

Original Article

Supportive Care Needs and Distress Levels of Patients Undergoing Radiotherapy

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Abstract

Objective: The study aimed to determine the distress levels and supportive care needs of patients undergoing radiotherapy in the first week of radiation therapy.

Methods: This was a cross-sectional with 260 individuals who attended the Radiation Oncology Clinic of an Oncology Training and Research hospital and who were going to receive at least 7 days of radiotherapy for curative purposes. Data were collected by using descriptive information form, Short-Form Supportive Care Needs Survey and Distress Thermometer.

Results: The rate of distress in the first week of radiation therapy of the patients was 41.2% (distress score ≥ 4). It was stated that the areas where the patients were having most distress were worry (49.9%), sadness (35.2%), fatigue (66.8%), pain (43.2%) and sleep (35.2%). The patients' supportive care needs were found in all fields. There was a positive correlation between psychological status, patient care and support, sexuality and total support needs and distress levels.

Conclusions: Diagnosis of distress levels and planning of population-specific intervention in the radiotherapy process, integration of supportive care services into the health system is recommended.

Keywords: distress, radiotherapy, support care

Introduction

A total of 165.350 new cases of cancer were diagnosed including about 96.200 men and 67.200 women in one year in Turkey (Cancer Statistics Report, 2017). At the same time with

chemotherapy, radiotherapy, target therapies and developments in surgical procedures, more cancer patients have chance of curative treatment, and the number of survivors from cancer is increasing steadily. Radiotherapy is one of the most commonly used cancer treatment modalities

because of its curing effect and its advantage in survival. Despite advances in radiotherapy techniques, however, many side effects (fatigue, nausea, diarrhea, skin problems, etc.) can be seen at varying degrees in patients receiving radiotherapy (Pollack et al., 2006; Gomez-Millan, 2009; Luutonena et al., 2011). These conditions, which are caused by the disease itself or the treatment toxicity, increase the distress levels experienced in the treatment process by adversely affecting the functional, psychosocial health of the patients (Theofanidis, 2015; Faller, et al., 2003; Fritzschea, et al., 2004; Buick et al., 2000).

Distress is used to describe the unpleasant feelings, emotions, and physical manifestations of the individual, which hinder their ability to cope with cancer. Distress is expanding into a continuity that can turn into situations like fear, anxiety, sadness, depression, anxiety disorder, isolation and spiritual crisis (National Comprehensive Cancer Network, 2016; Bultz, and Johansen, 2011). In many studies in the literature, it has been shown that patients have high anxiety and stress during the cancer process, and negative psychological consequences of the cancer process on these patients (Fitch, 2012; VanHoose et al., 2015; Chen et al., 2009). At the onset of RT, many patients experience decreased quality of life, pain, and emotional distress. Psychosocial stress is frequently elevated during and after RT and is increasing in the process (Habbous et al., 2017; Fritzschea, et al., 2004; Luutonena et al., 2011; Šoštarič, and Šprah, 2004; Faller, Olshausen, and Flentje, 2003).

The management of distress which patients experience in this process is an important component of effective treatment. Distress management can help cancer patients to cope with situations which were the source of distress of the patients and to improve their emotional states and to reduce functional deficits due to side effects. Insufficient distress management leads to inadequate psychosocial support and treatment of the patients. (Carlson, et al., 2012; Scotté, 2012; Uchida et al., 2011; Chen et al., 2009; Bultz, & Johansen, 2011). In the literature, it was stated that health professionals are incapable of diagnosing and treating distress of the patients due to workload, time issue, lack of training, etc., and it was stated that distress screening should be positioned as the 6th vital finding (National Comprehensive Cancer Network, 2016; Bultz, & Johansen, 2011)

Depending on the multiple problems experienced with the disease and the treatment process, the needs of the patients in this period are also multidimensional and varied (Yıldırım et al, 2013; Aranda et al., 2010; Mistry et al., 2010).

In the literature, it was determined that patients have needs in different fields in the periods of diagnosis, treatment, follow-up and palliative period. In a study of Landmark, et al (2008) on patients with active breast cancer, it was stated that women need information and psychosocial support regarding their physical, emotional and social aspects of daily life. In the study of Kav et al. (2012), the patients stated that they have information needs about the disease (76.8%) besides the treatment and side effects. In another study it was reported that there were support needs about the symptom control, psychosocial and daily life. (Carey et al., 2012).

