

## RESEARCH COMMUNICATION

# Psychological Symptoms, Illness-Related Concerns and Characteristics of Relatives of Turkish Patients with Cancer

Tarik Tuncay\*, Vedat Isikhan

### Abstract

Being the relative of a patient with cancer is often very stressful, and there is a need for information, support, and help for carers. It is also important for the relative to know that the patient receives care of a good quality. This research investigated the relationships between sociodemographic characteristics, illness related concerns and psychological symptom scores of relatives of the patients with cancer in an inpatient oncology clinic of the GATA. A Questionnaire and Symptom Distress Check List (SCL-90-R) was administered to 106 relatives of in-patients and statistically significant relationships were found between the following characteristics and psychological symptom scores: sex, education level, duration of stay in hospital, having emotional problems and having financial problems. It was established that most problems of relatives were psychological and financial ( $p < 0.05$ ). Cancer is still a great source of fear and it is evident that offering psychosocial support at a professional level in addition to medical treatment will yield more favorable results for both patients and their relatives.

**Keywords:** Patient care - relatives of cancer patients - psychological symptoms - oncology social work - Turkey

*Asian Pacific J Cancer Prev*, **11**, 1659-1667

### Introduction

Being a close relative of someone in the final phase of life is often complicated. It can be the relative's first concrete encounter with dying and death. In this situation, the relative must handle both his/her own sorrow and that of the dying person, in addition to solving a multitude of practical problems. All this in a life situation where existential questions come to a head and where it is not certain that the relative, the patient or the professional are prepared to talk about the situation. Living close to the patient and assuming responsibility for assuring that he/she feels as good as possible can be a matter of course for many relatives, while for others this can involve great sacrifices.

Cancer inevitably makes one confront many individual, physical and social problems. For many people, cancer denotes helplessness, uncertainty, guilt, abandonment, physical pain and death. The patient with cancer is fearful of death and full of anxiety about the future. Therefore, the patient with cancer may need emotional restoration for overcoming fear and contradictory feelings and psycho-social support for psychological, emotional and physical adjustment to the illness. Relatives of patients with cancer have important role at this stage. Relatives must understand the diagnosis, prognosis, and treatment in the patient if they are to participate in management decisions and to speak for the patient (Devlin, 2000). Good comprehension helps the relative to cope with

the psychological stress associated with all symptoms of cancer. Satisfaction of family members promotes favorable interactions with relatives seeking to meet the needs of the family.

A relative is someone involved in the patient's life whether they are a wife, an ex-wife, a husband, an ex-husband, a partner, a parent, a sibling, a child, a friend or any significant other. When a person is seriously ill and close to death, normal relations are often distorted and become asymmetrical. This includes the relationships among the group of relatives as well. Day-to-day caring for each other in the family may be disrupted (Ohlen et al., 2007). However, if the emotional ties are weak or the situation is too demanding, spontaneous caring may fail. Instead the relative may care out of duty, religious norms or ethical standards. More radically, relatives may withdraw from caring altogether. It is important to notice that a relative may be someone who cares, without being a caregiver. Not all relatives want to be caregivers and not all sick persons want to be cared for by a relative. For relatives of patients with cancer, the reciprocal dependencies in close relationships often become obvious. This may push relatives, not only to care and comfort the patient, but also to consider the well being of themselves; momentarily as well as in the long term. Relatives may simultaneously need support in caring for the patient, as well as mastering their own life situation and well-being during this period. Such a need exists across different health care organizations, since patients die in their homes,

in hospitals, nursing homes and in-patient hospice units. Consequently, there is a great need to understand better and address relatives' needs (Andershed and Ternestedt, 2001; Ohlen et al., 2007)

Relatives often experienced the situation as burdensome and as involving increased responsibility, which could have negative consequences such as fatigue, anxiety, agony, fear, difficulty sleeping, lack of time, loneliness, a loss of control, difficulty understanding, a feeling of helplessness, uncertainty, conflicts within the family, financial burdens, loss of dreams and/or speculations concerning the future and a new life situation (Yates and Stetz, 2000; Grbich, Parker and Maddocks, 2001; McGrath, 2001; Hudson, 2004; Milberg and Strang, 2004).

An important body of research has contributed to the understanding of the situation and needs of relatives resulted in a knowledge base of the situation for relatives. This is characterized as being fragile, with comparatively new responsibility and the demand for balance between burden and capacity, albeit with the opportunity of gaining positive values (B Andershed and Ternestedt, 2001; Hudson, 2003; Zimmermann and Rodin, 2004). Further, the needs of relatives were revealed to encompass quality assurance for patient care, the experience of feeling knowledgeable and gaining sufficient information about the process of the illness, spending time with the patient and receiving support and developing a trusting relationship with health care workers (Ohlen et al., 2007).

Borneman et al., (2003) studied quality of life of relatives of cancer patients in connection with palliative surgery and found that relatives were anxious about risks related to the operation and care after the operation. The results showed that relatives' quality of life was poorer after the operation than before. Relatives described the transition in roles involved in becoming a family caregiver and that this could be a time of uncertainty and turbulence (B Andershed and Ternestedt, 2001; Wennman-Larsen and Tishelman, 2002; Broback and Bertero, 2003). For example, relatives spent many hours checking on symptoms experienced by the patient, such as fatigue, pain, dry mouth, poor appetite, vomiting and constipation and these were experienced as difficult to manage (Aranda and Hayman-White, 2001). Payne et al., (1999) reported that the majority of relatives experienced an above normal level of psychological distress/strain and Hawkins, (2000) found that relatives (87%) experienced greater anxiety than the patient (36%) regarding the patient's anorexia. In a study by Weitzner et al., (1999), it was also found that ratings for both physical health and quality of life of relatives in palliative care were lower than ratings for relatives in curative care. Sometimes mental symptoms such as depression, confusion and hallucinations were also hard to handle. Another finding was the feeling of helplessness associated with progression of the illness, struggling to obtain the services they needed and the inability to relieve pain and discomfort (Weitzner et al., 1999; Oldham and Kristjanson, 2004).

