

## RESEARCH ARTICLE

# Symptom Frequency of Children with Cancer and Parent Quality of Life in Turkey

Asli Akdeniz Kudubes<sup>1\*</sup>, Murat Bektas<sup>2</sup>, Ozlem Ugur<sup>1</sup>

### Abstract

**Background:** This research was planned with the aim of determining the effect of symptom frequency of children with cancer on the quality of life of their parents. **Materials and Methods:** In gathering the research data, the Child and Parent Information Form, the Symptom Evaluation Form and the Family Version of Life Quality Scale in Cancer Patients were used. Evaluation was made by using percentage calculations, Kruskal Wallis test, Bonferroni adjusted t-test and Bonferroni adjusted Mann-Whitney U test. The significance level was accepted as 0.005. **Results:** Some 37.6% of the participant children were female and 62.4% were male, with an average age of 10.2±4.5. While 41.0% were newly diagnosed, 46.2% were in remission and 12.8% was in relapse. Highly significant differences were detected according to the symptom frequency with parent physical and psychological health, social anxiety, and spiritual wellness sub-dimensions, as well as total point averages. **Conclusions:** It is thought that following up the symptoms that might develop depending on cancer diagnosis and treatment and implementing nursing initiatives aimed at reducing the symptoms, knowing the importance of life quality, maintaining measures aimed at life quality and planning initiatives to increase the life quality will play a key role in maintaining and developing the health of Turkish paediatric oncology patients and their parents.

**Keywords:** Quality of life - symptom frequency - cancer child - family - symptom frequency and quality of life

*Asian Pac J Cancer Prev*, 15 (8), 3487-3493

### Introduction

Cancer is one of the important health problems in developed and under-developed countries. The number of cancer children and adults is gradually increasing in world population (Peter and Bernard, 2008). While childhood cancers constitute approximately 0.5-1% of total cancers, this rate differs depending on age periods. It is estimated that the new case number will be 11,630 in children among 0-14 ages in America (American Cancer Society, 2013). Childhood cancers five-year survival now exceeds 70-80% (Vegian et al., 2012). Of the cancers seen in a human being's lifetime, 1-2% are diagnosed in children. In Turkey, 2500-3000 children under the age of 15 are newly diagnosed with cancer each year (Emir, 2009). Depending on both the disease and the treatment, a great many of physical and psychosocial problems are encountered in cancer child (Bessel, 2001). In literature, it is stated that determining the physiological and psychosocial changes that might occur in patient child, planning and implementing the initiatives aimed at this issue make a positive effect on the health of child and the family in disease period (Varni et al., 2001).

Quality of life comprises such components as satisfaction with life, individual wellness, happiness,

functional adequacy and social wellbeing (Varni et al., 2001; 2002). Along with having importance in individuals and diseases of all ages, the concept of life quality is a subject that must be evaluated primarily in cancer children (Varni et al., 2001; Arslan et al., 2013).

The increase of the individuals diagnosed with cancer, extension of patients' survival time in parallel with the developments in diagnose and treatment methods caused family members of cancer patients to participate in care process and/or taking more care of the patients (Kitrungrote and Cohen, 2006; Mystakidou et al., 2007). According to "family systems theory", when a disease appears on a family, it does not only appear on an individual, this effect includes all family systems. For this reason, it can be said that the cancer is a family disease (Harris et al., 2010; Yakar and Pinar, 2013). Family members', who carry out home care for cancer patient, leaving their own health and needs aside and tending their all energy to maintain the care of their patient, pain management, patient mobilization, meeting daily life activities, contacting with health personnel, symptom management, providing transfer, meeting needs such as implementing medication at home result in both patients' and their relatives' health to be effected negatively (Lambert et al., 2012; Turkoglu and Kilic, 2012). With diagnose and starting to the treatment

<sup>1</sup>Department of Oncology Nursing, <sup>2</sup>Department of Pediatric Nursing, Faculty of Nursing, Dokuz Eylul University, Izmir, Turkey  
\*For correspondence: [peditriccan@gmail.com](mailto:peditriccan@gmail.com)

in paediatric oncology patients, disease event enters in the life of family members, impairs their daily order, causes conflict about their social roles, results in tension in domestic relations, restricts their daily activities, impairs their health and causes economic loss for them, impairs the child's and family's physical, emotional and economic balances, prevents them from being satisfied of life and reduces their life quality (Bergkvist and Wengstrom, 2006; Hassett, 2010; Bevans and Sternberg, 2012; Gaugler et al., 2012; Lambert et al., 2012; Turkoglu and Kilic, 2012).

