis on an ethical approach in the patient–physician relationship.

In order to ensure a high quality health service, it is essential to observe the patient's rights and meet their needs and expectations, as well as offering the best service possible. Patient rights as an extension of human rights can be taken as an application of basic human rights and values in health services[1] and are a fundamental tenet of medical ethics. The purpose of patient rights is to receive health services in conditions that are compatible with an individual's human rights. The fundamental concern here is to avoid breaching the patient's personal rights.[2] According to this, patients have the basic rights to take equal, accessible and constant health services, to receive information, to make decisions freely regarding methods of treatment and their physicians, to privacy and to have respect regarding their psychosocial and spiritual values.

Advances in the realm of medicine and expanding the limits of medical support require that the basic rights of the individual such as their bodily integrity and dignity be respected through various legal regulations. The most comprehensive legal regulation concerning patients' rights in Turkey is the ''Patient Rights Regulation'' (PRR), which came into effect in 1998. Among these rights are the patient's right to receive information and autonomy take priority. The patient's right to information is examined in three categories in the PRR: (1) the patient's acquisition of information about the physician and the institution that is offering the medical care, (2) to answer the questions that the patient has in mind about his/her illness and the treatment he/she will receive and (3) regarding the giving of detailed information to the patient about medical intervention and methods of diagnosis or treatment that necessitate an intervention in the patient's bodily integrity and obtaining the patient's consent.

According to the PRR, the patient has the right to self-determination and to make decisions freely regarding himself/herself. In the fulfillment of this right, it is necessary that the patient be given full and clear information by the physician about his/her health status including the medical facts about his/her condition and the benefits and possible harm of the treatment choices (see box 1). On the other hand, full information and truth-telling are sensitive subjects in diseases such as cancer. Withholding the truth in giving information and decision-making by a third party instead of the patient,[3] refusal of treatment and the physician's obligation to inform have a significant place among the ethical issues that may arise with cancer patients as regards patient rights.

Studies conducted in Turkey have usually focused on determining the physicians' and medical students' level of knowledge of patient rights.[4–9] Although studies conducted on patients' self-awareness have been examined,[10–16] the diagnosis of the disease has not been considered as a factor. It has also been pointed out that the nature of the disease and cultural differences are influential in approaches to rights.[17 18] The quality of service, with regard to patient rights, will be improved by obtaining the views of those who offer medical services as well as those who receive it, determining the nature of the disease and the effect of cultural differences.

This study aimed to determine the views of cancer patients on patient rights in the context of the right to information and autonomy.

METHODS

This study was carried out with cancer patients in the Medical Oncology Department of Uludağ University, Training, Practice and Research Hospital in Bursa, which offers services to the whole south Marmara region.

A random selection of patients was made from those attending the outpatient clinic for continuing treatment between June and September 2005.

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Box 1: Articles related to the issue in the Patient Rights Regulation[1]

► Right to receive information

The patient has the right to ask for verbal or written information about his health status, the probable benefits, risks and drawbacks of medical interventions, alternative treatment methods, the possible consequences of refusing treatment and the course and prognosis of the disease. This information may be demanded by the patient him/herself or by the guardian in cases where the patient is not competent. A patient may authorise someone else to receive information in his name (section 3, article 15). When the patient is being informed, the situation must be explained in clear and intelligible language. Medical terminology should be avoided as much as possible. The psychological status of the patient should be taken into account and polite expressions must be used. If the patient is foreign, an interpreter can be used if necessary (section 3, article 18). If the patient does not want any information to be given to himself or to his family, this wish should be respected (section 3, article 20).

► Physician's obligation to inform

With respect to consent, the requirement that permission be obtained before providing medical treatment is based on the patient's right to receive information adequate for him or her to exercise an informed decision to accept or refuse the treatment. The obligation of informing patients is part of the institutional dynamics for increasing patients' safety and comfort. It is the "standard of care" for a physician to provide the patient with complete and accurate information. The Patient Rights Regulation obligates physicians to provide complete and accurate information to their patients and if the health staff violate the usage of the patient rights they will have a responsibility according to the Turkish Penal Code and Turkish Civil Code (section 8, article 44).