Values related research about relatives in palliative care has tended to focus on problems and negative aspects. However, some studies have described relatives' valuable experiences including feelings of satisfaction,

thankfulness and pleasure. They could feel that coping with the situation gave meaning to the final time together with the dying person. Thus this time could be of importance to the relatives despite personal hardships. The fact that they felt of value and that they experienced an inner strength as well as other positive feelings could help them handle the situation (B Andershed and Ternestedt, 2001; Grbich et al., 2001; Proot et al., 2003; Hudson, 2004; Oldham and Kristjanson, 2004). They described how they could demonstrate their love for the patient, which was also a way of paying back what they had previously received from their loved one (Grbich et al., 2001). Relatives' sense of coherence, inner strength and fighting spirit were also found to be of importance in handling the situation (Andershed and Ternestedt, 2001; Milberg, Strang, Carlsson and Borjesson, 2003; Strang and Koop, 2003).

In patient care, an important need on the part of relatives was the assurance that the patient got care of high quality that the patient's wishes were respected and that the patient was content (Weitzner et al., 1999; Milberg et al., 2003; Mok et al., 2003). Relatives felt supported and experienced peace of mind when they knew that health care personnel were acting in their dying loved one's best interest. They could also feel that they had fulfilled their duties and responsibilities, 'they had performed what they could' (Mok et al., 2002). Dunne and Sullivan, (2000) found that the most stressful factor experienced by relatives was poor pain control (Ogasawara et al., 2003). Good palliative care could thereby decrease relatives' stress and workload and have positive effects on the family. However, many studies described how relatives felt forced to check that the patient got good care. These relatives experienced themselves as the patient's advocate, with the task of protecting the patient in different ways. They sometimes had difficulty reporting the patient's pain and how it was handled and they could withhold information from the health care personnel. Reasons for underreporting included fear of side effects, which they felt could shorten the patient's life and fear that the patient would become addicted (Ogasawara et al., 2003). Keefe et al. (2003) found that caregivers who rated their self-efficacy in helping cancer patients manage pain as high also reported lower levels of strange moods and an increase in positive moods in themselves.

There was a great need for information about the patient's condition, course of illness, symptoms and treatment and about alternatives and available resources, as well as for individualized information for relatives. Information was needed to know what to expect, to make decisions, to plan the day and to prepare for the care of the patient (Aranda and Peerson, 2001; Hudson et al., 2002; Strang et al., 2002). This knowledge also made it possible for relatives to function better as caregivers (Broback and Bertero, 2003). Giving information about details of care and the effectiveness of actions taken by health care personnel constituted straightforward interventions. They contended that the more families understood about the patient's care, the more satisfied they would be with the care. Andershed and Ternestedt (1998; 1999; 2000) were of the opinion that knowing was a prerequisite for

meaningful involvement, since relatives could then more easily choose what they were able to do and how to do this. Relatives were also afraid of not getting sufficient information and knowledge and they described how they could not have survived without information and/or support (Hudson et al., 2002). The need for information and communication also constituted main themes in many studies (Scott, 2001; Scott, Whyler and Grant, 2001; Broback and Bertero, 2003; Milberg and Strang, 2004).

Since the mid 1990s there has been a growing awareness for the need to develop a palliative care service in Turkey that would include not only pain relief and symptom control but also the psychosocial needs of the patient, their families, and relatives. Turkish people, particularly those who have migrated to urban areas where 75% of the population now live (Oguz, Miles, Buken and Civaner, 2003). With this change in socio-economic patterns fewer women are available to care for relatives in the home. Studies about problems and needs of the relatives of patients with cancer in our country are insufficient. The aim of the present study is to investigate the psychological symptoms of relatives of patients with cancer who are influenced from treatment process psychologically and in many other ways as much as the patient himself/herself and who try to give support to the care and treatment of the patient.

The present study also seeks to determine whether there is a relation between sociodemographic characteristics of the relatives of the patients and their ideas on patients, cancer experience and scores of psychological symptoms in Turkey.

The following are the hypothesis (questions) of the research:

Is there a relationship between gender of the relatives and psychological symptom scores?

Is there relationship between marital status of the relatives and psychological symptom scores?

Is there a relationship between education status of the relatives and psychological symptom scores?

Is there a relationship between the age of relatives and psychological symptom scores?

Is there a relationship between the closeness of the relatives and psychological symptom scores?

Is there relationship between the duration of accompaniment of patient by the relatives and psychological symptom scores?

Is there a relationship between the information level of relatives about the patient and psychological symptom scores?

Is there a relationship between the emotional problems experienced by relatives during care of the patient and psychological symptom scores?

Is there a relationship between financial problems of relatives and psychological symptom scores?