Supportive care is a care that helps an individual who is diagnosed with cancer and his or her family to cope with cancer and its treatment, in the processes of diagnosis, treatment, death and mourning after death. Supportive care includes symptom management, presentation of health information, food preparation, support of daily life activities, transportation, psychosocial support and counseling services (Smith, et al., 2015; Carey et al., 2012). Nowadays, supportive care is an important component of health services for cancer patients. Supportive care services are associated with better patient outcomes such as increased overall survival early stage patients, symptom control and improved functional status.

Unmet needs increase intestinal problems, sleep disorders, stress problems caused by stomach discomforts, decrease treatment compliance and increase physical and psychological distress (Yıldırım et al., 2013; Aranda et al., 2010; Gaertner et al., 2012; Smith, et al., 2015; Sutherland et al., 2009). For these reasons it is important to determine the support needs of the patients. Health professionals should define supportive care needs and include the necessary resources and interventions in the treatment plan.

Therefore, as part of care practices, it is quite important to increase self-management of patients in pre-treatment process and to support patients according to their needs (Aranda et al., 2010; Carlson, et al., 2012). Supportive needs and distress fields in cancer patients include physical, informational, psychological, sexual, social, spiritual, and many other fields. In this

process, awareness of the problems and distress of patients and their families and the planning of supportive care services for them will increase the quality of life of the patients and increase the satisfaction of care (Carey et al., 2012).

Methods

Study design and participants

The study was conducted as cross-sectional with patients who received radiotherapy treatment (RT). The population of study was patients with newly diagnosed cancer who applied at the Radiation Oncology Clinic of a Training and Research Hospital. The study included 310 patients who received treatment in the radiotherapy clinic of the hospital where the study was conducted between April 2017 and September 2017.

Patients who were diagnosed with cancer, who were over 18 years of age, who received at least 7 days of radiotherapy for curative purposes, volunteers to participate in the study, and had no communication problems were included in the study. Fifty patients who were scheduled for short-term RT (less than 7 days), who had previously received RT and did not agree to participate in the study, were excluded from the study and the study was completed with 260 patients.

Data Collection

One day before radiotherapy treatment, patients coming to the radiation oncology unit informed about RT process by the nurses by face to face interviews. After the training, one copy of education material about radiotherapy and coping methods with the problems that can be experienced were given to patients. At this phase, information about the research was given to the individuals who meet the criteria of participating in the research by the researchers. At the end of one week of radiation therapy, the patients were interviewed again and they filled out forms. In the collection of data, descriptive information form including demographic and disease related characteristics of the patients, Short Form of Supportive Care Needs and Distress Thermometer were used.

Short Form of Supportive Care Needs

The scale developed to determine the supportive care needs of cancer patients consists of 5 fields. Each item (field) is based on a 5-point Likert scale. *Psychological/Emotional Sub-dimension:*

evaluates the needs for emotions and coping. *Health System and Information Sub-dimension:* evaluates the requirements for information about disease, diagnosis, treatment, follow-up and treatment center. *Physical and Daily Life Sub-dimension:* evaluates the requirements related to coping with physical symptoms and side effects of treatment and realizing general tasks and activities. *Patient Care and Support Sub-dimension:* evaluates the needs of patients about the healthcare professionals who are sensitive to the privacy, choices and physical and emotional needs. *Sexuality Sub-dimension:* evaluates the requirements for sexuality. Calculation of scale score is done by formula. It was calculated by standardizing with the formula of “Total score x 100 / (m*(k-1)”. The total score is the sum of the scores in the sub-dimensions; m is the number of questions in the sub-dimension and the k is the number of choices in the Likert type (Aksuoglu & Şenturan, 2016).

Distress Thermometer

It was developed to measure psychosocial distress by Roth et al in 1998. On the scale the score of 0 indicates that the individual has no distress, and the score of 10 indicates that he or she has distress at the highest level. The problems on the list are collected in 5 different groups. The first group consists of daily life problems. These are sheltering, social security, work/school, transportation, child care.

In the second group, there are family problems. Spouses and children make up this group.

The third group consists of emotional problems, grief, sadness, depression and irritability. In the fourth group, problems related to faith were included and the questions about god, loss of faith and other problems were discussed. The fifth and last group consists of somatic (physical) problems. Somatic problems are pain, nausea, fatigue, sleep, walking around, bathing/dressing, respiratory disorder, mouth sore, eating, indigestion, constipation/diarrhea, urinary problems, fever, dry/itchy skin, nasal congestion, tingling in the hands/feet, bloating sensation and sexual problems. (NCNN, 2016; VanHoose et al., 2015)

Analysis of Data

The data were evaluated by using SPSS 21.00 software package. In order to examine the relationship between the descriptive characteristics of the patients and the distress

scores and support need scale mean scores, the t-test, Kruskal Wallis Variance Analysis and Mann Whitney U Test were used in independent groups. Correlation analysis was performed with the aim of examining the level of significance of the relationship between the distress scores of the patients and the support needs scale sub-dimensions. The mean and minimum maximum values were used in the distribution of scale scores. Statistical significance was accepted as $p < 0.05$.