► Right to refuse treatment

The patient has the right to refuse the treatment recommended by the physician even if the procedure has already started, as long as there are no medical contraindications. The patient also has the right to ask for the interruption of any treatment procedure that has already started. The possible medical consequences of his/her action should be explained to the patient, or to his legal representative or relatives and this should be certified by a written document. If this patient later chooses to consult the physician he had previously rejected, his previous decision cannot be used against him (section 5, article 25).

► Participation in treatment decision-making

The regulations contain no statement regarding the patient's involvement in the medical decision. However, articles 22 and 24 state that the patient's consent must be obtained for medical treatment and this may not be carried out without the patient's consent.

During this period 208 patients attended the clinic. The patients who took part in the study were chosen from those whose diseases had been precisely diagnosed. Patients were excluded from the study for the following reasons: unable to answer questions because of health problems, not giving consent to participate in the study or unknown diagnosis. After the exclusions, the final study group consisted of 104 patients. The median age was 51.6 years, with a range between 18 and 81 years (SD 12.78). Females represented 64.4% of the subjects. Of the participants 4.8% had no formal education, 40.4% had only primary (five years) education, 28.8% had 8–11 years of education and 26% had a university education.

Permission was obtained from the Medical Oncology Department before the interviews were conducted to avoid any claim of harassment. The study protocol was approved by the local ethics committee. The participants were informed of the purpose of the evaluation and given the opportunity to participate.

Data were collected during face-to-face interviews using a questionnaire. The questionnaire developed by the researchers consisted of two sections: (1) The demographic characteristics (age, sex and educational level), (2) the opinions of cancer patients towards patient rights in the context of being informed and autonomy. The second section was evaluated using one Likert-type question (agree, no idea, not agree).

Statistical comparison between the sections was performed using Pearson's χ^2 test. Fisher's exact test was used when expected frequencies were low. Continuous variables, which are reported as mean (SD) were compared with Student's t tests. A p value of <0.05 was regarded as significant. The statistical analyses of the data were applied using the SPSS for Windows V. 10.0.

Results

The socio-demographic and individual characteristics of the study sample are shown in table 1. Of the participants, 91.3% (n = 95) were still receiving treatment at the time of the study and 8.7% (n = 9) had not yet begun. Breast cancer was the main diagnosis at 37.5% (figure 1).

Asked whether the patient had the right to receive information about the diagnosis and the treatment, 86.5% of the participants (n = 90) stated that they agreed with this statement while only 13.5% of the participants (n = 14) did not or had no idea (table 2). Although no statistical significance was found in the answers to this statement with respect to age, sex and educational level, there is a reverse relationship with the increase in age and a positive relationship with the level of education. According to the level of education, there was a higher rate of agreement with the statement of the patient's right to receive information from those with a university education ($\chi^2 = 3.709$, $p = 0.05$) when compared to those who

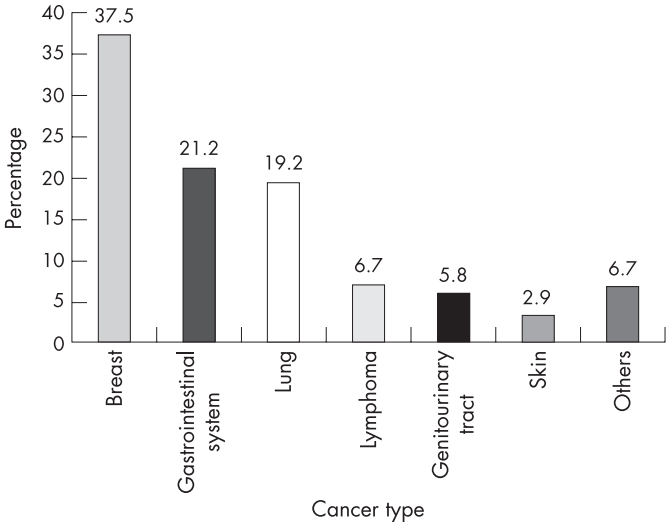


Figure 1 Cancer types of the study participants

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Table 1 Selected characteristics of the study sample (n = 104)