## **Materials and Methods**

The data source was 106 relatives of in-patients with cancer admitted to GATA Medical oncology clinic. Social worker working in the clinic has explained the aim of the study to the relatives of in-patients with cancer. Each

participant was informed, prior to the interview, about the purpose of the study, written informed consent was obtained, and participants were told that they had the right to refuse participation and could withdraw at any time.

In the study period, the number of relatives of the patients with cancer was 125. The participants were given no special inducement to participate in the study. However, since some relatives were outside of the hospital (at the time of study period), some came to the hospital after working hours, some had problems with their patients and others were against participating in the research. We could not be able to administer the questionnaire to 19 relatives. In sum, data obtained from one hundred and six relatives (n=106) were regarded as valid.

Data were obtained by Symptom Distress Check List (SCL-90) whose reliability and validity study was made and adapted to our country and the questionnaire developed by the researchers. A relative is someone involved in the patient's life whether they are a wife, an ex-wife, a husband, an ex-husband, a partner, a parent, a sibling, a child, a friend or any significant others. The term of 'relatives' in our study includes close relatives, such as parents, spouses, spouses of children, and friends of in-patients with cancer.

### *Measures*

**Questionnaire:** The questionnaire has been prepared by researchers taking into consideration the purposes of the research. It includes questions aiming to determine the sociodemographic characteristics of the relatives (gender, age, marital status, education status etc.) and some characteristics related to the illness and the patient (degree of closeness with the patient, duration of the time spent accompanying the patient, obtaining information from the physician and the nurse about the patient and the illness etc.).

**Symptom Distress Check List:** (SCL-90-R) is a scale developed by University of John Hopkins Psychometric Research Unit for determining the level of psychological distress symptoms and their extensions. As a part of the questionnaire the participants were asked to fill in the Symptom Check List, Revised Edition (SCL-90-R) henceforth referred to as SCL-90-R. The rating scale is a current, point-in-time, measurement of psychopathological dimensions, based on a 90- item self-report inventory originally developed to measure symptoms of psychological distress in medical and psychiatric patients.<sup>39</sup> The SCL-90-R comprises nine major factors or dimensions: Somatization, obsessive-compulsive symptoms, interpersonal sensitivity, depression, anxiety, hostility, phobia, paranoid ideation and psychoticism.

SCL-90-R is a usable instrument for the measurement of discomfort or lack of psychological well-being. Specifically, the SCL-90-R has demonstrated its usability in examining subclinical levels of psychological disturbances in individuals having experienced severe stressful life events like war, nuclear accidents and disasters of nature. Each item of the rating scale is rated on a 5-point scale of distress, ranging from "not at all" to "extremely".

The standard time set given with the questionnaire is “seven days including today”. In handling the SCL-90-R items several approaches were used. Each item included in the various psychological profiles based on the SCL-90-R was dichotomized, and a complaint was regarded as relevant if reported to be within the range moderate to severe (and given the value 1), and not relevant if reported to be either absent or present to a very low degree (and given the value 0).

The reliability and validity of the scale has been carried out and it is used by many researchers in Turkey (Nickel et al., 2006; Yildiz, Celebioglu, & Olgun, 2009 etc.). The lowest possible score that may be obtained with the scale is 0 and the highest is 177 (range=0-177). Interpretations were made based on Global Severity Index (GSI) obtained in this study. GSI is the best indicator of the degree and present state of the disturbance. Data analysis

The data was analyzed by the SPSS statistical package, version 17. Psychological symptom scores of the relatives were used as dependent variables. Sociodemographic characteristics of the relatives of the patient and their ideas on patients and illness were used as independent variables. This data file is available for further analysis if additional questions arise.

For the analysis of the findings, according to the type of the variables, number and percentage were used and variance analysis and t test were employed. T test was used in order to evaluate the relationship between gender, status of receiving information on the illness, emotional problems during care, and financial problems and psychological symptom scores. Variance analysis (F) was used to determine the significance of the relationship between, marital and educational status, age, closeness of the relation, duration of accompaniment and psychological symptom scores. Minimum acceptable level of significance was set at .05.

The ages of relatives were divided into four groups and statistical analyses carried out. Distribution of the minimum and maximum age and experience were taken into account. As the minimum age was 21 and the maximum was 65, age distribution was divided into four groups, namely under 30 ages, 31-40, 41-50 and 51 and over. Least-Significant Difference, among Post Hoc Multiple Difference methods, was used to determine the difference between groups.

## Results

In the evaluation of the sociodemographic characteristics of the relatives of the patients with cancer, it has been established that the majority is female, married, and graduate of university and between the ages of 41-50. They are mostly married, and with children and duration of their accompanying time varied between 1-15 days and they received information from health care personnel regarding the illness, experienced emotional problems during care and had serious financial problems due to illness (Table 1-2). The aim of this investigation was to establish whether there was a relation between certain characteristics of the relatives and their psychological symptom scores. The results obtained and

**Table 1. Socio Demographic Characteristics and Mean Symptom Scores of the Relatives**

Socio-Demographic Characteristics	No.	%	Mean Symptom Score	Test Results
Gender				T test: 3.58 *
Female	65	61.3	71.27	
Male	41	38.7	41.31	
Marital Status				F test: 0.28
Married	83	78.3	58.28	
Single	17	16.1	59.12	
Widow	6	5.6	61.27	
Education Status				F: 3.11*
Illiterate	19	17.9	98.55	
Primary school	26	24.5	75.77	
Secondary school	8	7.5	71.87	
High school	15	14.3	85.41	
University	38	35.8	45.68	
Age Groups				F: 0.46
Under 30	31	29.2	81.14	
31-40	20	18.9	80.00	
41-50	33	31.1	82.19	
51 and over	22	20.8	80.13	
Overall	106	100		