Ethical considerations: For the research, institutional permit from Dr. Abdurrahman Yurtaslan Oncology Education and Training Hospital Education Planning Commission. The patients who would be included in the research were informed about the purpose and the application steps of the study and the approvals were received.

Results

The average age of the patients is 54.52 ± 14.49 . 44.2% of the patients are female, 85% are married, 58.8% have primary school graduates and 22.7% have high school graduates. Diagnosed diseases of the patients are; breast cancer (29.2%), gastrointestinal system cancer (25.3%), urogenital system (19.7%), lung cancer (18.1%), head and neck cancer (7.7%). 30.8% of the patients were diagnosed 4-7 months before and 29.6% of the patients were diagnosed 3 months before. 17.3% of the patients were receiving chemotherapy treatment concurrently with radiotherapy. 34.6% of the patients have chronic disease except cancer. Before RT, 25.6% of the patients had chemotherapy treatment and 19.6% of them had surgical treatment.

The rate of experiencing distress of the patients receiving radiotherapy was found to be 41.2% (distress score ≥ 4) (distress score < 4). The average score of the distress was 3.35 ± 2.01 and the average score of the distress score ≥ 4 was 5.40 ± 1.42 . The fields of distress of the patients are shown in Table 1. The fields where the patients experienced the most distress were stated as emotional problems (irritability(34.2%), depression (33.7%), worry (49.2%), sadness (35.2%)), and somatic problems (fatigue (66.8%), pain (43.2%), sleep (35.2%), nausea (31.7%), dry/itchy skin (31.7%)).

In comparison of demographic characteristics with distress scores; It was found that married patients, young patients and patients receiving

concurrent chemo-radiotherapy had higher distress scores, and patients with a diagnosis time of 8-12 months had more distress than patients with a diagnosis time of 0-3 months (Table 3) ($p \leq 0.05$).

The mean score of the patients got from the sub-dimensions of Supportive Care Needs Scale were determined as; Emotional/psychological dimension 21.25 ± 7.12 , health system and information dimension 28.38 ± 10.85 , physical and daily life dimension 14.08 ± 4.36 , patient care and support dimension 10.24 ± 3.97 and sexuality dimension 7.23 ± 3.65 .

In comparison of supportive needs and demographics, it was found that those who graduated from primary education had higher sexuality score averages than those who had university degrees, those who had a diagnosis time of 8-12 months had a higher need for patient care than those with 0-3 months, married people had higher sexuality scores than bachelors, and patients receiving concurrent CRT were found to have more support needs in all areas ($p \leq 0.05$).

Correlation coefficients for determining the relationship between supportive needs scale sub-dimensions and distress levels are given in Table 2.

Discussion

In our study, the rate of distress incidence of RT patients was determined as 41.2%. In the study by Özalp et al. (2007), distress incidence rate was stated as 59.3%. Fritzchea and Liptaia (2004) have reported in their study that 9% of patients who were receiving RT had anxiety, 9% depression, 31% social life problems and 43% had functional disability.

The most frequently stated distress fields in our study are emotional problems (irritability (34.2%), depression (33.7%), worry (49.9%), sadness (35.2%)), and somatic problems (fatigue (66.8%), pain (43.2%), sleep (35.2%), nausea (31.7%), dry/itchy skin (31.7%)). Similarly, the most commonly stated stress fields in the study conducted by VanHoose et al. (2015) were stated as anxiety, irritability, walking around and sleep.

In the study of Habboush et al. (2015), the most frequent distress fields of RT patients were reported as fatigue, feelings, daily life activities and sleep.

Table 1. Distribution of distress areas of patients

Practical Problems	n	%
Child Care	12	6
Housing	7	3.5
Insurance/financial	6	3
Transportation	34	17.1
Work/school	15	7.5
Family Problems		
Dealing with children	13	6.5
Dealing with partner	18	9
Emotional Problems		
Depression	67	33.7
Fears	55	21.5
Nervousness	68	34.2
Sadness	70	35.2
Worry	98	49.2
Spiritual/religious concerns		
Loss of faith	2	1
Relating to God	2	1
Others	1	0.5