In the results of the researches carried out in order to determine the symptoms that affect the life quality of cancer patients basing on chemotherapy; it is discovered that they most frequently experienced pain, nausea and weakness, loss of appetite, alopecia, vomiting, fatigue, diarrhea, sleep withdrawal and digestive problems (Hedstrom et al., 2003; Gibson et al., 2005; Bergkvist and Wengstrom, 2006; Whitsett et al., 2008). It is found that the disorders related to such symptoms create a negative effect on the life quality of cancer patients and may reduce the compliance to the treatment suggestions (Stein et al., 2003). Frequent hospitalization, problems related to cancer treatment, pains that are not stopped, loss of self-control, inability to do basic activities, being hospitalized and not being able to meet the playing need because of various treatments, being separated from friends and school negatively affects the child's life quality. Cancer children experience the symptoms intensely because of the side effects of chemotherapy and radiotherapy as much as the symptoms resulted from the very disease process. While disorders related to such symptoms create a negative effect on the life quality of the children, they reduce the compliance to the treatment suggestions (Bergkvist and Wengstrom, 2006).

It is stated that the disease, side effects and complications resulting from the treatment, repeated hospitalization, treatment's lasting too long, and disease's causing metastasis causes patients' wellness to impair, their family/marriage/business life, health condition and social life to be affected negatively from this process; caregivers experience more emotional confusion, tension, anxiety, depression, fatigue, role conflict, social isolation and problems than the patients; different psychiatric problems and advanced level of anxiety problems such as stress disorder after trauma may appear on care givers and as a result of these, their immune systems is impaired and physical disease risks are generated (Carter, 2005; Gaugler et al., 2005; Grov et al., 2005; Dumont et al., 2006; Given et al., 2006; Kitrungrrote and Cohen, 2006; Langer et al., 2007; Mystakidou et al., 2007; Simmons, 2007). In litterateur, it is stated that as the problems of the patients increase and as the symptoms become more uncontrollable, the burden, depression, tendency of anxiety and sleep disorders of family members increase and their life quality reduces (Carter, 2005; Grov et al., 2005; Dumont et al., 2006; Mystakidou et al., 2007). Mothers participate more in care of child during the disease and working mothers have to quit their jobs. While these mothers cannot allow time for their own care and meet their own needs, they also delay their other healthy children's care, they cannot carry out housework or social

activities and this situation causes their care burden to increase (Karasuya et al., 2000; Hoekstra et al., 2001). Han (2003) stated in his study carried out with mothers who performs care for their cancer children that as the time passes after the diagnosis, mothers' psychosocial adaptation gets better and their anxieties reduce.

The disease or the problems resulted from treatment may affect morbidity, self-care ability, maintaining the treatment and life quality. For this reason, to prevent these complications, to make determination in early period and symptom control carry importance in nursing care. An important subject in patient initiatives is medical instruction. This instruction will reduce the doubt, fear and loss in patients and help to increase the life quality (Demirbag et al., 2013).

While there are studies conducted in order to evaluate the life quality of cancer patients in Turkey and the world, there is not adequate number of study evaluating the life quality of paediatric cancer patient relatives in Turkey (Tanir, 2011; Arslan et al., 2013). For this reason the aim of the research is; to determine the effect of symptom frequency of cancer children on life quality of their parents.

## Materials and Methods

### *Aim*

This descriptive, cross-sectional study was conducted to determine the effect of symptom frequency of cancer children on life quality of their parents.

### *Population and sample*

By using the point averages in the study of Karakaplan and others (2012) and by taking Type I error 0.05, Type II error 0.20 (80% POWER) in GPOWER statistical analysis program, it was determined that the necessary sample size is 60 persons. In order to indicate the relations among the variables in the study more clearly, it is planned to include 100 persons to the study. In the study, parents of 117 cancer children who applied to a training and research hospital and to a university hospital between the dates of 1<sup>st</sup> December 2013-31<sup>st</sup> January 2014 were contacted.

Research inclusion criteria: 1) having a child who is diagnosed with cancer and is between 0-18 ages, 2) To be the primer responsible for the care of child, 3) To be literate, 4) To accept to participate in the research voluntarily.

### *Data collecting instruments*

Child and Parent Information Form: "Child and Parent Information Form" that is improved by basing on litterateur was consisted of 8 questions including the children's socio-demographic features, diagnosis, disease phase, treatments they received, period of receiving diagnosis, treatment period, ages of parents and sex (Collins et al., 2000; Woodgate and Degner, 2003; Woodgate et al., 2003).