\* P<0.05

**Table 2. Comparison of Mean Symptom Scores With Respect to Characteristics of the Patients and Illnesses**

Characteristics	No.	%	Mean Symptom Score	Test Results
Closeness of the relation				F: 1.78
Sibling	23	21.7	61.14	
Parent	23	21.7	60.89	
Close relative, friend	8	7.5	59.37	
Spouse of child	52	49.1	62.22	
Duration of Accompaniment Period				F : 3.57 *
1-15 days	47	44.3	72.31	
16 days-3 months	43	40.6	86.23	
4 months or over	16	15.1	99.85	
Status of Receiving Information				T Test: 0.09
Yes	61	57.5	63.52	
No	45	42.5	55.45	
Emotional Problems During Care				T Test: 4.60 *
Yes	73	68.9	71.87	
No	33	31.1	32.72	
Financial Problems				T Test: 3.83 *
Yes	84	79.2	83.25	
No	22	20.8	49.50	
Overall	106	100		

\* P<0.05

their interpretations are presented below.

Undoubtedly, being the relative of a patient with cancer is often very stressful. Many studies have drawn attention to the need relatives have for information, support, and help in caring for the patient. It is also important for the relative to know that the patient receives care of a good quality. Participation in the care is considered positive by both the patient and the relative. Knowledge about the patient’s condition makes it easier for the family to deal with the stresses it faces. Insight into the situation also increases the possibility that members of the family

will talk with each other and experience intimacy and closeness during the final stages of life (Andershed and Ternstedt, 1999).

The health status of relatives of the patients with cancer before and after care has been compared, with their health being better before the onset of giving care and the most frequent complaints was reported to be sleep problems, weakness, lack of energy, weight and nutrition problems (Zakowski et al., 2003; Link, Robbins, Mancuso and Charlson, 2004; DeVita, Hellman and Rosenberg, 2005). In our study, mean score of psychological symptom was found to be 58.68 in the relatives (range 0-177), which was lower than the mean score accepted for adults. According to this result, it may be stated that relatives of patients in oncology clinics do not have high psychological symptom scores. This may be attributed to the various factors: namely, duration of hospitalization is short, problems experienced by the patient are stressed, neglecting their own problems, illness is accepted as fate, treatment given is considered adequate, and there is no other option for the management of these patients. Our results are inconsistent with those of Grbich et al., (2001), Mok et al., (2003), and Zakowski et al., (2003).

## **Discussion**

In many studies, those providing care were primarily women (e.g. Emanuel et al., 1999), but it was also shown that men were active in the care (Rhodes and Shaw, 1999). Female relatives are subjected more to various experiences of the patients such as pain, vomiting, fatigue than male relatives. It has been assumed in this study that this may have an impact on psychological symptom scores and first hypothesis was formulated accordingly, namely '*is there a relationship between gender of the relatives and psychological symptom scores?*' When hypothesis was tested, actually a difference was found between females and males ( $p < 0.05$ ). While the mean score of females was 71.3, it was 41.3 in males, with a statistically significant difference. The reasons for this significant difference may be that women are constantly attending the patient as they are mostly housewives as well as being forced to assume some responsibilities of the man they are caring for. As to male patient relatives, they may leave home for some time due to their job, leaving the problems behind as well. Even if it is the woman who is ill, as she keeps up fulfilling her responsibilities at home due to her traditional role, she is under more pressure. Our finding is consistent with the results of Emanuel et al., (1999), Rhodes and Shaw, (1999), and Zakowski et al., (2003).

It has also been assumed that marital status of patient relatives would be influential on their scores. The second hypothesis was based on this assumption: '*There is a relation between marital status of relatives and psychological symptom scores*'. When this hypothesis was tested, no such relation was found ( $p > 0.05$ ). In our society, being married or single imposes different roles and responsibilities to people. Our results may be attributed to coping methods of patient relatives and personal differences. It may also be that 49% of the attendants of married people are spouses and children while those of

single people are mostly friends and acquaintances. This result is consistent with the findings of Işıkhan et al (1998).

Education status is an important variable that may influence the psychological symptom scores. It has been established that relatives at low education status find it more difficult to accept the condition of the patient, do not act realistically and hardly grasp issues such as the course and treatment of the illness. Third hypothesis of our investigation was hence that '*is there a relation between education status of the relatives and the psychological symptom scores?*' When the hypothesis was tested, it was, in fact, found that there was a statistically significant relation between education status and psychological symptom scores. ( $p < 0.05$ ). Least-Significant Difference, among Post Hoc Multiple Difference methods, was used to determine the difference between groups. Psychological symptom scores of illiterate relatives was found to be higher (98.55) compared to others (graduate of primary school=75.77, secondary school=71.87, high school=85.41 and university graduate=45.68). It may be said that the higher the education level the lower the psychological symptom scores. This may be due to the fact that conscious coping mechanisms develop with education and that their social and material means become better. Studies also described that have a lower level of education (Weitzner et al., 1999; Scott, 2001; Cameron, Franche, Cheung and Stewart, 2002) could also increase the difficulties relatives experienced. The education level of the relatives of patients with cancer is important for understanding the behavioral changes of patients during treatment process. Our results are in keeping with those of Andershed and Ternstedt, (2001); Strang et al., (2002); Link et al., (2004); Hudson, (2004), and Winterling et al., (2004); Andershed, (2006).

