Journal of BUON **14:** 681-687, 2009

ORIGINAL ARTICLE

The level of satisfaction in cancer patients with completed treatments: A 7-year screening

S. Eyigor, H. Karapolat, O.K. Korkmaz, R. Uslu

Ege University, Faculty of Medicine, Physical Therapy and Rehabilitation Department, Tulay Aktas Oncology Hospital, Supportive Care Unit, Bornova-Izmir, Turkey

Summary

Purpose: *Cancer patients encounter many problems in the post-diagnosis period and they want to establish a good contact with the treatment team in order to get better information about their condition. This study attempted to investigate in patients with completed treatment the level of satisfaction they derived from the treatment and the treatment team.*

Methods: *The archive of medical records of the Medical Oncology Department comprising 4622 patients was randomly screened between the years 2000 and 2006. Charts of 528 patients were reached via phone and analysed for clinical data.*

Results: *Approximately 78.8% of the patients had been informed about their malignant diseases. The rates of satisfaction from the treatment team, the treatment itself, and communication with the physician was higher among informed patients compared to uninformed ones ($p<0.05$). Of all the evaluated patients, 38.5% had been recommended to practise general exercises.*

Conclusion: *The great majority of our patients were informed about their diseases and treatments, although without being given adequate importance, and the satisfaction rates were higher among informed patients. We believe that our study will provide new approaches in relation to the importance and methods of communicating with and informing patients.*

Key words: cancer patients, patient education, satisfaction

Introduction

Life expectancy in cancer patients is gradually increasing with the developments in diagnosis and treatment [1]. The recent general approach embodies the idea that patients must be provided with both medical and non-medical support therapy in order to increase their quality of life in the post-treatment follow-up period [2,3]. Patient education, constituting one of these steps, is among the indispensable elements also in the treatment of cancer patients as in other diseases [2,3]. It is of critical importance to provide cancer patients with information about their disease and treatment. It is noted that appropriate provision of information has a positive effect on the patient's participation to the treatment and on his/her psychological stress [4]. However, it is reported in the literature that most patients have difficulties in understanding the provided information, and cannot receive sufficient and reliable information [5]. The reason for this dissatisfaction is often related to the inadequacy in the doctor-patient relationship [6]. Coordination problems among the members of the treatment team, who are responsible for the patient follow-up, is believed to increase the stress and dissatisfaction of the patient [7]. Today, the assessment of patient satisfaction is recognized as the determinant of the quality of a health system [8]. It is significant in this respect that many mobile oncology patients have complained about the quality of the services [9].

As the significance of patient satisfaction and information provision for patients have started to be emphasized, different countries have commenced to introduce the satisfaction data of patients in their own treatment units [8,10-12]. However, specific data revealing satisfaction-related factors in cancer patients, and manuals providing information about how to approach patients are still unavailable. Thus, efforts for improving patient satisfaction are still carried on.

Correspondence to: Sibel Eyigor, MD. Ege University, Faculty of Medicine, Physical Therapy and Rehabilitation Department, 35100 Bornova-Izmir, Turkey. Tel: +90 2323903687, Fax: +90 2323881953, E-mail: eyigor@hotmail.com

Received 07-07-2009; Accepted 31-07-2009

In this respect, this study aimed to register the satisfaction status of the patients, whose treatments were completed at our oncology clinic, about information provision, treatment and treatment team.

Methods

This was a cross-sectional retrospective study. The evaluation included patients who were followed up in the period prior to the foundation of the "Supportive Care Unit" for the follow-up of cancer patients. Between the years 2000-2006, the Medical Oncology Department archive, which included 4622 patients, was randomly investigated. Randomization was made in accordance with the archive's numbering system by selecting the patient files with odd numbers. Patients with odd numbers pertaining to that year were contacted via phone. Only 2051 patients could be reached, since telephone numbers in some files were missing and some files were incomplete. It was not also possible to reach many patients due to address change and death. Thirty-four patients were not eligible for the study, 697 had died, and 792 could not be reached. The files of 528 patients, who were contacted through phone, accepted to participate in the study. The patients, whose treatments were completed, were examined for relevant clinical data. Identification of the telephone numbers and files were made by the same physician. The patients included in the study were over 18 years of age, had received treatment in our clinic, had histological diagnosis of cancer, and sufficient mental capacity to answer the questions. Patients who had a psychiatric disease, were hospitalized at the time of the contact, were receiving active therapy at the time of the contact, and developed other serious diseases (hip fracture, serious infection, etc.) were excluded from the study. A patient query form was used to obtain demographical data (i.e. educational level), and also other demographical data were explored with short-answer questions (i.e. marital status). The history of the disease was extracted from the patient records. Patients were asked questions on the phone about the diagnosis, treatment and treatment period. Their status of satisfaction about the treatment and the treatment team was assessed using a Likert Scale [10]. The duration of phone interviews was approximately 10±2 min. Approval was received from the local ethics committee, and oral consent was received from the patients during the phone interview.