Cancer Patient Caregiver Family Members' Life Quality Scale: Life Quality Scale Family Version which was improved for cancer patients is consisted of 37 articles. The scale, developed by Ferrell and Grant (2005)

to evaluate the cancer patients' life quality, was adapted in order to predispose the life quality of family members to be measured. The scale, consisted of 37 articles, consisted of four sub-dimensions that are; physical health condition, psychological health condition, social anxieties and spiritual (emotional) wellness condition. After being reviewed and organized, the scale, which is adapted to evaluate the life quality of family members, was tested between 1994-1998 years in a study conducted with 219 cancer patient relatives. Test-retest reliability results of the study was found  $r=0.86$  and internal consistency Alpha value was found  $r=.69$ . When scale's article total point correlations are examined; it is determined that article correlation values are between 0.00-0.64. Scale's total Cronbach Alpha coefficient was calculated 0.90. Factor analyses were corrected for scale's four sub-dimensions. Scale's validity and reliability in Turkey was checked by Figen Okcin (2007). As a result of validity and reliability analyses, scale's total Cronbach Alpha coefficient was calculated 0.90. When scale's article total point correlations are examined; article correlation values are found to be between 0.00-0.64. Study's test-retest reliability results was found  $r=0.86$ .

**Physical Health Condition Sub-Dimension:** This sub-dimension includes 1, 2, 3, 4, 5 numbered articles aimed at determining the change in physical health of cancer patient's relatives.

**Psychological Health Condition Sub-Dimension:** This sub-dimension includes articles numbered 6, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 17, 18, 19, 20, 21 that are aimed at determining the change in psychological health of cancer patient's relatives.

**Social Anxieties Sub-Dimension:** This sub-dimension includes the articles numbered 22, 23, 24, 25, 26, 27, 28, 29 and 30 that are aimed at determining the social conditions of cancer patient's relatives.

**Spiritual (Emotional) Wellness Condition Sub-Dimension:** This sub-dimension includes the articles numbered 31, 32, 33, 34, 35, 36 and 37 that are aimed at determining the spiritual conditions of cancer patients' relatives.

The questions in scale grades between 0 and 10 points, "10" refers to best, "0" refers to worst. In the scale, the questions between 1-4, 6<sup>th</sup>, 13-20, 22<sup>nd</sup>, 24-29, 33<sup>rd</sup> are coded reverse. For instance, if "3" is marked in these questions, coding is made as  $10-3=7$  in scoring. Scale is interpreted on the basis of total points and sub-dimension points; high point refers to high quality of life.

**Symptom Evaluation Form:** "Symptom Evaluation Form", improved by basing on the literature, was formed in order to determine the frequency of 28 symptoms experienced by children. (Chang et al., 2000).

#### Procedure

The researcher will obtain written and verbal approval by meeting the parents in advance and giving information about the aim of the research. The meetings were conducted whenever the parent was suitable and their privacy was taken into consideration. Parents were asked to fill "Cancer Patient Caregiver Family Members' Life Quality Scale" and "Symptom Evaluation Form". The researcher accompanied to parents while they were

filling the meeting form.

#### Ethical issues

The implementation of the research was started after 12.09.2013 dated and 1115-GOA protocol numbered resolution of Dokuz Eylul University Non-Invasive Research Ethics Committees. Institutional permissions were obtained in order to carry out the research. Besides, parents' written and verbal permissions were obtained by meeting them and giving them information about the aim of the research. Figen Okcin's, who carried out scale's validity-reliability study for the use of the life quality scale of cancer patient caregiver family members', permission was obtained via mail.

#### Analysis of the data

Percentage quarters were used to determine the level of symptoms in the analysis of study data. 0-10 symptom that equals to first and second quarter was determined as low, 11-15 symptom frequency that equals to third quarter was medium-level and 16-28 symptom frequency that equals to fourth quarter was determined as high level. Kruksal Wallis analysis was used the data analysis. Bonferroni adjusted t-test and Bonferroni adjusted Mann-Whitney U test were used post-hoc. Statistical significance was set at 0.05.

## Results

7.6% of the participant children were female and 62.4% were male. Average age of the children was  $10.2\pm 4.5$ . 41.0% of them was on the level of new diagnosis, 46.2% was on remission and 12.8% was on relapse level. 61.5% of these children were diagnosed with leucemia. 52.1% of children received chemotherapy and 32.5% of them have been treated for more than 10 months. It is found that 82.9% of children's caregiver is their mother and 55.6% of children's parents were at 30-39 age group.