Some researchers described that to be a young caregiver (Payne et al., 1999; Chan and Chang, 2000; Goldstein et al., 2004) could increase the difficulties relatives experienced. When age distribution of patient relatives was considered, it was established that those between 41 and 50 formed the largest group (31.1%), to be followed by those under 30 and over 51. The fourth hypothesis of our investigation was formulated as follows: '*is there a relation between the age of the relatives and psychological symptom scores?*' However, when it was tested, it turned out that there was no difference between different age groups with regard to psychological symptom scores ( $p > 0.05$ ). The reason for this may be that relatives are usually spouses and the children of the patient and experiences gained by relatives with age on cancer illness may be influential. This result is consistent with results of the Chan and Chan, (2000), Goldstein et al., (2004), Milberg and Strang, (2004).

Many spouses are plagued by worries about the patients' comfort, emotional responses to the illness, the patients' coming death as well as practical problems. This is an emotionally intense, exhausting, and singular experience, set in a world apart from everyday life pattern. Many relatives become caregivers, some in their own home, which means that they become the person with primary responsibility for providing care for their dying relative (Wennman-Larsen & Tishelman, 2002)

and their highest care priority is to give the patient comfort (Winterling et al., 2004). When the closeness of the relatives with the patient was examined, it was established that the majority were spouse and children (49.1%). Siblings accounted for 21.7% and parents for 21.7%. It was assumed that the degree of closeness of the relative may be influential on psychological symptom scores and fifth hypothesis was formulated accordingly. 'Is there a relation between the closeness of the relative and psychological symptom scores?' When it was tested, no such relation was found ( $p>0.05$ ). In conclusion, it may be said that cancer influences all members of the family similarly. It is thought that in such a chronic and anxiety and fear provoking illness as cancer, spouses are the strongest supporters of the patient in the struggle against the disease and that the attendant family member is usually the spouse. If a member of a family requires treatment as an inpatient or outpatient, it is usually the spouse or parents who accompany the patient. Although there may be conflicts and adverse events in the family, spouse is the most important source of support in the family. In an investigation carried out by Eylon (2001), it has been established that of the relatives accompanying the patients, spouse accounts for 42.5%. Our findings are consistent with this result and also with results of Işıkhan, (1998); Andershed and Ternstedt, (1999), Winterling et al., (2004), Andershed, (2006)

Patients' relatives staying in oncology clinics for a short period usually help the patients in procedures of admission to the hospital, drug administration and treatment. As the duration of hospitalization increases, they begin to feel that problems experienced by other patients and their relatives (fatigue, pain, death, difficulties encountered in treatment etc.) exert its effect on them and influence their psychological state. Sixth hypothesis of the investigation was that 'is there a relation between the period of hospitalization of the relatives and psychological symptom scores?' When the hypothesis was tested, a statistically significant relation was found between the period of accompanying patients and the psychological symptom scores ( $p>0.05$ ). In order to determine whether there is a difference between groups, Least-Significant difference was used among Post Hoc Multiple Difference Methods. Mean psychological symptom scores of relatives of patients for 1-15 days were found to be lower than others (72.31). (16 days-3 months=86.23, 4 months and more=99.85. As the duration of accompanying the patients is prolonged, relatives face many problems such as not being able to utilize their free time, not having any time for themselves and postponing many things, creating distress in them. Staying in a clinical environment for a long time may lead to the emergence of many problems. It has been reported in the literature that initiation of a new treatment modality and recurrence of the illness increases the duration of hospitalization, having an adverse effect on the patient and the family. Our findings are in keeping with those of Noone et al., (2000), Link et al., (2004), Winterling et al., (2004).

Andershed and Ternstedt, (1999) found that relatives tried to increase their understanding of the patient's situation by finding out how ill the patient was, how patient

viewed his or her situation, and what assistance he or she needed. 'To know' was not only a part of the relatives' involvement, but also a prerequisite for involvement in the light. Relatives are dependent on others; particularly the patient and health care personnel, in obtaining knowledge about the situation, and thereby have the possibility of supporting the patient in a positive way. The training and informing of the relative is also important in order that burnout does not occur in family members and they can cope with problems related to the illness better. When informing the relatives, a plain language should be used and unnecessary information should not be offered considering that illness process is severe and relatives have to bear a considerable weight in this process. Information should involve such issues as the prognosis, the causes of symptoms, their importance and control, patient care methods, probable sudden changes and how to behave in these circumstances and where to refer for help (Payne et al., 1999; Noone et al., 2000; Link et al., 2004 ). We also tried to determine whether relatives received information from the physicians and nurses regarding the patients and their illness and established that 57.5% of the relatives received such information while 42.5% did not do so. The seventh hypothesis of the investigation was that 'is there a relation between psychological symptom scores and the status of being informed by the physicians and nurses?' When we tested the hypothesis, it turned out that there was no statistically significant relation between psychological symptom scores and the status of being informed ( $p>0.05$ ). While mean psychological symptom score was 60.69 in those informed on the subject, it was 55.45 in those who were not informed. This result may be due to the fact that education level of the relatives was high and they had confidence in health care personnel about cancer and its treatment. Our result is compatible with those of Payne, (1999), Noone et al., (2000), Zakowksi, (2003).

