

A Study on Information Requests and Disclosure in Cancer Patients

Kanser Hastalarının Bilgi Edinme İsteği ve Bilgilendirilme Durumları Üzerine Bir Çalışma

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ABSTRACT Objective: The aim of this study was to evaluate information requests and disclosure in cancer patients. In addition, the reasons of dissatisfaction with information disclosure were discussed. **Material and Methods:** The research was conducted among patients in the Medical Oncology Department of Uludağ University Research and Practice Hospital in Bursa between June and September 2005. Data were collected during face-to-face interviews run by the main author using a questionnaire. **Results:** The study group consisted of 104 patients. Most patients (78.8%) were aware of their diagnoses and 81.7% wanted full information about their diagnosis and treatment. The information disclosure was mostly about "how the treatment was going to be done" (78.8%) and "what the side effects were" (69.2%). There was a satisfaction rate of 67% with the information disclosure and reasons for dissatisfaction included incomplete information (43.3%), the use of medical terminology during the information disclosure (33.3%) and that the physicians could not allocate adequate time for them (23.4%). When compared to the patients who were not informed by the doctors, the rate of satisfaction in informed patients and their rate of asking questions about what they wanted to know were higher ($p < 0.05$). There were no statistically significant differences between the demographic characteristics and information requests. **Conclusion:** Information disclosure about cancer diagnosis and treatment is not sufficient when the expectations of patients are considered. Even though consent is obtained from all, it is clear that patients may not find the information sufficient and therefore they cannot fully participate in the medical processes.

Key Words: Access to information; disclosure; physician-patient relations; neoplasms

ÖZET Amaç: Bu çalışmanın amacı, kanser hastalarının bilgi edinme isteği ve bilgilendirilme durumlarını değerlendirmektir. Ayrıca, hastaların bilgilendirilme ile ilgili memnuniyetsizlik nedenleri tartışılmıştır. **Gereç ve Yöntemler:** Araştırma, Haziran-Eylül 2005 tarihleri arasında Uludağ Üniversitesi Sağlık Uygulama ve Araştırma Hastanesi, Medikal Onkoloji Polikliniğine gelen hastalarla yürütüldü. Veriler, yazar tarafından karşılıklı görüşme yöntemi ile doldurulan formlar aracılığıyla toplandı. **Bulgular:** Çalışma grubu 104 hastadan oluşmaktadır. Hastaların çoğu (%78.8) tanısını bilmektedir ve %81.7'si tanı ve tedavileri hakkında her şeyi bilmek istemektedir. Bilgilendirme genellikle "tedavinin nasıl yapılacağı" (%78.8) ve "tedavinin yan etkileri" (%69.2) hakkındadır. Bilgilendirmeyi yeterli bulma oranı %67'dir. Hastaların bilgilendirmeyi yetersiz bulma nedenleri sırasıyla; eksik bilgi verildiğinin düşünülmesi (%43.3), tıbbi terimlerin kullanılması (%33.3) ve hekimin iş yoğunluğu nedeni ile yeterli zaman ayıramamasıdır (%23.4). Hekim tarafından bilgilendirilen hastalarda, bilgilendirilmeyi yeterli bulma ve bilmek istediklerini hekime sorma oranı, hekim tarafından bilgilendirilmeyen hastalara göre yüksektir ($p < 0.05$). Bilgilendirilme isteği ve tanılarını bilme durumu ile hastaların demografik özellikleri arasında bir ilişki bulunmamaktadır. **Sonuç:** Kanser hastalarının hastalıkları ve tedavileri hakkında bilgilendirilmeleri, hastaların beklentileri oranında yapılmamaktadır. Tüm hastalardan tedavi için onam alınmakla birlikte, hastaların bilgilendirmeyi yetersiz buldukları ve hastanın tıbbi süreçlere katılımının tam olmadığı görülmektedir.