Table 1. Comparison of Parents Quality of Life Scale Total and Sub-Dimension Score by Symptom Frequency of Children

Physical health condition sub-dimension point average of the group in which children have low symptom level is  $29.3\pm 11.2$ , the point average of the group who have medium level is  $20.6\pm 6.9$  and the point average of the group who have high level of symptom is  $16.2\pm 13.1$ . An advanced level of significance was detected statistically among the parents' physical health condition sub-dimension point averages according to the symptom frequency ( $X^2_{KW}=24,825$ ,  $p=0.000$ ). In the analysis conducted in order to determine which group the difference resulted from, it is found that the difference was resulted from the group that has low and high symptom frequency ( $t=4,571$ ,  $p=0.000$ ) and the group that has low and medium symptom frequency ( $U=338,000$ ,  $p=0.000$ ). No difference was detected among the physical health condition sub-dimension point averages of the group that has medium and high level of symptom frequency ( $U=265,000$ ,  $p=0.030$ ).

Psychological health condition sub-dimension point average of the group in which children have low

**Table 1. Comparison of Parents Quality of Life Scale Total and Sub-Dimension Score by Symptom Frequency of Children**

Scale sub-dimensions	Symptom frequency	Life quality scale means score		$X^2_{KW}$	p
		n	$X \pm SS$		
Physical health condition sub-dimension point	Low	60	29.3±11.2	24,825	0.000
	Medium	32	20.6±6.9		
	High	25	16.2±13.1		
Psychological health condition sub-dimension point	Low	60	40.6±14.7	23,251	0.000
	Medium	32	29.3±8.9		
	High	25	26.0±14.1		
Social anxieties sub-dimension point	Low	60	34.7±11.3	6,375	0.041
	Medium	32	32.9±9.2		
	High	25	28.6±11.0		
Spiritual (Emotional) wellness condition sub-dimension point	Low	60	35.7±7.2	9,555	0.008
	Medium	32	30.9±6.3		
	High	25	34.0±12.6		
Total points	Low	60	140.2±33.4	26,492	0.000
	Medium	32	113.8±21.3		
	High	25	104.8±35.5		

symptom level is 40.6±14.7, the point average of the group who have medium level is 29.3±8.9 and the point average of the group who have high level of symptom is 26.0±14.1. An advanced level of significance was detected statistically among the parents' psychological health condition sub-dimension point averages according to the symptom frequency ( $X^2_{KW}=23,251$ ,  $p=0.000$ ). In the analysis conducted in order to determine which group the difference resulted from, it is found that the difference was resulted from the group that has low and medium symptom frequency ( $t=3,970$ ,  $p=0.000$ ) and the group that has low and high symptom frequency ( $U=356,000$ ,  $p=0.000$ ). No difference was detected among the psychological health condition sub-dimension point averages of the group that has medium and high level of symptom frequency ( $U=321,500$ ,  $p=0.206$ ).

Social anxieties condition sub-dimension point average of the group in which children have low symptom level is 34.7±11.3, the point average of the group who have medium level is 32.9±9.2 and the point average of the group who have high level of symptom is 28.6±11.0. An advanced level of significance was detected statistically among the parents' social anxieties condition sub-dimension point averages according to the symptom frequency ( $X^2_{KW}=6,375$ ,  $p=0.041$ ). In the further analysis conducted in order to determine which group the difference resulted from, it is found that the difference was resulted from the group that has low and high symptom frequency ( $U=506,500$ ,  $p=0.019$ ). No difference was detected among the social anxieties condition sub-dimension point averages of the group that has low and medium level of symptom frequency ( $t=0,756$ ,  $p=0.452$ ) and the group that has medium and high level of symptom frequency ( $U=299,000$ ,  $p=0.104$ ).

Spiritual (emotional) wellness condition sub-dimension point average of the group in which children have low symptom level is 35.7±7.2, the point average of the group who have medium level is 30.9±6.3 and the point average of the group who have high level of symptom is 34.0±12.6. An advanced level of significance was detected statistically among the parents' spiritual (emotional) wellness condition sub-dimension point averages according to the symptom frequency ( $X^2_{KW}=9,555$ ,

$p=0.008$ ). In the further analysis conducted in order to determine which group the difference resulted from, it is found that the difference was resulted from the group that has low and medium symptom frequency ( $t=0.230$ ,  $p=0.002$ ). No difference was detected among the spiritual (emotional) wellness condition sub-dimension point averages of the group that has medium and high level of symptom frequency ( $U=371,000$ ,  $p=0.640$ ) and the group that has low and high level of symptom frequency ( $U=569,000$ ,  $p=0.080$ ).

Total point average of the group in which children have low symptom level is 140.2±33.4, the point average of the group who have medium level is 113.8±21.3 and the point average of the group who have high level of symptom is 104.8±35.5. An advanced level of significance was detected statistically among the parents' total point averages according to the symptom frequency ( $X^2_{KW}=26,492$ ,  $p=0.000$ ). In the further analysis conducted in order to determine which group the difference resulted from, it is found that the difference was resulted from the group that has low and medium symptom frequency ( $t=4,622$ ,  $p=0.000$ ) and from the group that has low and high symptom frequency ( $U=309,500$ ,  $p=0.000$ ). No difference was detected among the total point averages of the group that has medium and high level of symptom frequency ( $U=313,000$ ,  $p=0.162$ ).

