

Level of Knowledge and Awareness of Newly Diagnosed Cancer Patients About Cancer Diagnosis

Tıbbi Onkoloji Polikliniğine Başvuran Yeni Tanı Kansere Hastalarında, Hastalıkları Hakkındaki Bilgi ve Farkındalık Düzeyi

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Abstract

Objective: Cancer is a global health problem that threatens human lives worldwide. The awareness of cancer diagnosis varies over time. The level of knowledge and awareness of a cancer patient regarding his/her disease is one of the most important factors affecting the quality of life and psychology of the patient. This approach contributes to patient participation in treatment and decision-making. There have been very few studies on this subject in our country. Therefore, we aimed to measure the level of knowledge and awareness of newly diagnosed cancer patients admitted to our oncology unit.

Methods: Between January 1, 2018 and March 31, 2018, 159 newly diagnosed cancer patients admitted to the medical oncology outpatient clinic were included in the study. To evaluate the level of knowledge (sufficient or insufficient) and awareness of the patients and their relatives regarding their diseases, a questionnaire consisting of 21 questions was administered to them.

Results: Most patients (n=140, 88%) stated that they were informed about cancer diagnosis before being admitted to the oncology clinic. Eight patients (5%) reported that they did not receive any information. The relatives of 11 patients (7%) preferred not to reveal their cancer diagnosis. Relatives of elderly patients tended to conceal their diagnosis (p=0.023). Other demographic information and disease-related factors (organ, stage, etc.) did not influence awareness of the diagnosis. Although many patients with cancer and relatives were aware of their diagnosis, 25% of them defined their level of knowledge as insufficient. Older age, low income, diagnosis in non-surgical clinics, limited explanation time, and lack of clear language were associated with an insufficient level of knowledge. The most important expectations of patients from physicians were the prognosis of the disease, clear and understandable information about cancer, treatment options, and the side effect profile of the treatments.

Conclusion: The study revealed a high attitude toward providing information to patients with cancer at our hospital. The attitudes of patients' relatives should be improved to ensure that patients are better informed. Patient-physician communication is crucial for providing satisfactory patient information. Sufficient time should be allocated for explanations, and patients should be spoken to in a language they can understand. When providing explanations, patients' expectations should be considered.

Keywords: Neoplasm, communication, prognosis



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Öz

Amaç: Kanser, dünya çapında insan hayatını tehdit eden küresel bir sağlık sorunudur. Kanser tanısına ilişkin farkındalık zamanla değişim göstermiştir. Bir kanser hastasının hastalığı hakkındaki bilgi ve farkındalık düzeyi, hastanın yaşam kalitesini, psikolojisini etkileyen ve hastaların tedaviye ve karar alma sürecine katılımına katkıda bulunan en önemli faktörlerdendir. Ülkemizde bu konuda çok az çalışma yapılmıştır. Bu nedenle, onkoloji ünitemize başvuran yeni tanı almış kanser hastalarının bilgi ve farkındalık düzeyini ölçmeyi amaçladık.

Yöntem: Çalışmaya tıbbi onkoloji polikliniğine başvuran 159 yeni tanı kanser hastası dahil edildi. Hastaların ve/veya hasta yakınlarının hastalıkları hakkındaki bilgi ve farkındalık düzeylerini değerlendirmek amacıyla 21 sorudan oluşan bir anket uygulandı.