Anahtar Kelimeler: Bilgi edinme isteği; bilgilendirme; hekim-hasta ilişkisi; kanser

The physician and patient should work as complementary members of a team to go through the diagnosis and treatment processes and make the decisions together for the patient's well-being.¹ In order to achieve the highest benefit, the correct analysis of patients' values and respect for patient autonomy should be highly appreciated.^{2,3}

Patients should be well-informed to participate in treatment decisions. To obtain informed consent from a patient, information disclosure should include knowledge about the health condition and the benefits, side effects and possible risks of recommended treatment or other treatment alternatives.⁴ The concept of trust-based relationships and the right of an individual to take his/her own decisions are fundamental principles of information disclosure.⁵ The benefits of information for cancer patients include increased patient involvement in decision-making and greater satisfaction with treatment choices, improved ability to cope during the diagnosis, treatment, and post-treatment phases, reductions in anxiety and mood disturbances, and improved communication with family members.⁶ However, information disclosure is affected by prognoses, socio-cultural characteristics of the patients, the physician's approach and the amount of time they are able to allocate to each patient.⁷⁻⁹ Patient satisfaction is also achieved by meeting patient expectations with an information disclosure process. These are the key points for the quality of healthcare services.

Life-threatening diseases such as cancer violate the body's integrity and can sometimes be impossible or very difficult to treat. The greatest challenge for a physician may be being completely frank with information disclosure. However, frankness is necessary for the patient to have full information on the condition and thus be able to make a decision about treatment.¹⁰ In addition to the prognosis of the disease, age, sex, educational level and cultural differences are also factors affecting the information disclosure in cancer patients.^{8,11-14} Besides, there might be significant differences between a physician's assumption of

what the patient would like to know and what the patient really expects to learn.¹⁵ Thus, personalities, needs and conditions of the patients must be considered individually and their expectations must be well analyzed.¹⁶

Being completely truthful also creates a dilemma between respect to patient autonomy and the principles of beneficence and nonmaleficence.¹⁷⁻¹⁹ According to the "Patient Rights Regulation" (1998) in Turkey; a patient has the right to be informed, which is necessary for the patient to give consent independently. Conversely, the patient also has the right not to be informed about a disease with a very poor prognosis, which might cause anxiety and despair. In a situation where the truth might harm the patient, the physician has a responsibility to prevent the patient from being harmed.²⁰ Nevertheless; it has been observed that there is an expectation of hearing the truth even if it is not demanded explicitly.²¹ More studies should be carried out to evaluate the effects of cultural differences on information disclosure to cancer patients.

In this study we aimed to investigate information requests and awareness of diagnosis in cancer patients about their diseases, the information disclosures and patient satisfaction regarding disclosures. Reasons of dissatisfaction with information disclosure were also evaluated.

MATERIAL AND METHODS

The present study was carried out with cancer patients in the Medical Oncology Department of Uludağ University Research and Practice Hospital in Bursa, which offers services to the whole south Marmara region in Turkey with a population of 3.860.788 (according to the 2000 census).

Patients were selected among those attending the outpatient clinic for continuing treatment between June and September 2005. During this period, 208 patients attended the clinic. The patients who took part in the study were selected from those with accurate diagnoses. Patients were excluded from the study for the following reasons: unable to answer questions because of health

problems, unwilling to participate in the study or a complete diagnosis had not been made. After the exclusions, the final study group consisted of 104 patients.

Permission was obtained from the Department of Medical Oncology before the interviews were conducted to avoid any claim of harassment. Uludağ University Faculty of Medicine-Ethics Board approved the study protocol. The patients were informed of the purpose of the evaluation and those who agreed to participate were enrolled in the study.

The main author conducted face-to-face interviews with 104 cancer patients. The questionnaire developed by the researchers consisted of two sections: (1) demographic characteristics (age, sex, and educational level), (2) information request about the disease, the person who provided the information disclosure, the information disclosure itself and patient satisfaction regarding disclosure, and further request for more information from the physician. In addition, the reasons of dissatisfaction regarding disclosure the reasons for not requesting further information from their physician were assessed.

Statistical comparison between the sections was performed using Pearson's chi-square test. Fisher's exact test was used when expected frequencies were low. Continuous variables, which were reported as mean \pm SD were compared with Student's t-tests. A p value $<$ 0.05 was considered significant. Statistical Package for Social Sciences (SPSS) for Windows version 10.0 was used for statistical analyses.

RESULTS

The median age was 51.6 years, with a range between 18 and 81 years (SD \pm 12.78). Females represented 64.4% of the subjects and 40.4% had only primary (five years) education. Of the participants, 91.3% (n= 95) were on chemotherapy at the time of the study and 8.7% (n= 9) had not yet started. Breast cancer was the main diagnosis with a frequency of 37.5% (Table 1).

TABLE 1: Selected characteristics of the study sample (n= 104).