Statistical analysis

Analyses were made using the Statistical Package for Social Sciences (SPSS) for Windows 13.0. Demographic and clinical information was evaluated with descriptive statistics. Chi-square, Mann-Whitney, Kruskal-Wallis and Spearman's correlation analyses were used as nonparametric tests in the analysis of the data. Statistical significance level was put at $p<0.05$.

Results

The mean patient age was 56.22±10.99 years. The average postoperative follow-up period for operated patients was 60.29±29.62 months, and the average hospitalization period 13.29±10.12 days. Hospitalization period was longer in patients with metastasis ($p=0.001$). Socio-demographic and clinical characteristics of the patients are displayed in Table 1.

Approximately 78.8% of the patients had been informed about their disease. The rate of patients who had not been informed was higher in the primary school group ($p<0.05$; Table 2). The number of patients who believed that information provision had been sufficient was higher in the university group ($p<0.05$; Table 2).

Table 1. Demographic and clinical variables of cancer patients (n=528)

Variable	
Age (years), mean±SD	56.22±10.99
Gender (Female / Male %)	75.3/24.7
Educational level (%)	
Primary school	43.4
High school	29.9
University	20.3
No school	6.4
Marital status (%)	
Married	81.2
Single	8.8
Widowed	10
Occupation (%)	
Houseworking	49.2
Retired	34.6
Employee	5
Workman	6.1
Other	6
Cancer type (%)	
Breast	56
Gastrointestinal	18.8
Skin	5.5
Urogenital	7.4
Lung	5
Hematologic	0.5
Soft tissue-bone	5.5
Primary not known	1.6
Postoperative period (months, mean±SD)	60.29±29.62
Hospitalization period (days, mean±SD)	13.29±10.12
Metastasis (%)	31
Comorbidities (%)	52.1

SD: standard deviation

Table 2. Relations of patient information and satisfaction rates (n=528)

		p-value
Informed about the disease (Yes, %)		
Female	77.5	0.715
Male	75	
Informed about the disease (Yes, %)		
Primary school	67	0.013
High school	86.6	
University	84.8	
Satisfaction rate (Enough, %)		
Primary school	28.8	0.012
High school	25.9	
University	60	
Information about protection against lymphedema (%)		0.009
Yes	63.6	
No	36.4	
Information about protection methods against lymphedema (%)		0.000
Protection methods against lymphedema (Yes)	84.5	
Protection methods against lymphedema (No)	15.5	
Rate of satisfaction from treatment team (Very good, %)		0.000
Informed about the disease (Yes)	25.9	
Informed about the disease (No)	6	
Rate of satisfaction from treatment (Very good, %)		0.017
Informed about the disease (Yes)	23.5	
Informed about the disease (No)	6	
Rate of accessibility to physician (Usually,%)		0.000
Informed about the disease (Yes)	44	
Informed about the disease (No)	16	
Doctor-patient relationship (Very good,%)		0.000
Informed about the disease (Yes)	19.9	
Informed about the disease (No)	4	

The satisfaction rate of the informed patients about the treatment, treatment team and the attending physician was higher compared with the ones who were not provided with information ($p<0.05$; Table 2). Methods of information provision were: 94.2% face-to-face, 1.9% books/brochures, 3.2% acquaintances. Nearly 90% of the patients were provided information in the pretreatment period. Approximately 11.1% of the patients mentioned that there was disagreement about the treatment among the doctors who were responsible for their follow-up. The patients' knowledge and satisfaction status are given in Table 3.