Vulnerability was illustrated on a scale where burden was defined as vulnerability-increasing factors (care burden, restricted activities, fear, insecurity, loneliness, facing death and lack of support) and capacity as vulnerability-decreasing factors (continuing previous activities, hope, keeping control, satisfaction and good support). Relatives' emotional stress could increase if caregiving caused limitations in valued activities/interests, irrespective of care workload (Cameron et al., 2002; Goldstein et al., 2004). Cancer patients and their relatives mutually try to hide the various problems from each other in order that the other side does not feel sorry. This may lead to communication problems, which may have an adverse effect on the support and help they may give to each other. It is normal for cancer patients to feel sorrowful and mournful due to the illness and changes it causes in life. Yet, this should not be at such a degree that it will prevent the acceptance of the illness and adaptation to treatment. Payne et al., (1999) reported that the majority of relatives experienced an above normal level of psychological distress. The fact that relatives are forced to stay away from their close acquaintances when they attend patients and have to spend time continuously with health care personnel and relatives of the other patients may bring about the emergence of some

emotional problems. Accordingly, eighth hypothesis of the investigation was formulated as follows: '*is there a relation between the presence of emotional problems of the relatives and psychological symptom scores?*' When it was tested, a statistically significant relation has been found between emotional problems and psychological symptom scores ( $p < 0.05$ ). Mean psychological symptom score was 71.87 in relatives who reported experiencing emotional problems whilst it was 32.28 in those without emotional problems. This finding is in agreement with those of Hawkins, (2000), Işıkhan, (1998), Isikhan et al., (2001), Ruzsniowski, (2009), and Tsigaropoulos et al., (2009).

The treatment of cancer is a long and tiring process. As patients in our country are usually covered by social security, they do not have to pay many expenses. However, as treatment takes a long time, relatives may experience financial difficulties in coming to the hospital and other problems. In our study, it has been postulated that the majority of relatives are faced with financial problems, influencing their psychological health adversely. Hence, ninth hypothesis of the study was formulated as follows: '*There is a relation between the severity of financial problems experienced by relatives and psychological symptom scores*'. When this hypothesis was tested, a statistically significant relation has been found between psychological symptom scores and financial problems ( $p > 0.05$ ). Mean psychological symptom score of relatives who have financial difficulties was 83.25 while that of relatives without such problems was 44.50. The fact that patients focus on their illness and themselves may lead the relatives to assume all responsibility and hence to experience financial difficulty. This finding is in agreement with those of Francoeur (2001), Milberg and Strang (2004), Tsigaropoulos et al., (2009).

Cancer is still a great source of fear and it is an expected result that it gives rise to many psychosocial and economic problems. Therefore, it is evident that offering psychosocial support at a professional level in addition to medical treatment will yield more favorable results. Professional support should be offered to the patients and their relatives starting from the step of diagnostic procedures in order that the intensity of adverse emotions when they first learn the diagnosis is decreased and healthy coping mechanisms can be developed. The aim of the present study is to investigate the psychological symptoms of patient relatives who are influenced from treatment process psychologically and in many other ways as much as the patient himself/herself and who try to give support to the care and treatment of the patient. Our study showed that the mean psychological symptom score of relatives was found to be 58.68 (range 0-177), which is lower than the normal mean accepted for an adult (70-80). According to this result, relatives of the patients in the oncology clinic do not have high psychological symptom scores. It has been established that variables with an effect on psychological symptom scores are gender (being female), educational status (being illiterate), duration of time spent accompanying the patient, (4 months or more), and experiencing emotional and financial problems during care ( $p < 0.05$ ).

It was also seen that the family's feelings of security

and trust in the professional were found to be of great importance (Andershed and Ternstedt, 2000; Zakowski et al., 2003; Andershed, 2006). This should be of particular significance for poorly functioning families with a weaker sense of coherence and with a smaller social network, where the experience of security and trust conveyed by the care professional can be the factor that adds to and strengthens the family's resources. Our results also showed that identification of the family's situation and need for support could be easier if the professional's attitude was characterized by respect, openness and collaboration that could thereby inspire trust and security. *If we do not care for these family members at this difficult time in their lives, they may well become patients later on.* However, it can be said that the collective evidence is unequivocal; good patient care, communication, information and the attitude of the personnel are of decisive importance regarding satisfaction on the part of relatives.

Starting from the onset of the illness, in each important period or stage, relatives of the patient with cancer experience the fear, anxiety and anger related to that period. In our study, it has been observed that relatives try to keep away from the patient with the fear of contracting the disease in addition to other causes. Relatives experience many contradictory feelings since they want to display a more optimistic and cheerful attitude towards the patient although they are very sad meanwhile. Dealing with the care of the patient with cancer may lead the relatives to feel depressed, weaken their immune system and increase the probability of their becoming ill, rendering the family members in need of help themselves.

In brief, each crisis experienced by the cancer patient influences the family and relatives as well. Relatives are affected mostly at diagnosis stage, when a new treatment is instituted, during treatment process and recurrence of the illness and death. The experience of cancer may lead to socially disruptive effects on the patient's family as well as psychologically damaging ones. Therefore, primary function and duty of the social worker employed in oncology clinic should be helping patients and their relatives in coping with the problems they are faced with. Attempts to solve problems may be directed towards providing information about illness and its symptoms, meeting needs relatives and sharing feelings as well as informing the patients and relatives on social resources and helping them to use these resources.