## Discussion

In this section, how the symptom frequency of cancer children affects life quality of their parents is discussed. Life quality is consisted of a great many sub dimensions such as physical, psychological, social and spiritual, and the density of symptoms experienced by children threatens these areas (Stein et al., 2003).

In this study, it is observed that according to children's symptom frequency, parents' physical health condition sub-dimension is affected negatively and as the symptom frequency increases, parents' physical health condition sub-dimension point averages decrease significantly ( $p=0.000$ , Table 1). It is found that while the parents of children, who have low symptom frequency, have the highest physical health condition sub-dimension point average, the parents

of the children, who have high level of symptoms, have lower physical health condition sub-dimension point average (Table 1). In the further analyses, it is observed that there is a difference among the point averages of the group that has low symptom frequency and the group that has medium level ( $p=0.000$ ), the group that has low level and the group that has high level ( $p=0.000$ ); and there is not a difference between the point averages of the groups that has medium and the group that has high level ( $p=0.030$ ). When the literature is reviewed, it is discovered that as the symptom frequency increases, parents have difficulty in dealing with these symptoms, feel helpless, the time they allow for themselves decreases, they do not have any spare time, feel fatigue and have many physical health problems for these reasons (Karasuya et al., 2000; Hoekstra-Weebers et al., 2001). In this study, it is discovered that as the symptom frequency increases, physical health condition sub-dimension reduces significantly, and this is found to be in parallel with literature data. In addition to this, it is thought that the fact that there is no difference in the physical health condition sub-dimensions of the parents of children, who have medium and high level of symptom frequency, might be resulting from factors such as the difficulty and being hospitalized for too long which are brought by dealing with multiple and complex symptoms. Besides, it is considered that since the parents in these two groups allow most of their time for symptom management of their children, the decrease in the time that they allow for themselves might be similar and this is thought to affect negatively the behaviours to seek for health (Carter, 2005; Gaugler et al., 2005; Grov et al., 2005; Dumont et al., 2006; Given et al., 2006; Kitrungrrote and Cohen, 2006; Langer et al., 2007; Mystakidou et al., 2007; Simmons, 2007). In this research as well, it is discovered that as the symptom frequency increases, a significant decrease occurs in psychological health condition sub dimension and that this is in parallel with literature. Along with this, it is thought the fact that there is not difference among the psychological health condition sub-dimensions of parents of the children who experience medium and high level of symptom might be resulting from that mothers' psychosocial adaptations get better and their anxieties reduce as the time that passed after diagnose extends (Han, 2003). Besides, it is considered that another reason for having no difference might be the impairment of daily life activities, the side effect and complications that occur depending on the treatment, repeated hospitalization, too-long period of treatment, and metastasis of disease (Carter, 2005; Gaugler et al., 2005; Grov et al., 2005; Dumont et al., 2006; Given et al., 2006; Kitrungrrote and Cohen, 2006; Langer et al., 2007; Mystakidou et al., 2007; Simmons, 2007).

In this study, it is observed that parents' life quality psychological health condition sub-dimension is affected depending on the symptom frequency of children and that parents' psychological health condition sub-dimension point averages decrease significantly as the symptom frequency increase ( $p=0.000$ , Table 1). It is determined that while psychological health condition sub-dimension point averages of parents of the children, who have low symptom frequency, is highest, psychological health

condition sub-dimension point averages of parents of the children, who have high symptom frequency, is lower (Table 1). It is discovered in further analysis that there is a difference between the point averages of the group that has low symptom frequency and the group that has medium symptom frequency ( $p=0.000$ ), and of the group that has low symptom frequency and the group that has high symptom frequency ( $p=0.000$ ); and that there is not a difference between the point averages of the group that has medium symptom frequency and the one that has high frequency ( $p=0.206$ ). When the literature is reviewed, it is determined that as the symptom frequency increases parents experience problems such as emotional confusion, tension, anxiety, depression, role conflict, social isolation and problem and along with these they receive psychiatric disorder diagnoses such as stress disorder after trauma, advanced phase anxiety disorders. It is stated in literature that as the patients' problems increase and their symptoms become uncontrollable, caregiver family members' burden, tendency of depression and anxiety and sleep disorders increase and their life quality decreases (Carter, 2005; Gaugler et al., 2005; Grov et al., 2005; Dumont et al., 2006; Given et al., 2006; Kitrungrrote and Cohen, 2006; Langer et al., 2007; Mystakidou et al., 2007; Simmons, 2007). Also in this study, it is determined that with the increase in symptom frequency, there is a significant decrease in psychological health condition sub-dimension and that this is in parallel with literature. Besides, it is considered the fact that there is not a difference between psychological health condition sub-dimension of the parents of children, who have medium and high level of symptom frequency, may be resulting from that mothers' psychosocial adaptations get better and their anxieties reduce as the time that passed after diagnose extends (Han, 2003). Besides, it is considered that another for having no difference might be the impairment of daily life activities, the side effect and complications that occur depending on the treatment, repeated hospitalization, too-long period of treatment, and metastasis of disease (Carter, 2005; Gaugler et al., 2005; Grov et al., 2006; Given et al., 2006; Kitrungrrote and Cohen, 2006; Langer et al., 2007; Mystakidou et al., 2007; Simmons, 2007).

