

The difficulty of saying cancer diagnosis to the patients with cancer

Kanserli hastalara hastalıklarını söylemenin zorluğu

Hasan Mutlu¹, Zeki Akca², Yasemin Benderli Cihan³, Abdullah Büyükçelik⁴

¹Department of Medical Oncology, Acıbadem Kayseri Hospital, Kayseri

²Department of Radiation Oncology, Mersin Government Hospital, Mersin

³Department of Radiation Oncology, Kayseri Education and Research Hospital, Kayseri

⁴Department of Internal Medicine, Acıbadem University School of Medicine, Istanbul

Abstract

Cancer is located in the higher ranks of the most feared disease groups. The psychology of patients diagnosed with cancer and their relatives have significantly affected. At this stage, the attitude of doctor and requests of patients may change. A questionnaire about the diagnosis and the period of learning and being told to patients was applied to newly diagnosed cancer patients. A total of 6 questions about the stage of establishing diagnosis and being told to patients was asked to a total of 200 newly diagnosed patients and applied to Medical Oncology Department in Kayseri Education and Research Hospital for the first time in an appropriate environment by the same person. Of patients who have undergone minor or major surgical procedure for the diagnose, 58,5% did not know their disease. Of patients who did not know their disease, 85% wanted to know their diagnosis after the diagnosis was established. The most important reason for diagnostic procedures told to patients was mass with the rate of 34,5%. However, of the patients who did not know their disease, 33% stated that they intuited cancer as to be their diagnosis, although the diagnosis was not told them. The diagnosis of the patients are not told them with attitude of relatives, the patient and the physician although a number of examinations and interventional procedures, and this task is left to the medical oncologists. Although the patients' relatives and even patients themselves say that they do not know their diagnosis, at least 33% of patients intuit their diagnosis if they are carefully interrogated.

Keywords: Cancer; diagnosis; to say diagnosis; willingness learning the diagnosis

Özet

Kanser en çok korkulan hastalık grupları arasında üst sıralarda yer almaktadır. Kanser teşhisi konulan hastalar ve akrabaları ciddi şekilde etkilenmektedir. Bu noktada, doktorun tutumu ve hastaların istekleri değişebilir. Yeni kanser teşhisi konan hastalara teşhis, öğrenme ve bilgilendirme süreçleri ile ilgili bir anket yapılmıştır. Kayseri Eğitim ve Araştırma Hastanesi Onkoloji Bölümüne başvurmuş ve yeni kanser teşhisi konmuş 200 hastaya tanı konması ve teşhisin söylenmesi ile ilgili aynı kişi tarafından toplam 6 adet soru sorulmuştur. Tanı amaçlı küçük ya da büyük cerrahi operasyon geçiren hastalardan %58,5'i hasta olduklarından haberdar değildi. Hastalığından haberdar olmayan hastalardan %85'i tanı konulduktan sonra tanıyı bilmek istemiştir. Hastalara söylenen tanısız işlemlerin en önemli sebebi %34,5 ile kitle idi. Ancak, hastalığından haberdar olmayan hastaların %33'ü kanser olduklarını kendilerine söylenmeden sezdiklerini ifade etmişlerdir. Hastaların teşhisleri akrabaların tutumları ile, yapılan tıbbi müdahalelerle kendilerine söylenmemiş, bu görev tıbbi onkologlara bırakılmıştır. Her ne kadar hasta yakınları ve hatta hastaların kendileri de tanıdan haberdar olmadıklarını ifade etseler de hastaların en az %33'ü durumu sezdiklerini dikkatli bir sorgulama ile ifade etmişlerdir.

Anahtar kelimeler: Kanser; tanı; tanının söylenmesi; tanıyı öğrenme isteği

Introduction

According to recent data, the most common cause of death after cardiovascular diseases is cancer (1). Although incidence of the cancers is in second place (if we take into the traffic accidents, it is in 3rd place), and they also affect fewer populations, we guess it would not be wrong to say that that cancer is the most fearful disease group all over the world. End-stage cancer patients and their families often have complex needs requiring a multidisciplinary approach (2-4). Patients relatives are affected from this state and can be responsible for decision of disease course (5,6). Most patients want detailed prognostic information (7-12). The first question a medical oncologist does not want to hear from his patient and to respond due to giving emotional stress is "How long more will I live?". Therefore, making a decision together comes into prominence (13). Medical oncologists have a task after the diagnosis phase in 'diagnosis and treatment' process of the cancer, namely, in the treatment phase. From time

to time, although they support the process of diagnosis with their ideas, their most important task is to determine treatment strategy. Many different departments can take role in the process of diagnosis of cancer: Surgical sciences (general surgery, neurosurgery, orthopedics, etc), radio-diagnostic department, gastroenterology, dermatology, etc. The patients, who complete many phases for the diagnosis and undergo a lot of medical intervention, are experiencing more than one physician and are diagnosed with cancer. We wonder how they should be informed about their diagnosis from which department and physician? As a medical oncologist (the other medical oncologists probably agree with me), we think that the process of telling the diagnosis to the patient, which is the most difficult part, is left to the medical oncologists who are the last ring in the chain of diagnosis and the treatment of cancer. This study has been designed to explain the attitudes of the patients and doctors at the stage of learning and being told of the diagnosis to the patients

