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The Relationship Between Disease Features and Quality of Life in Patients With Cancer—I

KEY WORDS

Cancer

Quality of life

Psychosocial care

The high incidence and the severe symptoms of cancer have a considerable effect on quality of life in patients. The relationship between quality of life in patients with cancer and treatment, early diagnosis, disease acceptance, pain, psychological distress, loss of organ, duration of disease, and caregivers was investigated. This study included 508 patients with cancer treated in either inpatient or outpatient clinics of 5 oncology centers in Ankara, Turkey, between August 1998 and January 2000. Patients were selected by interviews. Data were collected by a questionnaire to determine disease features and to evaluate patients' quality of life. We found that several disease features, including treatment, early diagnosis, disease acceptance, pain, psychological distress, and caregivers, had an effect on patients' quality of life ($P < 0.05$), whereas loss of organ and duration of disease did not. The results of this study underline the significant effect of psychosocial care programs on quality of life. In the future, assessments of quality of life can help healthcare personnel to prepare psychosocial care programs.

■ Introduction

Cancer is a chronic disease with a remitting and relapsing course. The diagnosis of cancer is a traumatic experience for individuals, because the person diagnosed with cancer faces the danger of losing his economic power, job, organs, and even his or her life–diagnosis of cancer implies weakening of all normal adaptation mechanisms, frustration of plans and expectations, and incapacity. Cancer disrupts the life of the individual in all respects, significantly influencing the quality of life (QOL).[1-4]

Quality of life is a general term and is difficult to define exactly. The World Health Organization (WHO) defines quality of life as individual perception of life, values, objectives,

standards, and interests in the framework of culture. QOL life associated with a disease is related to all stages of that disease. For example, the cancer-specific QOL scale is composed of items related to cancer.[5,6]

The goal of cancer treatment is to provide a cure for patients. In other words, the goal is to increase survival and maintain QOL. Recently, there has been increasing interest in assessment of QOL to evaluate the empirical effect of cancer treatment and results of the given care. The US Food and Drug Administration (FDA) employs assessments of QOL in selection of anticancer drugs. The American National Cancer Institute uses QOL as a criterion in evaluation of clinical practice.[5,7,8]

Conventional approach uses such criteria as local recurrence, presence of metastasis, disease-free survival, overall survival, and major physical symptoms in evaluation of treatment outcome. This approach does not enable clinicians and investigators to evaluate the impact of cancer treatment on the daily life of patients with cancer and to determine the interventions required to maintain and improve QOL.[9-11]

Inability to maintain QOL has always been a major source of concern in patients with cancer. As mentioned, both the disease itself and the side effects of the treatment have profound biochemical effects on patients with cancer. Assessment of QOL can help to estimate the biopsychosocial status of patients and relevant needs of patients, to evaluate treatment outcome, and to predict the effects of treatments. Based on the assessments of life quality, effects of different treatment alternatives on QOL can be determined and decisions on long-term policies can be made.[5,12,13]

Based on the idea that culture (lifestyle), which may differ from country to country, affects psychosocial status, results of many QOL studies are not used when planning care for patients. In Turkey, QOL of patients with cancer has only recently been investigated, so there are few studies on this subject. Moreover, there is no study on how disease features affect QOL in patients with cancer. Therefore, a study on how the disease features affect QOL of patients with cancer in Turkey may help to determine the present situation, evaluate the effectiveness of the treatment alternatives offered and the care given currently, and may provide detailed information that will guide health care staff in determining appropriate treatment alternatives and care.

The aim of this study was to determine if there was any relation between the QOL in patients with cancer and the disease features. Therefore, we tried to address the following questions:

1. Is there a significant relationship between lifestyles of patients with cancer and QOL?
2. Is there a significant relationship between early diagnosis of the disease and QOL?
3. Is there a significant relationship between disease acceptance and QOL?
4. Is there a significant relationship between pain and QOL?
5. Is there a significant relationship between psychological distress and QOL?
6. Is there a significant relationship between loss of organ and QOL?

7. Is there a significant relationship between duration of the disease and QOL?
8. Is there a significant relationship between the caregivers and the patients' QOL?