The rates of satisfaction from the treatment itself and the treatment team did not show any difference between males and females ($p=0.715$; Table 2). The rate of satisfaction from the treatment team, and the rate of accessibility to the physician were higher in the primary school group ($p<0.05$; Table 2). Satisfaction from the treatment team increased in patients with longer hospitalization periods ($p=0.001$). Axillary nodal dissection had been performed on 50.2% of the subgroup of patients with operated breast cancer. The rate of lymphedema development in patients who had undergone axillary dissection was 45.3%. Limitation of shoulder movements developed in 10.5% of the patients with axillary dissection. It was observed that the rates of shoulder limitation development revealed differences between patients who had undergone axillary dissection and the ones who had not ($p=0.000$). Lymphedema developed in 22.8% of the patients with breast cancer. Shoulder limitation and pain in the shoulder/arm was observed in 4.6% and 11.1% of all breast cancer patients, respectively. Shoulder exercise was recommended to 80.2% of the patients, and 60.3% followed this instruction. Approximately 48.7% received information about protection against lymphedema. Information provision about this subject was considered sufficient by 23.6%, partially sufficient by 67.3%, and insufficient by 9.1% of the patients. Some 44.6% were careful about protection against lymphedema. Another 13.4% had received lymphedema therapy (physiotherapy, medical therapy). Approximately 38.5% believed that the therapy of lymphedema they had received was sufficient, while 61.5% considered it partially sufficient. Nearly 13.5% of the patients with lymphedema thought

Table 3. Patient knowledge and satisfaction status (n=528)

1. Informed about the disease (Yes %)	78.8
Satisfaction rate (%)	
Enough	33.3
Partly enough	50.1
Not enough	16.6
Reason of insufficiency (%)	
Difficulties of remembering	7.5
Not understand	27.5
No attention	65
2. Information given about chemotherapy (Yes %)	57.8
Satisfaction rate (%)	
Enough	33.8
Partly enough	52.1
Not enough	14.1
3. Information given about radiotherapy (Yes %)	40.8
Satisfaction rate (%)	
Enough	35.5
Partly enough	52.5
Not enough	12.0
4. Rate of satisfaction from treatment team (%)	
Very good	21.0
Good	53.9
Moderate	22.6
Mild	1.9
Bad	0.6
5. Rate of satisfaction from treatment (%)	
Very good	23.0
Good	50.0
Moderate	24.5
Fair	1.3
Bad	1.2
6. Rate of accessibility to physician (%)	
Always	8
Usually	33.3
Occasionally	46.2
Rarely	9.7
Never	2.8
7. Doctor-patient relationship (%)	
Very good	15.1
Good	31
Moderate	30.5
Fair	21.6
Bad	1.8

that the education provided for this subject was inadequate. Some 50% of the patients were recommended to use the arm on the operated side. Nearly 11.9% did not use the affected arm. The rate of paying attention to protection methods was found to be higher in patients who were informed about protection against lymphedema, compared to the ones who were not provided information ($p < 0.05$; Table 2).

General physical exercises were recommended to 38.5% of the assessed patients. These recommended exercises were considered as sufficient by 16.2%, partially sufficient by 68.3%, and insufficient by 15.5% of the patients. Only 30.2% of the patients did the recommended exercises. Physiotherapy consultation was requested only from 2.3% of the patients.

Discussion

At the end of this study it was observed that although most of the patients followed up in our oncology clinic were provided with information about the disease and its treatments, no necessary attention was paid to this issue. Satisfaction rates were higher in patients who received information, and almost for none of the patients consultation was requested for exercise or rehabilitation programs. It was concluded that physiotherapy approaches and advice about upper extremity are significant in terms of the potential problems that may develop in the subgroup of patients with breast cancer.