Bulgular: Hastaların büyük çoğunluğu (n=140, %88), onkoloji kliniğine başvurmadan önce kanser tanısı hakkında bilgilendirildiğini belirtmiştir. Ancak sekiz hasta (%5) herhangi bir bilgi almadığını belirtti. On bir hastanın yakını (%7) hastalarından kanser tanısını gizlemeyi tercih etti. Yaşlı hastaların yakınları kanser tanılarını gizleme eğilimindeydi (p=0.023). Diğer demografik bilgiler ve hastalıkla ilişkili faktörler (organ, evre vb.) arasında tanı farkındalığı yönünden farklılık yoktu. Kanser hastası ve/veya yakınlarının çoğu tanılarını bilmesine rağmen, %25'i kendilerine verilen bilginin yeterli olmadığını düşünmektedir. Bunun ileri yaş, düşük gelir düzeyi, cerrahi olmayan kliniklerde tanı alma, açıklama için yeterli zaman ayrılması ve anlaşılır bir dil kullanılmaması ile ilişkili olduğu bulunmuştur. Hastaların hekimlerden en önemli beklentileri hastalığın prognozu, kanser hakkında açık ve anlaşılır bilgi, tedavi seçenekleri ve tedavilerin yan etki profili olmuştur.

Sonuç: Çalışma, ülkemizde kanser hastalarına bilgi sağlama konusundaki tutumların Batı ülkelerindeki tutumlara benzer olduğunu ve zamanla iyileştiğini göstermiştir. Hastaların daha iyi bilgilendirildiğinden emin olmak için hasta yakınlarının tutumu iyileştirilmelidir. Hastalara tatmin edici bilgi sağlamak için hasta-hekim iletişimi çok önemlidir. Açıklamalar için yeterli zaman ayrılmalı ve hastalarla anlayabilecekleri bir dilde konuşulmalıdır. Açıklama yaparken hastaların beklentilerini göz önünde bulundurmak önemlidir.

Anahtar Kelimeler: Neoplazi, iletişim, prognoz

Introduction

Cancer is a global health problem that threatens lives worldwide. The incidence of cancer is increasing worldwide and in our country. It is one of the most common causes of death worldwide⁽¹⁾. According to 2022 Globocan data, the annual incidence of cancer in Turkey was 240,013 new cases, and the 5-year prevalence was 679,335 patients⁽²⁾.

The increasing prevalence of cancer, encouragement for screening programs, and increased awareness in written and visual media increase the level of knowledge about cancer in patients and healthy individuals^(3,4). The majority of patients with cancer worldwide are eager to understand the factors contributing to their condition, prognosis, and available treatment options. Patients frequently seek valuable insights from healthcare professionals, family members, fellow patients, and from written materials and online resources.

In previous decades, the attitudes of physicians and patient relatives have often involved limiting the information given to patients to protect them and to present a more positive picture of their diagnosis, stage, and life expectancy. This approach, however, has been changing in recent decades toward greater transparency and information sharing⁽⁵⁾. The level of knowledge and awareness of a cancer patient regarding his/her disease is one of the most important factors affecting the quality of life and psychology of the

patient. An increased level of awareness and knowledge contributes to patients' participation in treatment and decision-making, whereas insufficient information and miscommunication are associated with increased anxiety, non-compliance with treatment, and increased costs^(6,7). In this sense, oncology clinics, as well as all physicians and healthcare professionals involved in the diagnostic process of the disease, are responsible.

There have been very few studies on this subject in our country. A study conducted by Ateşçi et al.⁽⁷⁾ 20 years ago revealed that half of the patients were not informed about their cancer diagnosis, leading to an increase in psychiatric disorders. Therefore, we aimed to measure the level of knowledge and awareness of newly diagnosed patients with cancer admitted to the medical oncology outpatient clinic using a questionnaire prepared by us before their examination in medical oncology.

Materials and Methods

Between January 1, 2018 and March 31, 2018, patients newly diagnosed with cancer admitted to the medical oncology outpatient clinic were included in the study. The study was approved by the Dokuz Eylül University Non-interventional Ethics Committee, İzmir (decision no: 2017/29-03, date: 21.12.2017). The demographic characteristics and disease information of the patients were obtained from the hospital