■ Material and Method

The study population was composed of 508 patients treated in inpatient and outpatient clinics in Gülhane Military Hospital, Hacettepe University Oncology Hospital, Ankara Demetevler Oncology Hospital, Ahmet Andiçen Oncology Hospital, and Ankara University Ibni Sina Hospital in Turkey between August 1998 and January 2000. After written informed consent was obtained from all patients, questionnaires were distributed to them. The first part of the questionnaire was composed of questions on type of treatment given, early diagnosis, disease acceptance, pain, psychological distress, loss of organ, duration of the disease, and caregivers. Type of treatment was divided into inpatient and outpatient treatments. Information on the early diagnosis was derived from the files of patients. Diagnosis was based on Tumor-Node-Metastasis (TNM) classification (stage 0: in situ cancer [no invasion or lymphatic or venous metastasis]; stage I: early local invasion, no metastasis; stage II: limited local invasion and/or minimal lymph node involvement; stage III: extensive local invasion and/or extensive lymph node metastasis; stage IV: advanced local tumors or primary tumor and distant metastasis). Diagnosis of the disease at stages I and II was regarded as early diagnosis and at stages III and IV as late diagnosis.

Patients were asked about the duration of the disease and disease acceptance. The answers "I never accept my disease" or "I do not believe that I am ill" indicated that the patient did not accept his or her disease. The answers "I accepted the disease as it was" and "I got used to living with the disease and the changes it caused" indicated that the patient accepted his or her disease.

Patients were also asked whether they experienced pain, loss of organ, and psychological distress. Concerning the pain, patients were asked if they had pain due to their illnesses. They had two choices: "yes" or "no." Concerning loss of organ, they were asked whether they had sustained any loss of organ (eg, breast, uterus), and they had two choices: "yes" or "no." Concerning psychological distress, patients were asked if they felt distress severe enough to see a psychologist or a psychiatrist, and they had two choices: "yes" or "no."

The second part of the questionnaire was composed of a version of Rolls-Royce Life Scale modified by Özyilkan et al for patients in Turkey. According to this scale, items on the questionnaire must reflect areas that are important to patients suffering from disease, and these should be derived from what patients say about how the illness affects their lives.

The questionnaire consists of 42 items in 8 subscales, which asses general well-being, physical activity, physical symptoms, sleep dysfunction, appetite, sexual dysfunction, cognitive functions, medical interaction, social participation, and work performance from previously published QOL scales. During the

questioning process, each item was considered separately, and all data related to the item were carefully revised, including the relationship with other items within the same factor structures.

Decisions between items were made by considering the intercorrelations, clinical significance, and frequency of occurrence in 100 heterogeneous participants (10 physicians, 19 healthy volunteers, 10 patients' relatives, 28 patients on chemotherapy, 25 patients off chemotherapy). Patient groups were chosen from cases of neoplasia derived from different sites (16 hematopoietic, 8 breast, 7 gastrointestinal [GI], 4 lung, 2 bone, 3 genitourinary [GU], 3 head and neck, and 10 others).

There are 5 choices for each question. These are "Yes, fits me exactly," "Fits me very well," "Fits me partly," "Does not fit me well," and "Does not fit me at all." The choices above were scored as 5, 4, 3, 2, and 1, respectively, for positive questions and vice versa for negative questions. Scores obtained from each criterion for QOL were added and then the median score was calculated. One hundred was considered as the maximum score. There were 8 criteria for quality of life, so the total score was 800. High scores show high QOL.[14]

Variance analysis and Kruskal Wallis Variance Analysis were used to determine whether there was a relation between QOL and duration of disease, psychological distress, and caregivers. Student's t test and Mann Whitney U test were used to determine if there was a relation between QOL and type of treatment, early diagnosis, disease acceptance, loss of organ, and pain.