İletişim/Correspondence to: Hasan Mutlu, Medical Oncology Department, Acıbadem Kayseri Hospital, Kayseri, 38010, TURKEY
Tel: +90 532 695 8357 doktorhasanmutlu@gmail.com

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Materials and Methods

This study was conducted in Kayseri Training and Research Hospital. The patients who applied to Medical Oncology Clinic for the first time and were newly diagnosed with cancer included in the study. Before meeting with the doctor, they were asked questions by training nurses in a private room. The following questions were asked to the patients:

- 1 - Do you know the diagnosis?
- 2 - From whom did you learn your diagnosis?
- 3 - What was said for the purpose of diagnostic process?
- 4 - Did you want to know the diagnosis?
- 5 - Do you predict the diagnosis, although it was not told to you?
- 6 - Do you want to know the diagnosis now?

The questions above were asked to total 200 patients and answers were recorded by using Statistical Package for the Social Sciences (SPSS 16.0) statistics software. Mean, frequency analysis, crosstabs were performed.

Results

In our study including the patients from the first admission, gastrointestinal cancers are in the first place with the rate of 32%, and the lung cancers were in second place with the rate of 30%. 58.5% of patients did not know their diagnosis. The rate of not knowing the diagnosis is highest in patients with lung cancer with the rate of 72%. The rate of knowing the diagnosis and patients groups are given in table 1. Of patients who did not know their disease, 76% wanted to know their diagnosis after the diagnosis was established. The rate of willingness to learn the diagnosis among the patients with breast, lung, gastrointestinal cancers are same as to be 77%. However, when a total of 152 patients who want to learn the diagnosis is questioned, it was determined that 48% of them learned the diagnosis. The

reasons are given in table 2. Another question asked to the patients is that from whom they learned their diagnosis. 77(93%) of 83 patients, who know their diagnosis, learned the diagnosis from their doctor. Others learned from their relatives, friends or other patients. One of the important questions asked to the patients is: what was said as a reason for the diagnostic process. Only 4.5% of the patients were told to be performed diagnostic process with suspected cancer. The presence of a mass was the most important reason for the diagnostic procedure that was told to patients(34.5%). The reasons designated for diagnostic procedures are shown in table 3. We asked whether they want to know the diagnosis to 117 patients who did not know their diagnosis now, after they applied to clinic and our questionnaire was completed. 85% of patients who did not know their diagnosis stated that they wanted to learn. 8% of them said "no", and 7% of them did not comment. Finally, we asked whether they have ideas about their diagnosis to the patients who do not know their diagnosis, although they were not told their diagnosis. 33% of this group stated that they intuited to have cancer, although they were not told their diagnosis.

Table 1. Rates of patient groups and knowing the diagnosis.

Patient Group (n = 200, 100%)	Does he/she know the diagnosis?	
	Yes (n=83)	No (n=117)
Breast Cancer (n = 56, 28%)	32 (57%)	24 (43%)
Lung Cancer (n = 60, 30%)	17 (28%)	43 (72%)
Gastrointestinal cancers (n = 64, 32%)	24 (38%)	40 (62%)
Urinary Tract Cancers (n = 7, 3.5%)	4 (57%)	3 (43%)
Gynecologic Cancer (n = 5, 2.5%)	2 (40%)	3 (60%)
Other Cancers (n = 8, 4%)	4 (50%)	4 (50%)

Table 2. Willingness of the patients to learn the diagnosis.

Patient Group (n = 200, 100%)	Did you want to learn the diagnosis?		
	Yes (n = 152, 76%)	No (N = 38, 19%)	No comment (n = 10, % 5)
Breast Cancer (n = 56, 28%)	43 (77%)	7 (12%)	6 (21%)
Lung Cancer (n = 60, 30%)	46 (77%)	12 (20%)	2 (3%)
Gastrointestinal cancers (n = 64, 32%)	49 (77%)	14 (22%)	1 (% 1)
Urinary Tract Cancers (n = 7, 3.5%)	3 (43%)	4 (57%)	0 (0%)
Gynecologic Cancers (n = 5, 2.5%)	4 (80%)	0 (0%)	1 (20%)
Other Cancers (n = 8, 4%)	7 (88%)	1 (12%)	0 (0%)

Table 3. Reasons stated for the diagnostic procedures.