records. Patients were evaluated in two groups (non-surgical and surgical clinics. To assess patients' knowledge and awareness regarding their diseases, a 21-question survey prepared in Turkish was administered to them. The questionnaires were administered face-to-face to literate patients after obtaining patient and family consent. In cases in which primary information was given to the patient's relatives at the time of diagnosis and the patient was not directly informed, a questionnaire was administered to the patient's relatives. The relevant literature was used in the preparation of the questionnaire. The questionnaire consisted of four parts. In the first part, demographic data (age, gender, marital status, educational status, income level, etc.) were collected from the patients. In the second part, the question was raised as to whether information about the diagnosis of cancer was given. If information was not provided, the questionnaire was terminated. Patients who were informed about the diagnosis of cancer were asked questions about the disease (organ of origin, stage, etc.). In the third part, patients were asked to categorize their information level as sufficient or insufficient. In addition, questions measuring patient-physician communication and patient expectations from information sources were asked. In the last section, the sources of patient consultations other than physicians were questioned. The questionnaires were administered to 10 participants. The data obtained from these respondents were not included in the data to be obtained at the end of the study but were only used to identify problems that may be encountered during the application and to make some changes in the questionnaire form when necessary. The individuals included in the study were informed about the study in detail. After the informed consent form was obtained from the individuals who agreed to participate in the study, the questionnaire, which included questions to evaluate the intended information, was given to the participants, and the questionnaires were taken back after they were completed under outpatient clinic conditions.

Statistical Analysis

The Statistical Package for Social Science 22.0 program (SPSS, Inc., Chicago, IL, USA) was used to evaluate the results. In the analyses, normally distributed continuous numerical variables were expressed as mean $\pm$ standard deviation and non-normally distributed variables were expressed as median and minimum-maximum values. Nominal data were expressed as ratios (%), and comparisons of numerical data were made by Kruskal-Wallis H test, Mann-Whitney U-test, and chi-square test in dependent and independent samples.

In the intergroup comparisons, $p < 0.05$ values were accepted as significant.

Results

The study included 159 volunteers, with 148 patients and 11 patients' relatives participating in the questionnaire. The mean age of the participants was 59 ± 14.5 years; 72 (45.3%) were female, and 87 (54.7%) were male. Furthermore, 67 (42.1%) patients were 65 years of age or older, and 43% had an income level of minimum wage or less. The patient characteristics are summarized in Table 1. Out of 159 volunteers, 126 (79.3%) were referred to the medical oncology department of surgical clinics, while 33 (20.7%) were referred from non-surgical clinics. The most common types of cancer diagnosed among the patients were colorectal cancer, breast cancer, and lung cancer, which represented 60% of all cases. Genito-urinary tract cancer and head-neck cancers comprised the majority of the remaining cases.

Table 1. Patient characteristics

Age (Mean $\pm$ SD)		59 $\pm$ 14.54
Gender	Female	72 (45.3%)
	Male	87 (54.7%)
Education Status	Literate	25 (15.7%)
	Primary education	67 (42.1%)
	High school	33 (20.8%)
	University	34 (21.4%)
Marital status	Married	129 (81.1%)
	Singles	12 (7.5%)
	Divorced-widowed	18 (11.4%)
Income status	Minimum wage and below	69 (43.4%)
	Above minimum wage of	90 (56.6%)
Place of residence	Rural	76 (47.8%)
	Urban	83 (52.2%)
Referring clinic	Surgical	126 (79.3%)
	Non-surgical group	33 (20.7%)
Tumor site	Colorectal	43 (27%)
	Lung	31 (19.5%)
	Breast tissue	22 (13.8%)
	Non-colorectal GI	21 (13.2%)
	Genito-urinary	16 (10%)
	Head & neck	7 (4.4%)
	Other	19 (11.9%)
Disease stage	Local	94 (59.1%)
	Metastatic	65 (40.9%)

SD: Standard deviation, GI: Gastrointestinal

Of the patients, 41% were in the metastatic stage, whereas 59% were referred for adjuvant treatment and follow-up due to nonmetastatic cancer.