■ Results

The sociodemographic characteristics of all patients were as follows. (The relation between QOL and sociodemographic features of the patients, as the second arm of the study, was dealt with in another article.) The majority of patients (53.1%) were male, aged 16–44 years, with a mean age of 44 (50%), married (71.7%), primary school graduates (33.9%), housewives (32.3%) and had sufficient income (56.9%). Three hundred and eight patients had breast cancer, 60 GI cancer, 44 GU cancer, 37 head and neck cancer, 11 lymphoma, and 48 cervical cancer. Evaluation of disease features showed that the majority of patients were outpatients, their diseases were diagnosed early, duration of disease was between 0 and 1 year, they accepted their disease, because they did not experience loss of organ, they had pain and psychological distress and that they were cared for by their spouses (Table 1).

As to treatment of patients shown in Table 2, outpatients had high QOL scores compared with inpatients (574.81 vs 461.87). Outpatients had the highest score in "appetite" and "general well-being" subscales (78.58 and 76.77, respectively) whereas inpatients got the highest score in "perception of present state"[10(p62)] and "physical symptoms and activity" (62.10 and 62.10, respectively).[10(p62)] Statistical analysis showed that there was a relation between the patients' status (inpatients/outpatients) and their QOL ($P < 0.05$).

Patients diagnosed early had higher scores in general QOL and in all subscales than did patients whose diseases were diag-

Table 1 • Disease Features of Patients With Cancer

	N	%
Patients		
Inpatients	250	49.2
Outpatients	258	50.8
Early Diagnosis		
Yes	362	71.3
No	146	28.7
Duration of Disease		
0–1 y	184	36.2
1–3 y	112	22.0
3–5 y	131	25.8
More than 5 y	81	15.9
Disease Acceptance		
Yes	339	66.7
No	157	30.9
No answer	12	2.4
Loss of Organ		
Yes	210	41.3
No	298	58.7
Pain		
Yes	257	50.6
No	251	49.4
Psychological Distress		
Yes	219	43.1
Partly	177	34.8
No	112	22.0
Caregivers		
Spouse	189	37.2
Children	86	16.9
Parents	91	17.9
Close relatives	36	7.1
Attendant	5	1.0
No one	31	6.1
Myself	70	13.8
Total	**508**	**100.0**

nosed at a later stage. General QOL scores of the patients diagnosed early and those diagnosed late were 570.14 and 383.23, respectively. There was a significant relation between early diagnosis and QOL ($P < 0.05$).

Evaluation of the relation between duration of disease and QOL revealed that QOL scores were comparable in patients whose diseases lasted 0–1, 1–3, 3–5, or 5 or more years. No significant relation was found between duration of disease and QOL ($P > 0.05$).

As demonstrated in Table 2, total score for QOL and scores obtained from each subscale were much higher in those patients who accepted their diseases. In fact, score for QOL was 552.38 in patients who accepted their diseases, whereas it was 378.30 in those who did not accept their diseases. There was a significant relation between disease acceptance and QOL ($P < 0.05$).

Patients who experienced loss of organ and those who did not had comparable scores for both general QOL and QOL subscales (Table 2). In fact, the former group of patients had a