	51.63 \pm 12.78	
Age (mean and SD)	n	%
Gender		
Male	37	35.6
Female	67	64.4
Education level		
Literate	5	4.8
Elementary	57	54.8
High	42	40.4
Cancer type		
Breast	39	37.5
Gastrointestinal cancer	22	21.2
Lung	20	19.2
Lymphoma	7	6.7
Genitourinary cancer	6	5.8
Skin	3	2.9
Others	7	6.7
Undergoing chemotherapy		
Yes	95	91.3
Not yet	9	8.7

Most patients (81.7%) indicated their desire to be fully informed on the diagnosis and treatment (Table 2). The rate of patients who were knew their exact diagnoses was 78.8%. The age, sex, educational level, information requests and knowledge on diagnosis did not show any significant differences between patients (p $>$ 0.05).

While 82.7% of the patients indicated that the physicians had provided the information disclosure, 4.8% had been informed by their families, and 12.5% had not been informed at all. The information given to the 95 patients under treatment was mostly about "how the treatment was going to be done" (86.3%) and "what the side effects were" (75.7%); 7.3% of the patients had not been informed about the treatments in any way (Table 3). Although written (n= 29, 30.5%) or oral (n= 66, 69.5%) consent had been obtained for treatment in all 95 patients, only 80% had taken an active role in the treatment decision.

The percentage of satisfaction with the information disclosure was 67.0%. The 36-55 age group

TABLE 2: Information requests of the patients (n= 104).

Gender	Age	Education Level	Wishing to know everything		Finding the information disclosure sufficient		Wishing to be informed only about the diagnosis or only about the treatment		Wishing to receive no information	
			n	%	n	%	n	%	n	%
Female	18-35	Literate	-	-	-	-	-	-	-	-
		Elementary	2	100	-	-	-	-	-	-
		High	4	66.7	1	16.7	1	16.7	-	-
	36-55	Literate	1	50	-	-	-	-	1	50
		Elementary	16	80	-	-	3	15	1	5
		High	15	93.8	-	-	1	6.3	-	-
	55 +	Literate	2	66.7	-	-	1	33.3	-	-
		Elementary	10	83.3	-	-	2	16.6	-	-
		High	6	100	-	-	-	-	-	-
Male	18-35	Literate	-	-	-	-	-	-	-	-
		Elementary	-	-	-	-	-	-	-	-
		High	3	100	-	-	-	-	-	-
	36-55	Literate	-	-	-	-	-	-	-	-
		Elementary	10	83.3	-	-	2	16.7	-	-
		High	7	87.5	-	-	1	12.5	-	-
	55 +	Literate	-	-	-	-	-	-	-	-
		Elementary	7	63.6	-	-	2	18.2	2	18.2
		High	2	66.7	-	-	1	33.3	-	-
TOTAL		85	81.7	13	12.5	2	2	4	3.8	

was dissatisfied more often than other age groups ($p < 0.05$). The reasons for dissatisfaction were inadequate information (n= 13, 43.3%), use of medical terminology (n= 10, 33.3%) and allocation of inadequate time by the physicians due to their workloads (n= 7, 23.4%).

The percentage of asking questions to the physicians about their diseases was high (80.8%). Patients with higher education were more likely to ask their physicians questions ($p < 0.05$). According to the patients who stated that they had not asked any questions (n= 20), 35% (n= 7) indicated that they did not want to be informed at all, 30% (n= 6) said that they thought the information disclosure was adequate, 25% (n= 5) said that they thought they would not have been answered anyway and 10% (n= 2) said that they hesitated to ask questions. The satisfaction of informed patients for the items of information disclosure and the rate of asking questions about their diseases were higher ($p < 0.05$), when compared to the patients who were not informed by the physicians.

TABLE 3: Information disclosure on treatment (n= 95).

Informed about	n	%
How the treatment is going to be done	82	86.3
Side effects	72	75.7
Points to take into consideration during the treatment	56	58.9
Treatment duration	55	57.8
Negative aspects of treatment	53	55.7
The effects of treatment on body	48	50.5
No information was given about the treatment	7	7.3

DISCUSSION

Patient rights, such as easy access to health services when needed and receiving the highest benefit from those services at equal conditions with others, are valid worldwide. However, in the approach of informing patients, there may be dilemmas especially between telling the truth and considering what patients expect to learn. Given the large cultural diversity in most developed countries today, individual preferences may be even more va-

ried than we expect. Studies carried out in western countries indicate that most cancer patients want to know everything.^{8,12,22} Whereas this figure was more than 90.0% in USA, patients had a much lower inclination to be fully informed in the Balkans and Mediterranean countries.^{13,23,24} In eastern populations, the percentage is only between 1 and 50%.^{17,25} These results show that cultural differences are an important factor in patient-physician relationships and the approach to complete truthfulness. The tendency in the West is towards the right of patients to know everything whereas in the East physicians initially tend to share a bad diagnosis with the families.²⁶