In the present study, 88% of patients (n=140) were clearly informed about their cancer diagnosis and were referred to a medical oncology clinic. Only 5% of patients (n=8) were not aware of their diagnosis and were not given any information about the cancer. However, 7% (n=11) of the patients' relatives chose not to disclose their cancer diagnosis. Instead, they provided limited information without using the word "cancer". Cancer diagnosis was concealed in 13% of older patients (≥ 65 years old), compared to only 3% of younger patients ($p=0.023$). Education level, income level, gender, and other demographic factors did not affect diagnostic awareness. It was also noted that 75% of the patients who were not informed about their cancer diagnosis were over 65 years old, and five were in the low-income group. However, this result did not reach statistical significance due to this group's small number of patients ($p=0.89$ and $p=0.67$, respectively).

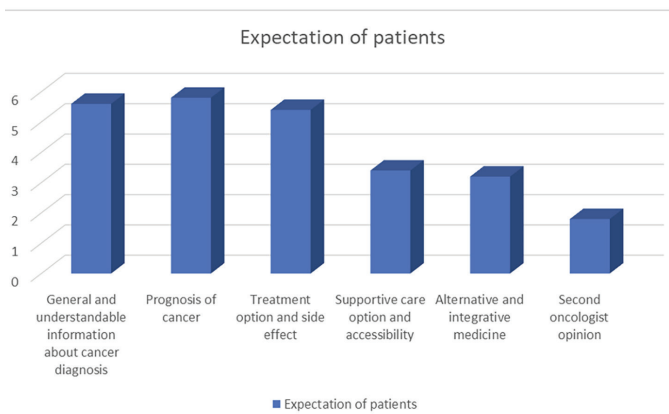
After excluding eight patients who were unaware of their cancer diagnosis, the remaining 140 patients and 11 patients' relatives were questioned about whether the information given to them was sufficient and accurate. Almost all the volunteers who participated in the study knew the organ or tissue from which the cancer originated. Only five patients (3.3%) were not aware. However, 65% of patients were unaware of their disease stage, and 45% did not receive information about treatment options in medical oncology. Additionally, when questioned regarding whether the information provided was sufficient, one in four participants stated that it was insufficient. Insufficient knowledge level was significantly higher among patients with advanced age, low-income individuals, and those referred from non-surgical clinics ($p<0.001$, $p=0.037$, $p=0.016$, respectively). However, patient-related factors, such as gender, education level, rural or urban environment, and disease-related factors, such as organ of origin and disease stage, did not have any effect (see Table 2).

In the information process, 74% of patients reported that they were given enough time, whereas 87% indicated that the information was presented in a clear and understandable language. A lack of sufficient time and the use of difficult language were linked to an insufficient level of patient knowledge. ($p<0.001$ and $p<0.001$, respectively).

Half of the participants reported an increase in their knowledge level using sources other than medical sources. Out of the 81 participants, 56 (70.3%) mentioned benefiting from the internet, while 24 (29.7%) stated that they received information from patients who were diagnosed with cancer. We asked one last question: what do patients and their relatives want to know about their diagnosis. This question covered six topics, and we requested patients to rank them from most to least preferred for learning. As shown in Graph 1, the volunteers were most curious about the prognosis of the disease, general and understandable information about cancer, treatment options, and side effect profiles of the treatments.

Table 2. Knowledge level and associated factors

Knowledge level	Sufficient n(%)	Insufficient n(%)	p-value
Age			p<0.001
65 and above	41 (61.2%)	26 (38.8%)	
Under 65	78 (84.8%)	14 (15.2%)	
Gender			p=0.438
Woman	56 (77.8%)	16 (22.2%)	
Male	63 (72.4%)	24 (27.6%)	
Income status			p=0.037
Minimum wage	46 (66.7%)	23 (33.3%)	
Minimum wage	73 (81.1%)	17 (18.9%)	
Education status			p=0.492
Primary education and	67 (72.8%)	25 (27.2%)	
High school and above	52 (77.6%)	15 (22.4%)	
Referring clinic			p=0.016
Non-surgical	18 (58.1%)	13 (41.9%)	
Surgical	101 (78.9%)	27 (21.1%)	
Disease stage			p=0.175
Local	74 (78.7%)	20 (21.3%)	
Metastatic	45 (69.2%)	20 (30.8%)	
Allocation sufficient time			p<0.001
Yes	99 (83.9%)	19 (16.1%)	
No	20 (48.8%)	21 (51.2%)	
Use of understandable language			p<0.001
Yes	112 (81.2%)	26 (18.8%)	
No	7 (33.3%)	14 (66.7%)	
References to different sources of information			p=0.002
Yes	69 (85.2%)	12 (14.8%)	
No	50 (54.1%)	28 (35.9%)	