In this study, a difference is found between the point averages of social anxieties condition sub-dimension of the life quality of parents depending on the symptom frequency of children ( $p=0.041$ , Table 1). It is determined that while social anxieties condition sub-dimension point averages of parents of the children, who have low symptom frequency, is highest, social anxieties condition sub-dimension point averages of parents of the children, who have high symptom frequency, is lower (Table 1). It is discovered in further analysis that there is a difference between the point averages of the group that has low symptom frequency and the group that has high symptom frequency ( $p=0.019$ ), and that there is not a difference between the point averages of the group that has low symptom frequency and the one that has medium symptom frequency ( $p=0.452$ ) and of the group that has medium symptom frequency and the one that has high frequency ( $p=0.104$ ). When the literature is studied, it is found that the parents of cancer children have impairment in their

daily order, conflict about their social roles and tension in their marital and domestic relationships (Bergkvist and Wengstrom, 2006; Hassett, 2010; Bevans ve Sternberg, 2012; Gaugler et al., 2012; Lambert et al., 2012; Turkoglu and Kilic, 2012). The reason for the difference between the point averages of social anxiety condition sub-dimension of the parents of the children, who have medium and high symptom frequency and who have low and medium symptom frequency, is thought be resulting from the fact that the parents, who give care for cancer child, perceive the situation as they should leave their own health, needs and social life aside and should concentrate their all energy on the treatment of their children (Lambert et al., 2012; Turkoglu, 2012).

In this research, it is observed that parents' life quality spiritual wellness condition sub-dimension is affected negatively depending on the symptom frequency of their children, and that their spiritual wellness condition sub-dimension point averages decrease significantly as the symptom frequency increases ( $p=0.008$ , Table 1). It is seen that while the spiritual wellness sub-dimension point averages of parents of the children, who have low symptom frequency, is highest, the spiritual wellness sub-dimension point averages of parents of the children, who medium symptom frequency, is lower (Table 1). In the further analysis, it is found that there is difference between the point averages of the group that has low symptom frequency and the group that has medium frequency ( $p=0.002$ ), and that there is not difference between the point averages of the group that has low and the group that has high frequency ( $p=0.080$ ) and the group that has medium and the one that has high symptom frequency ( $p=0.640$ ). When the litterateur is examined, it is found that as the symptom frequency increases, the parents have difficulty in dealing with these symptoms and feel helpless (Hoekstra et al., 2001; Karasuya et al., 2000). In this study, it is discovered that there is a significant decrease in spiritual wellness sub-dimension as the symptom frequency increases and that this is in parallel with the litterateur. Along with this, the reason for the fact that there is not difference among the spiritual wellness sub-dimension of the parents of the children, who have medium and high, and low and high symptom frequency, might be resulting from that parents' adaptation to the disease and the symptoms increase as the time that passed after diagnosis extends and that their anxieties decrease (Han, 2003).

In this research, it is observed that parents' life quality is affected negatively depending on the symptom frequency of their children, and that their life quality total point averages decrease significantly as the symptom frequency increases ( $p=0.000$ , Table 1). It is seen that while total point averages of parents of the children, who have low symptom frequency, is highest, total point averages of parents of the children, who high symptom frequency, is lower (Table 1). In the further analysis, it is found that there is difference between the point averages of the group that has low symptom frequency and the group that has medium frequency ( $p=0.000$ ), and the group that has low and the group that has high frequency ( $p=0.000$ ); and that there is not difference between the