Literature review reveals that appropriately provided information has a positive effect on the patient's participation in the treatment and on his/her psychological stress [4,7]. It is noted that insufficient provision of information may lead to an increase in the anxiety due to the diagnosis of cancer, may cause doubts in the patients about the efficacy of treatment, and symptoms and side effects may be missed out in case of insufficient provision of information [13]. A study showed that although the majority of patients thought that they are fully informed about their disease, 37% stated that they wished to receive additional information [14]. Although the patients' demands for information provision are high, this situation is not reflected in clinical practice. The study by Bober et al. demonstrates that patients with breast and ovarian cancer are not asked to come back for examination to receive advice about the treatment, and that some of these patients either misunderstand these recommendations, or do not understand them at all [15]. The patients who participated in our study designated the reasons behind the insufficient provision of information, stating that physicians do not pay enough attention to information provision and they do not understand what is told to them. Since recommendations about cancer and its treatment may cause stress to the patient, the probability of remembering them would decrease. Therefore, it may not be reasonable to give information to the patients with only one attempt about what they should pay attention to, and then expect them to remember what they were told. A study has suggested that satisfaction from information provision has increased from 63% to 95% when a second interview has been made with the nurse [14]. However, the patients who participated in our study had been provided with general information only in the pretreatment period.

Patients want the health personnel to ask them questions about their physical and psychological situation besides the routine clinical assessment [16,17]. Some patients and their families are not satisfied with the treatment they have received, and believe that they could not receive the treatment they needed due to insufficient assessment [17]. However, the physician-patient relationship is known to affect the patient compliance, communication, participation in the treatment, patient's ease in asking for help, understanding and application of the provided information, and finally the quality of treatment [18,19]. It is noted that a better communication between the physician and the patient increases patient satisfaction, and makes the patients feel better emotionally [20]. Lerman et al. stated that patients with breast cancer experience communication problems with the treatment team, which in turn causes stress to the patients [21]. According to our findings, approximately one third of the patients defined the level of their communication with the physician as good, while one third of them defined it as moderate. The majority of the patients stated that they could access their physician only once in a while. Therefore, it would be appropriate to establish a support unit to enable communication between the patient and the physician.

Literature review revealed a connection between disease-related variables and patient satisfaction [8]. In our study, patient satisfaction rate was higher in patients with longer hospitalization periods. This may be related to the fact that patients are in contact with the health personnel during their hospitalization period, and can find the opportunity to receive answers to their questions. Results of the present study also demonstrated a relationship between the patient's educational level and patient satisfaction, which is in agreement with the results of similar studies [8]. Patient satisfaction from the treatment team was higher among primary school graduates compared with university graduates. This result may be related to the lower level of expectations in this group of patients with lower educational level. On the other hand, provision of information was insufficient in the primary school group compared with the university group, and this was associated with the difficulty these patients have in understanding the provided information.

In this study, most patients were given information about the disease and treatment through face-to-face contact. The success of information provision in our patients may have been affected, since written and visual materials are more effective as an information provision method in patients [8]. In the study by Haggmark et al. the patients who participated in the education group and continued receiving information personally were more satisfied compared with the patients who were informed through standard information provision [22]. Only less than half of the patients stated that they had received information also in the post-discharge period [23]. The patients in our study noted that they were informed in the pretreatment period. These results support the fact that each patient should be assessed separately, and information process should be on a continuing basis.

Even though the treatment team tries to spare the time for answering patients' questions and providing them with information [24], there may be gaps in information provision and deficiencies in interdisciplinary communication [23,25]. Another study proved that the ones working in different disciplines do not have much information about what the other group has done and said about the patient's situation [26]. Some 11.1% of the patients in our study noted inconsistencies between the information they received from different physicians in the treatment team. These findings are quite significant in terms of the cancer patients' confidence in the treatment team. Therefore, communication of all the people in the team plays a critical role in the treatment, when the treatment success is considered at all points.

Since the hospitalization period of patients with breast cancer - who were classified as a subgroup in our study - is short, the information provision process is also thought to be shorter. Thus, patients should be followed up not only in terms of recurrence but also for the purpose of rehabilitation. We observed that many of the patients had upper extremity lymphedema and shoulder problems. Despite this fact, most of the patients were not provided with practical information concerning these postsurgical problems. Informed patients acted more carefully in their daily activities and paid more attention to protection. Similarly, it was reported in a study carried out in Sweden that patients with breast cancer lacked information about postoperative rehabilitation, and did not have sufficient information about exercises, carrying weight and doing work with the arm of the operated side [27]. Contrary to the findings of the study by Karki et al. [23] and our study, a study from the United States revealed that 60% of the patients with breast cancer did not receive any information about exercises from physicians [28]. In order to prevent lymphedema and upper extremity problems in the postsurgical period and to provide an effective treatment, it is important that all the members of the treatment team believe in the rehabilitation approaches, and pay attention to these complications for their early diagnosis and treatment.