Physical Problems		
Appearance	38	14.61
Bathing/dressing	12	6
Breathing	54	27.1
Changes in urination	21	10.6
Constipation / Diarrhoea	58	29.1
Eating	43	21.6
Fatigue	133	66.8
Feeling swollen	51	25.6
Fevers	19	9.5
Getting around	35	17.6
Indigestion	56	28.1
Memory/concentration	23	8.84
Mouth sores	53	26.6
Nausea	63	31.7
Nose dry/congested	32	16.1
Pain	86	43.2
Sexual	20	10.1
Skin dry /itchy	63	31.7
Sleep	70	35.2
Tingling in hands/feet	63	31.7

Table 2. Correlation level of patients distress level and supportive care needs

Distress level	Supportive care needs					
	Psychological	Health system and Information	Physical and daily life,	Patient care and support	Sexuality	Total
r	0.625	0.219	0.228	0.559	0.436	0.556
p	<0.001	<0.001	<0.001	<0.001	<0.001	<0.001

Table 3. Sociodemographic characteristics of th relationship between distress level

Demographic data	Disress level	F	p
Gender			
Female	1.39±0.49	1.265	0.570
Male	1.42±0.48		
Marital status			
Married	1.44±0.49	6.70	0.07
Single	1.23±0.42		
Education status			
No literate	1.45±0.50	0.501	0.735
Primary education	1.39±0.48		
High school graduate	1.47±0.50		
Undergraduate	1.33±0.48		
Master	1.33±0.51		
Chronic disease			
Yes	1.46±0.49	4.23	0.190
No	1.38±0.48		
Age			
19-32	1.33±0.48	1.226	0.295
33-50	1.35±0.48		
51-68	1.45±0.59		
Treatment			
Radiothreapy	1.06±0.41	17.25	0.001
Chemoradiothreapy	1.53±0.69		
Diagnostic time			
0-3 ay	1.37±0.48	2.50	0.53
4-7 ay	1.40±0.49		
8-12 ay	1.59±0.49		
13 ay önce	1.34±0.47		

The results of our study may be correlated with the most common side effects of RT and high psychological stress levels of patients. The least problematic area of our study is beliefs. There may be belief-related issues that are least annoying field because of in Muslim countries the existence of fatalism and the faith on role of god in subjects related the diseases. In our study, it was determined that socio-demographic and disease-related characteristics affect distress fields. In our study, the increase in the duration of the disease can be interpreted with the increased level of distress, the fear of recurrence of the disease and the reduction of expectations and hopes about treatment. Similarly, in the study of Graeff et al. (2000), it was reported that the study showed a decrease in emotional function and an increase in the incidence of depression at 6th and 12th months. In our study, younger age and marital status were found to be related to distress in accordance with the literature.

In our study, it was determined that patients needed support in all fields. Similarly, in the study of Fitch (2012), patients reported that support was needed in almost all areas. In the study of Guiliani et al. (2016), it was determined that there was a supportive need in the fields of health care system and information (52%), psychological/spiritual condition (66%), physical care (58%), patient care (24%) and sexuality (20%). In a study conducted, 36% of patients who received RT treatment stated that they have needed additional support (Faller, et al., 2003). It was stated in the literature that demographic data are associated with unmet supportive fields (Sutherland et al., 2009). In our study, it was found that the supportive needs of patients who had primary school graduates were found to be higher than those who had university graduates. Similarly, in the study of Cheah et al. (2016), patients who had primary school graduates reported more unmet needs. In our study, it was determined that patients who had a diagnosis time of 8-12 months had a higher need for patient care than those who had 0-3 month diagnosis time. In a similar study, unmet needs were found to increase after 6 months after treatment (Armes et al., 2009)

Perceptions related to the unmet needs of the patients were found to be related to distress and psychosocial well-being (Armes et al., 2009). In

our study, the perceptions related to the unmet needs of the patients were found to be related to the fields of distress levels, psychological/spiritual condition, patient care and support and sexuality. In a study conducted, symptom scores were found to be related to unmet needs (Guiliani et al., 2016). In addition, VanHoose et al. (2015) found supportive care was associated with psychological distress.

Study limitations

A cross-sectional design was used in the study to identify supportive care needs and distress level among undergoing radiotherapy patients. These data are confined to only the first week of radiotherapy treatment. Further work is needed to develop in a larger cases and in different time settings. Supportive care needs are more common in patients and the further research should evaluate the impact of needs on negative health outcomes of patients prospectively. Psychiatric consultation was requested for patients with high distress levels but the results were not followed.

Conclusions

It is important to identify the stresses experienced by the patients in different populations and to determine their supportive care needs. Our study is important for the first time to show the distress levels and supportive needs of patients receiving RT. It has been determined in the literature that there are very few intervention studies to improve patients' distress and support needs in the radiotherapy process. In order to reduce the distress level and meet the support needs, it is suggested to develop the interventions together with the diagnostic studies.

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