point averages of the group that has medium and high symptom frequency ( $p=0.162$ ). When the litterateur is examined, it is determined that as the disease is diagnosed and treatment is started with the cancer child, the disease event enters into family members' live, impairs their daily order, restricts their daily activities, impairs their health condition, disrupts the physical and emotional balances of the child and family, prevents them from having satisfaction from the life and decreases their life quality (Bergkvist and Wengstrom, 2006; Hassett, 2010; Bevans and Sternberg, 2012; Gaugler et al., 2012; Lambert et al., 2012; Turkoglu and Kilic, 2012). In this study, it is determined that the life quality significantly decreases as the symptom frequency increases and that this is in parallel with the litterateur. Along with this, the reason for the fact that there is not difference between the total point averages of the parents of the children, who have medium and high level of symptom frequency, is thought to be resulting from the difficulty, staying in hospital for too long, parents' being unable to allow time for his/her own care and to meet his/her own requirements which are brought by dealing with cancer diagnosis and the symptoms that develop depending on the treatment (Karasuya et al., 2000). Besides, it is considered that this situation might have been affected by the fact that these two groups learnt to deal with the increasing symptoms and received support related to symptom management from the health personnel during they stay in hospital.

In conclusion, as a result of the study, it is determined that as the symptoms experienced by children increase, parents' life quality, total points and sub-dimension point averages decrease and their life quality reduces.

Consequently, it is considered that following the symptoms that might develop depending on the cancer diagnosis and treatment and practicing the nursing initiatives aimed at reducing the symptoms, knowing the importance of life quality, maintaining the works aimed at life quality and planning the initiatives that will increase life quality will play a key role in maintaining and developing the health of paediatric oncology patients and their parents. The initiatives aimed at increasing life quality must involve providing the appropriate support to the parent and increasing the physical, psychological, social and spiritual aspects of their life as much as they do for the child. The support that will be provided for the parent must include constituting and maintaining training programs related to symptom management at home, evaluating the efficiency of training programs, and providing support for family members from their social surroundings and health personnel.

## References

- American Cancer Society (2013). Cancer Facts&Figures–2013. [http://www.cancer.org/acs/groups/content/@epidemiology\\_surveillance/documents/document/acspc-036845.pdf](http://www.cancer.org/acs/groups/content/@epidemiology_surveillance/documents/document/acspc-036845.pdf). Accessed January 14, 2014.
- Arslan FT, Basbakkal Z, Kantar M (2013). Quality of life and chemotherapy-related symptoms of Turkish cancer children undergoing chemotherapy. *Asian Pac J Cancer Prev*, **14**, 1761-8.
- Bergkvist K, Wengstrom Y (2006). Symptom experiences during