Characteristics	n (%)
Gender	
Female	67 (64.4)
Male	37 (35.6)
Age	
18–35	11 (10.6)
36–55	58 (55.8)
Over 55	35 (33.7)
Educational level	
Literate	5 (4.8)
Elementary	57 (54.8)
High	42 (40.4)
Getting cancer therapy	
Yes	95 (91.3)
Not yet	9 (8.7)

had only been to primary school ($\chi^2 = 3.709$, $p = 0.05$) or who had received less education.

Asked whether the physician should inform the patient of the disease and choices of treatment, 92.3% of the participants (n = 96) responded positively. Only eight participants (7.7%) did not agree or had no idea (table 2). No statistical significance was found in the answers to this statement with respect to age, sex and educational level.

Asked whether the physician is obliged to inform the patient, 76.9% of the participants (n = 80) said that physicians were responsible for providing information both about the diagnosis and the treatment while 14 participants (13.5%) had no idea and 10 participants (9.6%) did not assign any responsibility to the physician (table 2). No statistical significance was found in the answers to this statement with respect to age, sex and educational level. The agreement rate was higher from those who had been to high school or university.

Table 2 Cancer patients' views on patient rights regarding the informing and the autonomy aspects (n = 104)

Gender	Age	Education Level	Response	Patient has the right to receive information about the diagnosis and the treatment	Physician should inform the patient of the disease and choices of treatment	Physician is obliged to inform the patient about the diagnosis and treatment	Patient has the right to refuse the treatment recommended by the physician	Patient should participate in decisions about the treatment and a consent should be taken
				n (%)	n (%)	n (%)	n (%)	n (%)
Female	18–35	Literate	Agree	–	–	–	–	–
			No idea/not agree	–	–	–	–	–
		Elementary	Agree	2 (100.0)	2 (100.0)	1 (50.0)	–	2 (100.0)
			No idea/not agree	–	–	1 (50.0)	2 (100.0)	–
		High	Agree	5 (83.3)	6 (100.0)	4 (66.7)	5 (83.3)	5 (83.3)
			No idea/not agree	1 (16.37)	–	2 (33.3)	1 (16.7)	1 (16.7)
Female	36–55	Literate	Agree	1 (50.0)	1 (50.0)	2 (100.0)	1 (50.0)	1 (50.0)
			No idea/not agree	1 (50.0)	1 (50.0)	–	1 (50.0)	1 (50.0)
		Elementary	Agree	18 (90.0)	18 (90.0)	17 (85.0)	7 (35.0)	17 (85.0)
			No idea/not agree	2 (10.0)	2 (10.0)	3 (15.0)	13 (65.0)	3 (15.0)
		High	Agree	15 (93.8)	15 (93.8)	13 (81.3)	9 (56.3)	12 (75.0)
			No idea/not agree	1 (6.3)	1 (6.3)	3 (18.8)	7 (43.8)	4 (25.0)
Female	55 +	Literate	Agree	2 (66.7)	2 (66.7)	2 (66.7)	–	3 (100.0)
			No idea/not agree	1 (33.3)	1 (33.3	1 (33.3)	3 (100.0)	–
		Elementary	Agree	12 (100.0)	9 (75.0)	9 (75.0)	4 (33.3)	9 (75.0)
			No idea/not agree	–	3 (25.0)	3 (25.0)	8 (66.7)	3 (25.0)
		High	Agree	6 (100.0)	6 (100.0)	5 (83.3)	4 (66.7)	5 (16.7)
			No idea/not agree	–	–	1 (16.7)	2 (33.3)	1 (83.3)
Male	18–35	Literate	Agree	–	–	–	–	–
			No idea/not agree	–	–	–	–	–
		Elementary	Agree	12 (100.0)	9 (75.0)	7 (58.3)	5 (41.7)	9 (75.0)
			No idea/not agree	–	3 (25.0)	5 (41.7)	7 (58.3)	3 (25.0)
		High	Agree	3 (100.0)	3 (100.0)	2 (33.3)	–	1 (33.3)
			No idea/not agree	–	–	1 (66.7)	3 (100.0)	2 (66.7)
Male	36–55	Literate	Agree	–	–	–	–	–
			No idea/not agree	–	–	–	–	–
		Elementary	Agree	–	–	–	–	–
			No idea/not agree	–	–	–	–	–
		High	Agree	7 (12.5)	8 (100.0)	8 (100.0)	6 (75.0)	8 (100.0)
			No idea/not agree	1 (87.5)	–	–	2 (25.0)	–
Male	55 +	Literate	Agree	–	–	–	–	–
			No idea/not agree	–	–	–	–	–
		Elementary	Agree	10 (90.9)	9 (81.8)	7 (63.6)	3 (27.3)	8 (27.3)
			No idea/not agree	1 (9.1)	2 (18.2)	4 (36.4)	8 (72.7)	3 (72.7)
		High	Agree	3 (100.0)	2 (66.7)	3 (100.0)	1 (33.3)	2 (66.7)
			No idea/not agree	–	1 (33.3)	–	2 (66.7)	1 (33.3)