Quality of Life Disease Features	General Well-Being	Symptoms and Physical Activity	Sleep	Appetite	Sexual Dysfunction	Perception	Medical Interaction	Social Relationships and Work Performance	Total	P
Patients										<0.05
Inpatients	53.38	60.24	59.08	51.64	58.63	62.10	56.71	60.09	461.87	
Outpatients	76.77	68.86	70.35	78.58	70.84	67.19	72.95	69.27	574.81	
Early Diagnosis										<0.05
Yes	72.36	72.05	69.41	72.49	67.77	74.57	71.47	70.29	570.41	
No	47.64	47.71	53.37	47.16	43.30	43.35	49.01	51.70	383.23	
Duration of Disease										
0–1 y	68.66	57.95	66.38	69.86	46.14	62.22	60.28	64.61	496.10	
1–3 y	67.50	59.79	64.10	66.49	48.50	62.50	61.60	63.94	494.42	
3–5 y	66.22	57.21	63.51	63.09	49.82	59.34	57.55	62.74	479.48	
More than 5 y	64.86	55.50	60.61	64.92	42.58	58.70	57.02	62.59	466.87	
Disease Acceptance										<0.05
Yes	38.57	44.17	51.71	52.58	56.32	40.16	46.34	48.46	378.30	
No	74.10	70.79	66.58	66.10	64.13	73.05	69.36	68.27	552.38	
Loss of Organ										
Yes	71.97	68.70	62.08	72.37	64.52	64.15	70.44	66.59	540.82	
No	69.68	62.01	66.59	69.59	64.72	65.06	68.63	63.23	529.51	
Pain										<0.05
Yes	42.90	45.14	45.91	54.85	59.71	47.20	40.84	49.82	386.37	
No	91.46	88.21	87.14	87.14	69.82	85.36	94.87	81.88	688.88	
Psychological Distress										<0.05
Yes	64.12	54.24	57.00	63.50	44.64	54.08	55.78	60.41	453.77	
Partly	66.15	58.02	65.88	64.14	52.50	63.07	60.37	64.85	494.98	
No	74.77	64.29	75.72	76.50	43.10	71.14	64.70	68.15	538.37	
Caregivers										<0.05
Spouse	69.83	69.75	65.63	66.11	62.63	63.30	62.77	64.72	524.74	
Children	68.42	59.58	67.52	67.55	54.80	60.39	58.48	65.76	502.50	
Parents	64.09	54.02	56.52	68.23	38.00	58.17	58.05	59.30	455.38	
Close Relatives	57.55	46.55	54.70	55.91	46.35	51.05	48.81	53.32	414.24	
Attendant	50.80	50.44	48.60	54.33	25.00	58.60	42.11	47.00	376.88	
No One	50.38	52.22	49.80	56.29	28.61	52.83	53.22	58.45	401.80	
Myself	56.71	60.84	52.28	54.45	57.58	52.40	51.30	52.61	438.17	

total QOL score of 540.82 and the latter group of patients 529.51. Statistical analysis showed no relation between loss of organ and QOL ($P > 0.05$).

Patients suffering from pain had rather low QOL scores compared with those not suffering from pain (Table 2). The former group scored 386.37 and the latter 688.88. There was a significant relation between QOL and pain ($P < 0.05$).

Patients who had psychological distress had an average QOL score of 453.77, those who had partly experienced psychological distress 494.93, and those who never had such problems 538.37 (Table 2). There was no significant relationship between psychological distress and QOL ($P < 0.05$).

As shown in Table 2, patients whose caregivers were their spouses had the highest QOL score (524.74), followed by those patients whose caregivers were their children (502.50). Patients cared for by an attendant, who was not a family mem-

ber, had the lowest QOL score (376.88). There was a significant relationship between QOL and caregivers ($P < 0.05$). This finding, that the category of patients cared for by caregivers received the lowest QOL scores, was striking.

■ Discussion

QOL is difficult to define for both social scientists and clinicians, although it is intuitively understood. Because the physical condition of the individual influences his or her psychosocial functions, the term QOL focuses generally on physical, economical, social, and emotional factors.[15]

In this study, it was established that the outpatients' QOL was better than that of inpatients. Hospitalization restricts a patient's whole life, adversely influencing QOL in all respects.

In Turkey, it is usually the patients with an advanced stage of the disease or with poor general condition who are hospitalized. Therefore, the result was not surprising, which may be one of the reasons why QOL was lower for inpatients. These results may be congruent with those of Hann et al,[16] who found a relationship between long-term hospitalization and poor physical condition. That outpatients scored the lowest on the "perception" subscale is interesting. Cancer is believed to be a disease with an uncertain prognosis and that can recur at any time. Therefore, patients do not feel relaxed even if their general well-being is maintained. This may explain our finding that patients whose treatments were followed in the outpatient clinic had high scores for general well-being, sleep, appetite, medical interaction, social relationships, work performance, and sexual functions but felt bad about their current states. Although outpatients with cancer were better in terms of general well-being, sleep, appetite, medical interaction, social relationships, and occupational and sexual performance, they felt bad in terms of perception of their current states because the prognosis of cancer is uncertain. This led patients to achieve lower scores for perception of their current states (a subscale).

In this study, we also found that QOL was higher for patients diagnosed early compared with those diagnosed late. It is only natural that the patients diagnosed early have a better estimate of their present status than the patients not diagnosed early. When the disease is diagnosed late, patients have a more negative opinion about their present status. In addition, they may be confronted with more problems, adversely influencing their QOL.