It is established that aerobic exercises are effective in the physical-psychological symptoms of cancer patients even during chemotherapy and radiotherapy [28]. However, our study revealed that less than half of the patients were advised to do general exercises, and only one third of these patients performed these exercises.

Although exercises play an important role in patients' daily activities as well as in their emotional conditions, only 1.8% of them required consultation for physical treatment. In the study by Karki et al. 81% of the patients were noted to require consultation for physical treatment [23]. This result indicates that a majority of our patients did not receive sufficient supportive treatment. Zissiadis et al. demonstrated that the patients were satisfied with the information they received about the disease and toxicity, while they lacked information about life style and practical issues [18]. As a matter of fact, cancer patients who return to their social routine after the completion of their primary medical treatment develop several secondary problems. Rehabilitation approaches are quite significant in terms of the preventable problems. Currently, most of the patients are also being evaluated on the basis of rehabilitation approaches by our actively working support team.

The strong aspects of our study are: a) the effort made to contact the patients who were followed up for a long period of time; b) there is no other similar data available in the literature; c) we learned about the patients' satisfaction with the clinic, which helps creating statistics over this issue in our country; and d) its results will provide guidance for making patient-oriented treatment and follow up plans in the future.

Our study has, on the other hand, some limitations. It would have been helpful to include questions about pain and its treatment, which stands out as an important problem in cancer patients. Moreover, patient groups handled in similar studies generally consist of patients with breast cancer. Yet, breast cancer patients were taken as a subgroup in this study. The number of patients with other types of cancer was low. Our findings consist of data obtained from only one hospital; therefore, results including data from different hospitals could have reflected the general panorama of the whole country. In addition, the data we have obtained belong to the period prior to the foundation of the multidisciplinary support team in our hospital. The aim of our next study will be to compare these data with those belonging to the period after the foundation of this support team.

Consequently, the data obtained at the end of this study have revealed that we have some deficiencies in the quality of information provision in cancer patients, and the support treatment system is insufficient in the period when patients return to their social life after the completion of their primary treatment. However, the basic approach should aim to detect and resolve these problems. We believe that the multidisciplinary support unit founded in our oncology department will reduce these deficiencies and insufficiencies to the minimum level.