The convention of obtaining permission from the patient before a medical intervention has been based upon law (Statute on Medical Deontology; Official Gazette 19 Feb 1960, no 10436) since 1928 in Turkey. Yet, the patient's rights to give informed consent and to participate in the decision-making process are recent concepts. Over the course of time, the paternalistic aspect of the patient-physician relationship will change with the emphasis shifting towards patient rights.

In one of the few studies conducted in Turkey, 36.6% of 82 cancer patients were informed about their diseases and the patients with higher educational levels were informed more often. In the present study, 78.8% of the patients knew their diagnoses and most (82.7%) had been informed by their physicians. There was no statistically significant difference for this rate between different educational levels. This could be interpreted as a sign that the paternalistic attitudes in the relationship between cancer patients and physicians have changed since the "Patient Rights Regulation" came into effect in Turkey in 1998. However, in another study conducted by Atıcı as a doctorate thesis (2005) carried out in the same hospital on adult leukemia patients (n=106), that rate was 48.1%. This shows that prognosis can affect patient expectations when information is disclosed and that further studies must be carried out with larger numbers of patients of different cancer types. In another study in Turkey, 96.9% of surgical patients knew their diagnoses and 97.2% were willing to be fully informed.²⁷ The results indicate that a

life threatening disease has a strong influence on the patient's need for information.

Previous studies have shown that besides cultural differences, age and educational level also affect telling the truth. The older and less educated patients less wanted to be fully informed.^{12,17,18,28,29} However, in the present study there was no statistically significant difference.

Although most of the patients were informed by their physician, information disclosure ratio about the things that must be attended to during the treatment, the negative aspects, the effects and the duration of the treatment were less than as it should be. Even though all patients had given informed consent, the rate of dissatisfaction for disclosure was high. The negative psychological effects of the truth on patients, lack of time for communication and using medical terminology were the main reasons for dissatisfaction. When a physician fails to give clear, accessible and correct information to a patient, the treatment could be accepted as an intervention without consent. Inadequate information could cause fear and anxiety in patients and as a result, this could affect the treatment negatively.²⁰ Moreover, the information should be given by the physician for the validation of informed consent. Thus, a physician should allocate adequate time for patient-physician communication until he/she is sure that the patient has fully understood the information disclosed and received satisfactory answers to any questions.³⁰

In the present study, 35% of the patients did not want to consult physicians for any further information and this attests to their wish to use the right of not being informed. On the other hand, another 35% pointed out that they thought they would not have been answered even if they had consulted the physician or that they were reluctant to ask physicians questions. This leads us to believe that some patients had communication problems with their physicians. For a healthy information process, the patient must be given the opportunity to ask questions and express any concerns.

When compared to the patients who were not informed by the physicians, the rate of satisfaction

with information disclosures and the rate of asking questions about the disease in informed patients were higher. As stated above this substantiates the informed consent criteria put forward by Kodish et al.¹⁰ In a good patient-physician relationship, the physician is supposed to do the informing and thus be aware of what the patient expects and answer his or her questions in an appropriate way.

According to the results of the present study, the information disclosure about cancer, diagnosis and treatments, is not sufficient when the expectations of cancer patients are considered. Even though their consent is taken, it is clearly seen that the patients may not consider the information sufficient and cannot fully participate in the medical processes. In such cases, the consents would be ethically invalid. There were no statistically significant differences between the age, sex, educational level and information requests and knowledge on the diagnosis among patients. However, the rate of dissatisfaction with disclosures among middle-aged patients and the rate of asking questions to the physicians among well-educated patients were relatively high.

In conclusion, a good analysis of what a patient expects is the basis for a healthy patient-physician relationship. The physician initially should establish and maintain good communication with patients. Good labor conditions should be provided for the physicians to allocate enough time for each patient. A physician must provide information disclosure without using medical terminology throughout as well as giving the patient the opportunity to ask questions. The truth should be disclosed at the appropriate time and in an appropriate manner that patients can cope with and maintain hope. Especially for life threatening diseases such as cancer, the aim has to be the sufficiency and continuity of education on the approaches to patients, communication skills and ethics.

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