In this study, no relationship was found between the duration of illness and QOL. This finding is not consistent with that of Kizilci[17] who found that QOL decreases in the first 6 months of the disease and then remains the same. However, it is in keeping with the results of Hann et al,[16] showing no relationship between the duration of the disease and the QOL in patients with cancer who underwent bone marrow transplantation.

That the patients who were unable to accept their disease had a higher QOL score than those accepting their disease is interesting. Although it was our initial expectation that the patients accepting their disease had a higher QOL, our findings suggested that patients who did not accept their disease possibly employed denial or avoidance defence mechanisms to cope with their disease. The higher QOL found in these patients may be attributed to them using those mechanisms.

In this study, no relationship was found between QOL and the loss of organ, namely the QOL did not show any significant difference between patients who experienced loss of organ and those who did not. In another study, patients undergoing mastectomy were found to have lower QOL solely in the "somatic" area compared with patients undergoing lumpectomy.[16] In the study conducted by Miloviç et al, no difference was found between patients undergoing partial mastectomy and those undergoing total mastectomy with respect to QOL, except distortion of body image.[18] The patients undergoing partial mastectomy were always concerned about the possibility of recurrence of the disease in the remaining part of the breast. In our study as well, the majority of patients have stated that being healthy was far more important for them than was the loss of an organ. This approach may account for the results.

Despite efficient therapies, more than half of all patients with cancer experience uncontrollable pain for the duration of their disease and its management.[19] We do not believe that there is a study on this subject in Turkey. However, the rate of feeling severe pain is estimated to be high. In this study, it was determined that patients feeling pain had a lower QOl compared with those without pain. Our results are in keeping with those of Wyatt and Friedman[20] who found that patients experiencing pain had a lower QOL in all subscales. Frequent hospitalization, unrelieved pain, loss of personal control, and limitation in activities of self-care are factors adversely influencing the QOL in patients with cancer.[20]

In this study, it was observed that patients experiencing psychological distress had a lower QOL compared with those patients who did not experience distress. It was stated in the literature that in the long-term the psychological health of patients deteriorated and that this took place particularly after the diagnosis of cancer.[21] Psychological distress itself is a factor that decreases the QOL. However, poor QOL may lead to psychological distress or vice versa. It is difficult to distinguish cause and effect.

Wyatt and Friedman stressed the importance of the support of friends in psychosocial management of cancer.[20] They observed that some women patients with cancer felt abandoned by their friends. In another study performed by Roberts et al on patients with cancer,[22] a moderate relationship was found between the lack of social support and the extent of psychological distress. In this study, it was also established that there was an association between the individuals caregivers and the QOL. The QOL was highest in those patients who were cared for by their spouses and children, followed by those cared for by their parents and those cared for by close relatives. Patients cared for by an attendant or cared for by no one had the lowest QOL. It was seen that the patients preferred to be cared for by their spouses and children. Although there were a few patients who were cared for by caretakers, the patients in our study group did not prefer to be helped by caretakers. This result is not surprising in a culture in which people are not used to getting professional help. Stuifbergen[23] stated that, in the study of Dimond on 36 dialysis patients, there was a direct relationship between the support of the spouse and the emotional state of the patient. Our findings support those of Dimond.

■ Conclusions

Cancer is an important health problem influencing QOL in both patients and their families. As mentioned, the number of studies on QOL performed in Turkey is limited. Furthermore, there has been no study on the features of cancer. Therefore, the results of this study are quite important because this is the first study to determine these features in Turkey. In fact, the obtained results will guide health staff to select appropriate treatment and provide care to patients with cancer. If the staff is aware of how the disease features affect QOL and which

aspects of QOL are affected, they can choose more accurate and realistic interventions.

In this study, inpatients, patients diagnosed late, those suffering from pain or psychological distress, and those noting that they had no relative to care for them had a low QOL. These results should be considered when both medical interventions and nursing care are planned.

Finally, further studies using the disease features determined in this study and taking other disease features into account will strengthen the obtained results and may provide information on the relationship between QOL and other features of the disease.

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