

Research Paper:

The Burden of Care and Life Satisfaction of the Turkish Mothers of Children With Cancer

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Citation: Baran, G. 2018. The Burden of Care and Life Satisfaction of the Turkish Mothers of Children With Cancer. *Journal of Client-Centered Nursing Care*, 4(4), pp. 175-184. <https://doi.org/10.32598/jccnc.4.4.175>

 <https://doi.org/10.32598/jccnc.4.4.175>

**Article info:**

Received: 13 Apr 2018

Accepted: 25 Sep 2018

Published: 01 Nov 2018

Keywords:

Cancer, Acute Lymphoblastic Leukemia (ALL), Care burden, Life satisfaction, Mother

ABSTRACT

Background: Cancer could be called family-involving disease. The current study aimed at determining the relationship between the burden of care and life satisfaction of the Turkish mothers of children with cancer.

Methods: The current descriptive cross-sectional study was conducted on mothers of 194 children with acute lymphoblastic leukemia referred to a chemotherapy polyclinic. Data were collected using a demographic questionnaire, the Zarit Caregiver Burden Scale, and Life Satisfaction Scale, and analyzed with Student's t-test for independent groups, One-way ANOVA, Mann Whitney U test, Kruskal Wallis, and regression tests using SPSS V. 16.

Results: Mean age of children was 7.26±3.78 (years), 53.6% were male, and 64.4% were previously enrolled at school but could not continue to study due to illness. A significant difference was observed between the average life satisfaction scale scores and economic status of the mothers ($P<0.005$). According to Pearson Product Moment Correlation analysis, a statistically significant negative correlation was observed between life satisfaction and caregiver burden scores ($P<0.05$) ($r=-.420$, $P=0.000$).

Conclusion: Health care team and especially pediatric nurses should help the mothers by providing information about support systems and counseling services available in the community and facilitating the use of these resources to alleviate their stress and increase their life satisfaction.

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Highlights

- The caregiver burden is a subjective and extremely stressful experience that is perceived by the caregiver.
- The current study was conducted on mothers of children with cancer to determine the relationship between the burden of care and their life satisfaction.
- A significant relationship was observed between the average life satisfaction scale scores and the economic status of the mothers.
- A significant negative relationship was found between life satisfaction and caregiver burden scores.
- The health care team and especially pediatric.

Plain Language Summary

Cancer can involve not only the patient but also his or her family as caregivers. The caregiver burden is a subjective experience that is perceived by the caregiver as being extremely stressful. It is also a condition that affects the physical and psychological well-being of caregivers and affects their personal and social relationships. The current study was conducted on mothers of 194 children with acute lymphoblastic leukemia to determine the relationship between the burden of care and life satisfaction of the Turkish mothers of children with cancer. Based on the results, a significant relationship was observed between the average life satisfaction scale scores and the economic status of the mothers. Also, a significant negative relationship was found between life satisfaction and caregiver burden scores. As a result, the health care team and especially pediatric nurses should help the mothers by providing information about support systems and counseling services available in the community to alleviate their stress and increase their life satisfaction.

1. Background



Acute Lymphoblastic Leukemia (ALL) is a malignant transformation and proliferation of lymphoid progenitor cells in bone marrow, blood, and extramedullary regions (The National Cancer Institute 2017).

Acute Lymphoblastic Leukemia (ALL) is the most common pediatric malignancy and makes up 25% of the cancers occurring before the age of 15 and 19% of cancers occurring before the age of 20 (Hunger et al. 2012).

The incidence of ALL in the United States is estimated as 1.6 per 100,000 people. Approximately 3,250 children are diagnosed with leukemia every year in America, and 2,400 of them are diagnosed with ALL (The National Cancer Institute 2013). The incidence of ALL among children aged 0-14 years in Turkey was reported as 41.4 per 100,000 (Kutluk 2007).

Families of children with ALL have a high level of anxiety (Kholasehzade et al. 2014). Although many parents adapt well to a diagnosis of cancer, it is shown that they struggle with mental fatigue, anxiety, and post-traumatic stress symptoms during the treatment of cancer in their

children (Rocha-Garcia et al. 2003; Maurica-Stam et al. 2008). Mothers, providing the most primary care experienced more stress, anxiety and depression than fathers (Ghufran, Andrades & Nanji 2014; Barrera et al. 2012).

It is noteworthy that in some studies all caregivers were females (Stone, Cafferata & Sangl 1987). Children with ALL need more care from their mothers in order to meet their needs during the treatment of ALL. Over time, the mother can experience problems such as a sense of having lost her maternal role, inability to care for other children, deterioration of her daily life, failure to care for herself, a decline in her quality of life, excessive fatigue, depression, emotional suffering, bad mood, social problems and loneliness. Manifestation of these symptoms is the main reason for an increase in the caregiver burden of the mother (El-cigil & Conk 2010).