Psycho-social support groups may be planned for the relief of psychological and financial problems experienced by the relatives. Such a group study may contribute to the determination of issues especially relevant to relatives of patient and hence to finding solutions. Moreover, it will also contribute to development of the support of relatives to the patient via becoming more informed and their finding a new source of social support by cooperating with people who have problems in common with them (Fainsinger, Nunez-Olarte and Demoissac, 2003; Tuncay, 2010).

In the professional support offered to relatives, particularly to first degree of relatives, relieving the feeling of loss of a close one and enhancing the positive aspects of the families should be emphasized. Thus, some emotional

problems that may be experienced by relatives may be alleviated. Oncology social worker employed at the clinic should prepare an intervention plan in the attempt to solve the problems of relatives of the patients. They must help in the establishment of a healthy communication between relatives and the patient. Professional interventions should stress the potentially strong aspects of the family and the patient in the framework of the empowerment approach.

## References

- Andershed B (2006). Relatives in end-of-life care--part 1: a systematic review of the literature the five last years, January 1999-February 2004. *J Clin Nurs*, **15**, 1158-69.
- Andershed B, Ternstedt BM (2001). Development of a theoretical framework of understanding about relatives' involvement in palliative care. *J Adv Nurs*, **34**, 554-62.
- Andershed B, Ternstedt BM (1998). Involvement of relatives in the care of the dying in different care cultures: Involvement in the dark or in the light? *Cancer Nurs*, **21**, 106-16.
- Andershed B, Ternstedt BM (1999). Involvement of relatives in care of the dying in different care cultures: Development of a theoretical understanding. *Nurs Sci Q*, **12**, 45-51.
- Andershed B, Ternstedt BM (2000). Being a close relative of a dying person. Development of the concepts "involvement in the light and in the dark". *Cancer Nurs*, **23**, 151-9.
- Aranda S, Peerson A (2001). Caregiving in advanced cancer: lay decision making. *J Palliat Care*, **17**, 270-6.
- Aranda SK, Hayman-White K (2001). Home caregivers of the person with advanced cancer: an Australian perspective. *Cancer Nurs*, **24**, 300-7.
- Borneman T, Chu DZ, Wagman L, et al (2003). Concerns of family caregivers of patients with cancer facing palliative surgery for advanced malignancies. *Oncol Nurs Forum*, **30**, 997-1005.
- Brockback G, Bertero C (2003). How next of kin experience palliative care of relatives at home. *Eur J Cancer Care*, **12**, 339-46.
- Cameron JI, Franche RL, Cheung AM, et al (2002). Lifestyle interference and emotional distress in family caregivers of advanced cancer patients. *Cancer*, **94**, 521-7.
- Chan CW, Chang AM (2000). Experience of palliative home care according to caregivers' and patients' ages in Hong Kong Chinese people. *Oncol Nurs Forum*, **27**, 1601-5.
- DeVita VT, Hellman S, Rosenberg SA (2005). *Cancer, principles & practice of oncology* (7th ed.). Philadelphia, PA: Lippincott Williams & Wilkins.
- Devlin J (2000). Pain assessment in the seriously ill patient: can family members play a role? *Crit Care Med*, **28**, 1660-1.
- Dunne K, Sullivan K (2000). Family experiences of palliative care in the hospital setting. *Int J Palliat Nurs*, **6**, 170-8.
- Emanuel EJ, Fairclough DL, Slutsman J, et al (1999). Assistance from family members, friends, pain care givers and volunteers in the care of terminally ill patients. *N Eng J Med*, **23**, 956-63.
- Eylen B (2001). *Bilgisel danışmanın kanser hastalarının ailelerinin sosyal destekleri üzerine etkisi (The influences of informational consultation on the ability of social support of families with cancer)*. Ankara university institutes of social sciences: (Unpublished Ph.D.Thesis).
- Fainsinger RL, Nunez-Olarte JM, Demoissac DM (2003). The cultural differences in perceived value of disclosure and cognition: Spain and Canada. *J Palliat Care*, **19**, 43-8.
- Francoeur RB (2001). Reformulating financial problems and interventions to improve psychosocial and functional outcomes in cancer patients and their families. *J Psychosoc Oncol*, **19**, 1-20.
- Goldstein NE, Concato J, Fried TR, et al (2004). Factors associated with caregiver burden among caregivers of terminally ill patients with cancer. *J Palliat Care*, **20**, 38-43.
- Grbich C, Parker D, Maddocks I (2001). The emotions and coping strategies of caregivers of family members with a terminal cancer. *J Palliat Care*, **17**, 30-6.
- Hawkins C (2000). Anorexia and anxiety in advanced malignancy: the relative problem. *J Hum Nutr Diet*, **13**, 113-7.
- Hudson P (2003). A conceptual model and key variables for guiding supportive interventions for family caregivers of people receiving palliative care. *Palliat Support Care*, **1**, 353-65.
- Hudson P (2004). Positive aspects and challenges associated with caring for a dying relative at home. *Int J Palliat Nurs*, **10**, 58-65.
- Hudson P, Aranda S, McMurray N (2002). Intervention development for enhanced lay palliative caregiver support - the use of focus groups. *Eur J Cancer Care*, **11**, 262-70.
- Isikhan V, Guner P, Komurcu S, et al (2001). The relationship between disease features and quality of life in patients with cancer - I. *Cancer Nursing*, **24**, 490-5.
- İşikhan V, Kömürçü S, Ahmet Ö, et al. (1998). Kanser hastalarının sosyal destek sistemleri, benlik saygıları ve bazı ruhsal belirti düzeyleri (Social support, self esteem and some psychological symptoms of cancer patients). *J Turkish Hematology Oncol*, **8**, 215-21.
- Keefe FJ, Ahles TA, Porter LS, et al (2003). The self-efficacy of family caregivers for helping cancer patients manage pain at end-of-life. *Pain*, **103**, 157-62.
- Link LB, Robbins L, Mancuso CA, et al (2004). How do cancer patients who try to take control of their disease differ from those who do not? *Eur J Cancer Care*, **13**, 219-26.
- McGrath P (2001). Caregivers' insights on the dying trajectory in hematology oncology. *Cancer Nurs*, **24**, 413-21.
- Milberg A, Strang P (2004). Exploring comprehensibility and manageability in palliative home care: an interview study of dying cancer patients' informal carers. *Psychooncology*, **13**, 605-18.
- Milberg A, Strang P, Carlsson M, et al (2003). Advanced palliative home care: next-of-kin's perspective. *J Palliat Med*, **6**, 749-56.
- Mok E, Chan F, Chan V, et al (2002). Perception of empowerment by family caregivers of patients with a terminal illness in Hong Kong. *Int J Palliat Nurs*, **8**, 137-45.
- Mok E, Chan F, Chan, V, et al (2003). Family experience caring for terminally ill patients with cancer in Hong Kong. *Cancer Nurs*, **26**, 267-75.
- Nickel M, Cangoez B, Bachler E, et al. (2006). Bioenergetic exercises in inpatient treatment of Turkish immigrants with chronic somatoform disorders: a randomized, controlled study. *J Psychosom Res*, **61**, 507-13.
- Noone I, Crowe M, Pillay I, et al (2000). Telling the truth about cancer: views of elderly patients and their relatives. *Ir Med J*, **93**, 104-5.
- Ogasawara C, Kume Y, Andou M (2003). Online exclusive: family satisfaction with perception of and barriers to terminal care in Japan. *Oncol Nurs Forum*, **30**, E100-5.
- Oguz NY, Miles SH, Buken N, et al (2003). End-of-life care in Turkey. *Camb Q Hlthc Ethics*, **12**, 279-84.
- Ohlen J, Andershed B, Berg C, et al (2007). Relatives in end-of-life care--part 2: a theory for enabling safety. *J Clin Nurs*, **16**, 382-90.
- Oldham L, Kristjanson LJ (2004). Development of a pain management programme for family carers of advanced