Graph 1. Expected patients

Discussion

It has been observed that patients with insufficient knowledge and awareness struggle more when coping with cancer⁽⁸⁾. The level of knowledge they possess also affects their psychiatric well-being and active involvement in treatment⁽⁷⁻⁹⁾. However, delivering bad news is a challenging task that requires specific training. Regrettably, many physicians, including medical oncologists, do not receive sufficient training in effectively communicating bad news and discussing prognosis with their patients^(10,11).

As we survey the global landscape, we find that the level of awareness among patients with cancer regarding their diagnosis varies widely, with some regions reporting awareness rates as high as 90% and others as low as 50%. This disparity raises essential questions about access to information, healthcare systems, and cultural attitudes toward cancer. The rate of awareness regarding cancer diagnosis is reported to be 50-60% in Eastern and Middle-Eastern countries, whereas it is approximately 90% in Western Europe⁽¹²⁻¹⁴⁾. Upon reviewing the available literature, it has come to our attention that there is a scarcity of studies on this subject in our country. A study conducted by Ateşçi et al.⁽⁷⁾ two decades ago indicated that awareness of cancer diagnosis among patients treated in the oncology unit was only at a 50% level. It is worth noting that this rate aligns with similar findings in our neighboring countries, as previously mentioned. In another study conducted with more than 3,500 patient relatives in Ankara, the capital and second largest city of Turkey, in 2015, 70% of the patients were aware of their cancer diagnosis. In addition, only 65% of the volunteers preferred to be informed openly if they were diagnosed with cancer⁽¹⁵⁾. Our research conducted in İzmir,

Turkey, indicates that the level of awareness among patients regarding cancer diagnosis is comparable to that in Western Europe. Considering that the studies were conducted at different times, the awareness rate can be interpreted as increasing over time. However, it was also observed that there was a 5% rate of patients who stated that they were not aware of this diagnosis; this is still an important ratio for our patients.

Another finding was that 7% of the relatives of the patients concealed the cancer diagnosis from them. In both developed and developing countries, most physicians tell the truth directly to patients. Still, in some geographical areas, the prevailing attitude is to convey the truth to relatives rather than to the patient^(3,4,15). In another study conducted 15 years ago in Turkey, only half of the relatives of patients preferred to be informed about their patient's cancer diagnosis⁽¹⁶⁾. It has been shown that our country's perspective has changed over time. In previous studies, the rate of awareness regarding cancer diagnosis was found to be inversely associated with advanced age, low-income level, and low education level^(7,8,12). In our study, only being 65 years of age or older was associated with awareness of cancer diagnosis. Low income, educational status, and gender had no effect on diagnostic awareness. It is important to note that the attitudes of the patient's relatives can significantly influence the patient's willingness to participate in treatment. Additionally, these attitudes may impact the psychological well-being of the relatives themselves⁽¹⁷⁾. Telling the truth does not negatively impact cancer patients^(18,19). Informing patients' relatives about this fact can help change their attitude.