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Asked whether the patient had the right to refuse the treatment recommended by the physician, only 46 participants (43.3%) said that they agreed (table 2). No statistical significance was found in the answers to this statement with respect to age, sex and educational level. The agreement rate was higher from those who had a university education ($\chi^2 = 6.718$, $p = 0.001$).

Asked whether the patient should take part in decisions about their treatment, 82 participants (78.8%) said that the patient should (table 2). No statistical significance was found in the answers to this statement with respect to age, sex and educational level.

Asked what should be done if there were more than one treatment option for decision-making, 68 participants (65.4%) said that they wanted to share the decision with the physician (table 3). No statistical significance was found in the answers to this statement with respect to age, sex and educational level.

Discussion

Studies have been conducted in different provinces in Turkey about patient awareness of their rights since the PRR was passed in 1998. In these studies, patients of internal medicine and general surgical wards were asked whether they knew about PRR. According to these five studies, in order 35%, 23%, 37%, 38% and 9.0% of the hospitalised patients were aware of their rights.[14 16 19–21] Another study reported that 69.2% of patients wished to give consent after having been informed prior to treatment.[13] These results indicate that actions should be undertaken to inform and educate the public and healthcare professionals about patient rights in order to increase people's awareness and consciousness about patient rights for better health services.

In the present study, patient awareness of their rights was not directly examined. We aimed to determine the views and expectations of cancer patients in the context of information and autonomy. We evaluated patients' responses according to the articles related to the issue in the PRR.

The majority of patients declared that receiving information about both diagnosis and treatment to be a patient right (86.5%) and that a physician should inform the patient (92.3%). However, few regarded it to be an obligation for the physician to provide information (76.9%). According to these results, the patients see the physician as having a duty to inform but that he is not obliged to. In a study conducted in Turkey by Eksen *et al* it was reported that 62.8% of the patients were aware of the right to receive information.[15] In a recent study on patients' awareness about their rights amongst patients admitted to a primary level health care facility by Deveci *et al,* 37.1% of the patients were aware of the right to receive information.[12] In comparison to these studies, our results show a much higher rate, which could be because diseases affecting average life expectancy and quality of life affect the behaviour of the patient. In a study conducted in the United States by Sullivan *et al*, 99% of the patients thought that patients have right to know about their condition and physicians have an obligation to inform patients.[22] These rates are higher than the ones we obtained. It can be interpreted as a wider adoption of the concept of patient rights in the west and as an indication of the fact that the paternalistic approach is still widespread in our culture.