References

1. Hwang SS, Scott CB, Chang VT, Cogswell J, Srinivas S, Kasimis B. Prediction of survival for advanced cancer patients by recursive partitioning analysis: role of Karnofsky Performance Status, quality of life, and symptom distress. Cancer Invest 2004; 22: 678-687.
2. Grunfeld E, Dhesy-Thind S, Levine M. Clinical practice guidelines for the care and treatment of breast cancer: follow-up after treatment for breast cancer. CMAJ 2005; 172: 1319-1320.
3. Hewitt ME, Bamundo A, Day R, Harvey C. Perspectives on post-treatment cancer care: qualitative research with survivors, nurses, and physicians. J Clin Oncol 2007; 25: 2270-2273.
4. Mills ME, Sullivan K. The importance of information giving for patients newly diagnosed with cancer: a review of the literature. J Clin Nurs 1999; 8: 631-642.
5. Jones R, Pearson J, McGregor J. Cross-sectional survey of patients' satisfaction with information about cancer. Br Med J 1999; 319: 1247-1248.
6. Steward MA. Effective physician-patient communication and health outcomes: a review. Can Med Assoc J 1995; 152: 1423-1433.
7. Gysels M, Higginson IJ. Interactive technologies and videotapes for patient education in cancer care: systematic review and meta-analysis of randomised trials. Support Care Cancer 2007; 15: 7-10.
8. Brédart A, Coens C, Aaronson N et al. EORTC Quality of Life Group and EORTC Quality of Life Unit. Determinants of patient satisfaction in oncology settings from European and Asian countries: preliminary results based on the EORTC IN-PATSAT32 questionnaire. Eur J Cancer 2007; 43: 323-330.
9. Weingart SN, Price J, Duncombe D et al. Patient-reported safety and quality of care in outpatient oncology. Jt Comm J Qual Patient Saf 2007; 33: 83-94.
10. Chang JT, Chen CJ, Lin YC, Chen YC, Lin CY, Cheng AJ. Health-related quality of life and patient satisfaction after treatment for breast cancer in northern Taiwan. Int J Radiat Oncol Biol Phys 2007; 69: 49-53.
11. Richardson A, Miller M, Potter H. Developing, delivering, and evaluating cancer nursing services: searching for a United Kingdom evidence base for practice. Cancer Nurs 2002; 25: 404-415.
12. Weingart SN, Flug J, Brouillard D et al. Oral chemotherapy safety practices at US cancer centres: questionnaire survey. Br Med J 2007; 334: 407.
13. D'haese S, Vinh-Hung V, Bijdekerke P et al. The effect of timing of the provision of information on anxiety and satisfaction of cancer patients receiving radiotherapy. J Cancer Educ 2000; 15: 223-227.
14. Negrier S, Gomez F, Chauvin F et al. Treatment planning visit in oncology: factors predictive of satisfaction with the meeting with the physician and benefits of a second interview with a nurse. Presse Med 2007; 36: 779-785.
15. Bober SL, Hoke LA, Duda RB, Tung NM. Recommendation recall and satisfaction after attending breast/ovarian cancer risk counseling. J Genet Couns 2007; 16: 755-762.
16. Mesters I, van den Borne B, De Boer M, Pruyn J. Measuring information needs among cancer patients. Patient Educ Couns 2001; 43: 253-262.
17. Richardson A, Medina J, Brown V, Sitzia J. Patients' needs assessment in cancer care: a review of assessment tools. Support Care Cancer 2007; 15: 1125-1144.

18. Zissiadis Y, Provis A, Harper E, Kearney E, McDonald L, Dhaliwal S. Patient satisfaction in radiation oncology. Aust Rad 2006; 50: 455-462.
19. Shakespeare TP, Tang JI, Shen L et al. Does the implementation of radiation oncology outpatient infection control measures adversely affect patient satisfaction with doctor-patient interaction? Singapore Med J 2007; 48: 246-251.
20. Rosenbloom SK, Victorson DE, Hahn EA, Peterman AH, Cella D. Assessment is not enough: a randomized controlled trial of the effects of HRQL assessment on quality of life and satisfaction in oncology clinical practice. Psychooncology 2007; 16: 1069-1079.
21. Lerman C, Daly M, Walsh WP et al. Communication between patients with breast cancer and health care providers. Determinants and implications. Cancer 1993; 72: 2612-2620.
22. Häggmark C, Bohman L, Ilmoni-Brandt K, Näslund I, Sjödén PO, Nilsson B. Effects of information supply on satisfaction with information and quality of life in cancer patients receiving curative radiation therapy. Patient Educ Couns 2001; 45: 173-179.
23. Karki A, Simonen R, Malkia E, Selfe J. Postoperative education concerning the use of the upper limb, and exercise and treatment of the upper limb: cross sectional survey of 105 breast cancer patients. Support Care Cancer 2004; 12: 347-354.
24. Mok E. Empowerment of cancer patients: from a Chinese perspective. Nurs Ethics 2001; 8: 69-76.
25. Gysels M, Richardson A, Higginson IJ. Communication training for health professionals who care for patients with cancer: a systematic review of effectiveness. Support Care Cancer 2004; 12: 692-700.
26. van Wersch A, Bonnema J, Prinsen B, Pruyn J, Wiggers T, van Geel AN. Continuity of information for breast cancer patients: the development, use and evaluation of a multidisciplinary care protocol. Patient Educ Couns 1997; 30: 175-186.
27. Boman L, Andersson JU, Bjorvell H. Needs as expressed by women after breast cancer surgery in the setting of a short hospital stay. Scand J Caring Sci 1997; 11: 25-32.
28. Young-McCaughan S, Sexton DL. A retrospective investigation of the relationship between aerobic exercise and quality of life in women with breast cancer. Oncol Nurs Forum 1991; 18: 751-757.