Another aspect we examined was the extent to which patients found the information sufficient after being informed of their cancer diagnosis. Although this was a subjective question, a notable finding was that 25% of the patients described the information provided as inadequate. Our result is valuable because we have not found any other study that assesses the adequacy of patient information. We mentioned that advanced age and low income are associated with awareness of diagnosis^(8,9). Similarly, it is anticipated that satisfaction with the level of information provided will be associated with this result. In contrast to the existing literature, no discernible effect of education level was observed. It is possible that this can be attributed to the varying expectations of individuals with different educational backgrounds.

Enhancing patient-physician communication within the context of severe and life-limiting diseases is a crucial ethical

obligation. Preparing clinicians for timely, high-quality conversations with patients with cancer requires addressing several barriers. These include inadequate training in communication skills for clinicians, time constraints, uncertainties about when to initiate specific conversations, ambiguity regarding the responsible clinician for initiating conversations, and inadequate healthcare systems to support clinicians^(20,21). The findings of the present study suggest that using understandable language and allowing sufficient time is crucial for adequately informing patients. Our findings showed that surgical department patients appeared to be better informed. Furthermore, existing evidence in the literature suggests that more practical information is available in surgical clinics⁽²²⁾. Oncologic surgery and multidisciplinary tumor councils are actively performed in our hospital. These results confirmed our knowledge of surgical branches regarding oncologic treatments and our experiences with providing bad news.

Consistent with the literature, the most common sources of information for patients were the internet and other sources of cancer diagnosis^(23,24). Although this contributed positively to the level of knowledge in our study, it should be kept in mind that misinformation, especially from the internet, may negatively affect patient compliance.

The study makes a valuable contribution to the literature by shedding light on patient expectations from physicians. In addition to seeking general information about their condition, patients expressed interest in understanding the prognosis and available treatment options. This insight can help healthcare providers better meet the needs of their patients. This should be considered the most fundamental right of a patient diagnosed with cancer. Both ethically and medico-legally, patients should be informed in detail about their diagnosis, stage, prognosis, and treatment options. Due to the scarcity of studies on the level of knowledge and awareness of patients with cancer in our country, we believe that these results will make an important contribution to the literature and guide physicians.

Study Limitations

Our study was constrained by the 3-month time limit, which resulted in a limited sample size of 159 volunteers. An expanded patient population could facilitate more robust statistical analysis and potentially yield different findings. The study was conducted in a university hospital with regular multidisciplinary tumor councils. Results may vary among centers with less experience in cancer diagnosis

and treatment. Given our country's large population, it is important to recognize that patient and family attitudes may differ across various geographical and cultural regions. The findings of this study may have limited generalizability across the country because of the constraints of the sample population.

Conclusion

The current study assessed the level of knowledge and awareness among patients with cancer. We found that patients were highly aware of their diagnosis. We observed that although a small number of patients were not initially aware of severe and vital conditions such as cancer at the time of diagnosis, this finding presents an opportunity for increased awareness and early detection initiatives. Although the results cannot be generalized nationwide, we have demonstrated an increasing awareness rate among patients with cancer in our country over time. The attitudes of patients' relatives should be improved to ensure that patients are better informed. Patient-physician communication is crucial for providing satisfactory patient information. Sufficient time should be allocated for explanations, and patients should be spoken to in a language they can understand. When providing explanations, it is important to consider patients' expectations. More study is needed on this topic in our country.

Ethics

Ethics Committee Approval: The study was approved by the Dokuz Eylül University Non-interventional Ethics Committee, İzmir (decision no: 2017/29-03, date: 21.12.2017).

Informed Consent: The demographic characteristics and disease information of the patients were obtained from the hospital records.

Footnotes

Authorship Contributions

Surgical and Medical Practices: S.Ö., Z.G.G., H.E., İ.Ö., Concept: S.Ö., Z.G.G., İ.Ö., Design: İ.Ö., Data Collection or Processing: S.Ö., H.E., Analysis or Interpretation: H.E., Literature Search: S.Ö., Z.G.G., İ.Ö., Writing: S.Ö., Z.G.G., H.E., İ.Ö.

Conflict of Interest: No conflict of interest was declared by the authors.

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