- chemotherapy treatment-with focus on nausea and vomiting. *Eur J Oncol Nurs*, **10**, 21-9.
- Bessel A (2001). Children surviving cancer: psychosocial adjustment, quality of life, and school experiences. *Exceptional Children*, **67**, 345.
- Bevans MF, Sternberg EM (2012). Caregiver burden, stress, and health effects among family caregivers of adult cancer patients. *JAMA*, **307**, 398-403.
- Carter PA (2005). Bereaved caregivers' descriptions of sleep: impact on daily life and the bereavement process. *Oncol Nurs Forum*, **32**, 741.
- Collins JJ, Byrnes ME, Dunkel IJ (2000). The measurement of symptoms in children with cancer. *J Pain Symptom Manage*, **19**, 363-77.
- Demirbag BC, Kurtuncu M, Guven H (2013). Knowledge of Turkish mothers with children in the 0-13 age group about cancer symptoms. *Asian Pac J Cancer Prev*, **14**, 1031-5.
- Dumont S, Turgeon J, Allard P, et al (2006). Caring for a loved one with advanced cancer: determinants of psychological distress in family caregivers. *J Palliat Med*, **9**, 912-21.
- Emir S (2009). Childhood cancers and how we can protect our children against cancer. *Pediatrics Bulletin*, **6**, 2-8.
- Gaugler J, Hanna N, Linder J, et al (2005). Cancer caregiving and subjective stress: a multi-site, multidimensional analysis. *Psychooncology*, **14**, 771-85.
- Gaugler JE, Eppinger A, King J, Sandberg T, Regine WF (2012). Coping and its effect on cancer caregiving. *Support Care Cancer*, **21**, 385-95.
- Gibson F, Garnett M, Richardson A, Edwards J, Sepion B (2005). Heavy to carry: a survey of parents' and healthcare professionals' perceptions of cancer-related fatigue in children and young people. *Cancer Nurs*, **28**, 27-35.
- Given B, Given C, Sirkorski A, et al (2006). The impact of providing symptom management assistance on caregiver reaction: results of a randomized trial. *J Pain Symptom Manage*, **32**, 433-43.
- Grov EK, Dahl AA, Moum T, Fossa SD (2005). Anxiety, depression and quality of life in caregivers of patients with cancer in late palliative phase. *Ann Oncol*, **16**, 1185-91.
- Han HR (2003). Korean mothers' psychosocial adjustment to their children's cancer. *J Adv Nurs*, **44**, 499-506.
- Harris JN, Hay J, Kuniyuki A, et al (2010). Using a family systems approach to investigate cancer risk communication within melanoma families. *Psycho-Oncology*, **19**, 1102-11.
- Hassett MJ (2010). The full burden of cancer. *Oncologist*, **15**, 793-5.
- Hedstrom M, Haglund K, Skolin I, Von Essen L (2003). Distressing events for children and adolescents with cancer: child, parent, and nurse perceptions. *J Pediatr Oncol Nurs*, **20**, 120-32.
- Hoekstra-Weebers JE, Jaspers JP, Kamps WA, Klip EC (2001). Psychological adaptation and social support of parents of pediatric cancer patients: a prospective longitudinal study. *J Pediatr Psychol*, **26**, 225-35.
- Karasuya RT, Pogljar B, Takeuchi R (2000). Caregiver burden and burnout. *Postgraduate Medicine*, **108**, 119-23.
- Kitrungle L, Cohen MZ (2006). Quality of life of family caregivers of patients with cancer: a literature review. *Oncol Nurs Forum*, **33**, 625-32.
- Lambert SD, Girgis A, Lecathelinais C, Stacey F (2012). Walking a mile in their shoes: anxiety and depression among partners and caregivers of cancer survivors at 6 and 12 months post-diagnosis. *Support Care Cancer*, **12**, 1495-7.
- Langer SL, Rudd ME, Syrjala KL (2007). Protective buffering and emotional desynchrony among spousal caregivers of cancer patients. *Health Psychology*, **26**, 635-43.
- Mystakidou K, Tsilika E, Parpa E, Galanos A, Vlahos L (2007). Caregivers of advanced cancer patients: feelings of hopelessness and depression. *Cancer Nurs*, **30**, 412-8.
- Okcin F, Karadakovan A (2012). Reliability and validity of the quality of life-family version (qol-fv) in Turkish family caregivers of patients with cancer. *Asian Pac J Cancer Prev*, **13**, 4235-40.
- Simmons LA (2007). Self-perceived Burden in Cancer Patients: validation of the Self-perceived Burden Scale. *Cancer Nurs*, **30**, 405-11.
- Stein KD, Denniston M, Baker F, et al (2003). Validation of modified Rotterdam symptom checklist for use with cancer patients in the united states. *J Pain Symptom Manage*, **26**, 975-89.
- Tanir MK, Kuguoglu S (2011). Turkish validity and reliability of a pediatric quality of life cancer module for children aged 8-12 and parents. *Asian Pac J Cancer Prev*, **12**, 125-30.
- Turkoglu N, Kilic D (2012). Effects of care burdens of caregivers of cancer patients on their quality of life. *Asian Pac J Cancer Prev*, **13**, 4141-5.
- Whitsett SF, Gudmundsdottir M, Davies B, McCarthy P, Friedman D (2008). Chemotherapy-related fatigue in childhood cancer: correlates, consequences, and coping strategies. *J Pediatr Oncol Nurs*, **25**, 86-96.
- Woodgate RL, Degner LF (2003). Expectations and beliefs about children's cancer symptoms: perspectives of children with cancer and their families. *Oncol Nurs Forum*, **30**, 479-91.
- Woodgate RL, Degner LF, Yanofsky R (2003). A different perspective to approaching cancer symptoms in children. *J Pain Symptom Manage*, **26**, 800-17.
- World Health Organization, International Agency for Research on Cancer (2008). World cancer report 2008. [http://www.iarc.fr/en/publications/pdfs-online/wcr/2008/wcr\\_2008.pdf](http://www.iarc.fr/en/publications/pdfs-online/wcr/2008/wcr_2008.pdf). Accessed March 19, 2014.
- Varni JW, Seid M, Kurtin PS (2001). The PedsQL 4.0 reliability and validity of the pediatric quality of life inventory version 4.0 generic core scale in healthy and patient populations. *Med Care*, **39**, 800-12.
- Varni JW, Burwinkle TM, Katz ER, et al (2002). The PedsQL in pediatric cancer: reliability and validity of the pediatric quality of life inventory generic core scales, multidimensional fatigue scale, and cancer module. *Cancer*, **94**, 2090-106.
- Vegian LH, Lubin JH, Anderson H, et al (2012). A pooled analysis of thyroid cancer incidence following radiotherapy for childhood cancer. *Radiat Res*, **178**, 365-76.
- Yakar HK, Pinar R (2013). Reliability and validity of Turkish version of the caregiver quality of life index cancer scale. *Asian Pac J Cancer Prev*, **14**, 4415-9.