Eksen *et al*[15] reported that 56.1% of patients, and Deveci *et al*[12] reported that 19.1% of patients were aware of the right to refuse treatment. In the present study, 43.3% of patients stated that the patient has the right to refuse the treatment recommended by the physician. The wide variation in these results may be due to the difference in provinces and different characteristics of the illnesses. Patients have a right to refuse treatment, but sometimes this can conflict with what a physician thinks is best.

The increase in rates of agreement in considering giving information as a right, the obligation of the physician and the right to refuse treatment, rising in parallel to education levels conforms with other studies.[22–25]

Studies tend to indicate that patients without cancer wish to play a more active role in decision-making.[23 24 26 27] However in the process that has evolved since the 1980s when patient rights began to be adopted, an increase has been observed in cancer patients' desire to participate in treatment (Cassileth *et al* (62.5%), Blanchard *et al* (66%), Rothenbacher *et al* (73%) and in the present study (78.8%)).[27–29] Sekimoto *et al*[24] stated that older and less-educated patients were less likely to want to participate in decision-making and education was also significantly associated with patients' preferences. However, there was no statistical significance in our study.

Gattellari *et al*[30] and Degner *et al*[31] stated that a shared role in decision-making was most commonly preferred in cancer patients. According to another study conducted in Japan, respondents to the cancer questionnaire were less likely to prefer an active role and were more likely to prefer family involvement in decision-making compared to non-cancer questionnaire respondents.[24] In the present study, the majority of the patients wanted to share decision-making with their physicians (n = 68, 65.4%) if there was more than one treatment option. Only eight patients (7.7%) allowed the decisions to be made by the physicians. This means that paternalism exists to a certain extent and is not only acceptable to patients, but is also welcome. Patient-centred models and shared decision-making are determined as the best in the patient-physician relationship. Nevertheless, these models ignore the characteristics and values of patients who prefer family-facilitated decision-making like patients in Japan and other non-western communities including several subcultures.[32]

Table 3 Preferences for participation in treatment decision-making (n = 104)

Decision-making	Physician & patient should make the decision (n = 68)	Patient make the decision (n = 4)	Physician should make the decision (n = 8)	Thorough the committee (n = 24)
Characteristics	**n (%)**	**n (%)**	**n (%)**	**n (%)**
Gender				
Female	45 (67.2)	2 (3.0)	4 (6.0)	16 (23.9)
Male	23 (62.2)	2 (5.4)	4 (10.8)	8 (21.6)
Age				
18–35	6 (54.5)	–	1 (9.1)	4 (36.4)
36–55	39 (67.2)	3 (5.2)	3 (5.2)	13 (22.4)
55+	23 (65.7)	1 (2.9)	4 (11.4)	7 (20.0)
Educational Level				
Literate	4 (80.0)	–	–	1 (20,0)
Elementary	38 (66.7)	4 (7.0)	7 (12.3)	8 (14.0)
High	26 (6.9)	–	1 (2.4)	15 (35.7)

Conclusion

Patient rights are necessary in proper medical practice, in the improvement of the health system and the legal justification of medical intervention. These rights should be regarded as rights that should be defended by both patients and physicians for a

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better healthcare environment. To support active participation of the patients in the health services must be one of the goals in the efforts to improve patient rights. However patient rights are not used as much as desired. As a consequence of this, one of the main violations of patient rights is a lack of knowledge on the part of patients regarding their rights. As a result of this lack of knowledge, patients do not quite know what they can demand from a health institution and the healthcare staff. Furthermore, the traditional respect felt towards physicians may influence patients' behaviour.

Extensive efforts are being made in Turkey to make patient rights a significant supportive component of health services and for patient rights to become a natural part of medical practice, it is necessary to give priority to the education of both patients and physicians. Although physicians have a responsibility to protect patient rights, this education could help physicians to lay emphasis on an ethical approach in the patient-physician relationship.

Acknowledgements: We would like to thank O Manavoglu for his contribution and the patients who participated in this study.

Competing interests: None.

Ethics approval: The study was approved by Uludağ University Faculty of Medicine – Ethics Board.

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