Patient Group (n = 200, 100%)	No comment (N = 77)	Reason stated for Diagnostic Intervention			
		Cancer (N = 9)	Wound (n = 25)	Mass (n = 69)	Other (n = 20)
Breast Cancer (n = 56, 28%)	11(14%)	1(11%)	2(8%)	41(59%)	1(5%)
Lung Cancer (n = 60, 30%)	45(59%)	1(11%)	4(16%)	6(9%)	4(20%)
Gastrointestinal cancers (n = 64, 32%)	13(17%)	5(56%)	19(76%)	13(19%)	14(70%)
Urinary Tract Cancers (n = 7, 3.5%)	3(4%)	1(11%)	0(0%)	2(3%)	1(5%)
Gynecologic Cancers (n = 5, 2.5%)	1(1%)	0(0%)	0(0%)	4(6%)	0(0%)
Other Cancers (n = 8, 4%)	4(5%)	1(11%)	0(0%)	3(4%)	0(0%)

Discussion

Our study was planned to determine whether the patients with cancer learned their diagnosis, until they came to medical oncology department. 58.5% of the patients who were applied to Medical Oncology Department for the first time and newly diagnosed was determined to be not known their diagnosis. Relatives were informed during diagnostic procedure and examinations. The patients' not to be informed may be due to several reasons: the attitude of the relatives of the patient, the patient's request and the doctor's attitude. The most important reason can be the attitude of the relatives of the patient.

Another result of our study is that 85% of the patients who did not know the diagnosis wanted to know their diagnosis. However, they were not told their diagnosis at that moment, and they were advised to apply to oncology department for follow-up and the treatment process. In addition, doctor declared that the presence of a mass was the most common cause of diagnostic procedure which has an application area from minor biopsy to a major surgical interventions. We found that only 4.5% of the patients accepted to undergo a biopsy or a surgery with the suspicion of cancer. An interesting result is that although patients and patients' relatives said that they did not know the diagnosis, 33% of patients said that they intuited their diagnosis. It has a great importance that the psychological evaluation of the current situation should be done and psychological support should be given to the whole family to eliminate this problem. In order to tell the diagnosis to the patients who were diagnosed with cancer is one of the most difficult tasks for the doctors. Since physicians are faced to the patients who are prone to having psychological devastation telling them that they are cancer is a significant problem. Since it is a difficult situation for both relatives of patients and the patients, this difficult task is left to the medical oncologist with approval of doctors who established the diagnosis. Hence, medical oncologists undertook this task. Because of the psychology of the patient, medical oncologists should provide an appropriate and continuous psychological support to their patients as well as medical treatment.

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References

1. Parkin M, Psiani P, Ferlay J. Global cancer statistics. *CA Cancer J Clin* 1999;49(1):33-64.
2. Borgsteede SD, Deliens L, van der Wal G, Francke AL, Stalman WA, et al. Interdisciplinary cooperation of GPs in palliative care at home: A nationwide survey in the Netherlands. *Scand J Prim Health Care* 2007;25:226-31.
3. Murray SA, Kendall M, Boyd K, Grant L, Highet G, Sheikh A. Archetypal trajectories of social, psychological, and spiritual wellbeing and distress in family care givers of patients with lung cancer: Secondary analysis of serial qualitative interviews. *BMJ* 2010;340:c2581.
4. Johnsen AT, Petersen MA, Pedersen L, Groenvold M. Symptoms and problems in a nationally representative sample of advanced cancer patients. *Palliat Med* 2009;23:491-501
5. Brogaard T, Jensen AB, Sokolowski I, Olesen F, Neergaard MA. Who is the key worker in palliative home care? *Scand J Prim Health Care* 2011;29(3):150-6.
6. Gözüm S, Akçay D. Response to the needs of Turkish chemotherapy patients and their families. *Cancer Nurs.* 2005;28(6):469-75.
7. M. Beccaro, M. Costantini, P.G. Rossi, G. Miccinesi, M. Grimaldi and P. Bruzzi, Actual and preferred place of death of cancer patients. Results from the Italian survey of the dying of cancer (ISDOC), *J Epidemiol Community Health* 2006;60:412-416.
8. Lobb E.A., Butow P.N., Meiser B. et al., Tailoring communication in consultations with women from high risk breast cancer families, *Br J Cancer* 2002;87:502-508.
9. Durusoy R, Karaca B, Junushova B, Uslu R. Cancer patients' satisfaction with doctors and preferences about death in a university hospital in Turkey. *Patient Educ Couns* 2011;85(3):e285-90.
10. Chen S.C., Lai Y.H., Liao C.T., Chang J.T.G., Lin C.C. Unmet information needs and preferences in newly diagnosed and surgically treated oral cavity cancer patients, *Oral Oncol* 2009;45:946-952.
11. Karaöz B, Aksu H, Küçük M. A qualitative study of the information needs of premenopausal women with breast cancer in terms of contraception, sexuality, early menopause, and fertility. *Int J Gynaecol Obstet* 2010;109(2):118-20.
12. Ozbayir T, Malak AT, Bektas M, Ilce AO, Celik GO. Information needs of patients with meningiomas. *Asian Pac J Cancer Prev* 2011;12(2):439-41.
13. Oskay-Özcelik G., Lehmacher W., Könsgen D., Christ H., Kaufmann M., Lichtenegger W., et al., Breast cancer patients' expectations in respect of the physician-patient relationship and treatment management results of a survey of 617 patients, *Ann Oncol* 2007;18:479-484.