- cancer patients. *Int J Palliat Nurs*, **10**, 91-9.
- Payne S, Smith P, Dean S (1999). Identifying the concerns of informal carers in palliative care. *Palliat Med*, **13**, 37-44.
- Proot IM, Abu-Saad HH, Crebolder HF, et al (2003). Vulnerability of family caregivers in terminal palliative care at home; balancing between burden and capacity. *Scand J Caring Sci*, **17**, 113-21.
- Rhodes P, Shaw S (1999). Informal care and terminal illness. *Hlth Soc Care Community*, **7**, 39-50.
- Ruszniewski M (2009). Healthcare personnel and patient families. *Psycho Oncol*, **3**, 118-24.
- Scott G (2001). A study of family carers of people with a life-threatening illness. 2: implications of the needs assessment. *Int J Palliat Nurs*, **7**, 323-30.
- Scott G, Whyler N, Grant G (2001). A study of family carers of people with a life-threatening illness 1: the carers' needs analysis. *Int J Palliat Nurs*, **7**, 290-1.
- Strang VR, Koop PM (2003). Factors which influence coping: home-based family caregiving of persons with advanced cancer. *J Palliat Care*, **19**, 107-114.
- Strang VR, Koop PM, Peden J (2002). The experience of respite during home-based family caregiving for persons with advanced cancer. *J Palliat Care*, **18**, 97-104.
- Tsigaropoulos T, Mazaris E, Chatzidarellis E, et al (2009). Problems faced by relatives caring for cancer patients at home. *Int J Nurs Pract*, **15**, 1-6.
- Tuncay T (2010). Support groups in coping with cancer (Kanserle başetmede destek grupları). *Toplum ve Sosyal Hizmet*, **21**, 59-71.
- Weitzner MA, McMillan SC, Jacobsen PB (1999). Family caregiver quality of life: Differences between curative and palliative cancer treatment settings. *J Pain Symptom Manage*, **17**, 418-28.
- Wennman-Larsen A, Tishelman C (2002). Advanced home care for cancer patients at the end of life: a qualitative study of hopes and expectations of family caregivers. *Scand J Caring Sci*, **16**, 240-7.
- Winterling J, Wasteson E, Glimelius B, et al (2004). Substantial changes in life: Perceptions in patients with newly diagnosed advanced cancer and their spouses. *Cancer Nurs*, **27**, 381-8.
- Yates P, Stetz KM (2000). Families' awareness of and response to dying. *Clin J Oncol Nurs*, **4**, 46.
- Yildiz A, Celebioglu A, Olgun H (2009). Distress levels in Turkish parents of children with congenital heart disease. *Australian J Advanced Nur*, **26**, 39-46.
- Zakowski SG, Harris C, Krueger N, et al (2003). Social barriers to emotional expression and their relations to distress in male and female cancer patients. *Br J Health Psychol*, **8**, 271-86.
- Zimmermann C, Rodin G (2004). The denial of death thesis: sociological critique and implications for palliative care. *Palliat Med*, **18**, 121-8.