Care giving is a concept based on human needs, mutual relationships, trust, affective characteristics and moral dimensions, and it requires scientific knowledge and specialized psychomotor skills (Leyla 2010). The caregiver burden can be defined as a subjective experience that is perceived by the caregiver as being extremely stressful (Schebring 2002).

Caregiver burden is also a condition that affects the physical and psychological well-being of caregivers and their personal and social relationships (Girgis et al. 2012). Among caregivers in Larsen's study, 60.6% stated that they did not have time to spend for their caregiving responsibilities, 78.8% stated that they felt tired, 84.9% said that they had communication difficulties with the patient, and 56.9% of them declared that they experienced financial difficulties (Larsen 1998).

Caring for a patient is not limited to a single type of help; it can involve emotional support, physical or financial aid, coordination of social services, routine health care (drug intake, treatment, follow-up etc.), personal care (bathing, feeding, going to the toilet and dressing, etc.), transport, shopping, doing housework, money management and financial assistance, and living in the same house (Toseland, Smith & McCallion 2001).

"Life satisfaction" is an individual's general evaluation of the quality of their own life according to the criteria they have chosen. Areas in which satisfaction can be found include work, family, leisure time, health, money, self-respect, and the person's immediate surroundings (Diener & Oishi 2000). The diagnosis and treatment of a disease can have the physical, emotional, and financial balance of the family, prevent them from finding satisfaction in life and reduce their quality of life (Gülses, Yıldırım & Büyükavcı 2014).

In general, many studies can be found on anxiety, stress, quality of life, and depression of the mothers of children with cancer (Kholasehzadeh et al. 2014; Barrera et al. 2012; Elcigil & Conk 2010; Demirtepe-Saygılı & Bozo 2011; Boştancı et al. 2007; Neu et al. 2014; Malpert et al. 2015; Chen 2015; Sherief et al. 2015). However, considering the culture of parental life in Turkey and the socio-economic status of the mothers, conducting such a study was felt necessary. The current study aimed at determining the relationship between the burden of care and life satisfaction of the Turkish mothers of children with ALL.

2. Materials and Methods

Research design and sample

The current descriptive cross-sectional study was conducted on the mothers of 194 children with ALL attending the pediatric hematology clinic of chemotherapy polyclinic of the Dicle University Children's Hospital to

receive chemotherapy. Data were collected using convenience sampling method from April to November 2017.

The number of patients, accessibility, and team cooperation were taken into consideration in the selection of the hospital. Inclusion criteria for the mothers were: 1. Mothers with children diagnosed with ALL at least a month ago; 2. Mothers with children in the remission period; 3. Mothers with no psychiatric disorders and cognition problems; 4. Mothers who could fulfil their own and their children's self-care needs; and 5. Mothers who consented to participate in the study.

Data collection tools

In order to collect the data, an introductory information form, the Zarit Caregiver Burden Scale, and the Life Satisfaction Scale were applied to the mothers providing care. Introductory Information Form was a semi-structured form created by the researcher. This form was filled out by the researcher during face-to-face interviews with the mothers. It was designed to record information about the age, employment, and educational status of the mother/ father, the gender of the child, the type of family, the diagnosis of the patient, the age of the child, the number of siblings, and attendance of the child in a school.

Caregiver Burden Scale was developed by Zarit, Reever & Bach-Peterson (1980). It is used to assess the difficulties experienced by people caring for the ones in need of care. In the scale, there are 22 Likert-type items that determine the effect of care giving on the individual's life. The scale has a Likert-type rating that ranges from 0 to 4, in the form of "never", "rarely", "sometimes", "frequently", or "almost always".

The scores that can be obtained from the scale range from 0 to 88, and higher scores indicate higher incidence of burden. The validity and reliability study on the Turkish version of the scale was checked by İnci and Erdem (2006). The internal consistency coefficient was 0.87 to 0.94 while the test-retest reliability was 0.71 (İnci & Erdem 2008). In the current study, the Cronbach's α reliability coefficient for the scale was 0.91.

Life Satisfaction Scale: This Scale was developed by Diener et al. (1985) and its adaptation into Turkish was performed by Köker (1991). The scale consists of five items related to life satisfaction. Each item is answered according to a graded answer system running from 1 to 7 (1: "not suitable"; 7: "very suitable").

The scale, which aims to measure general life satisfaction, is suitable for all ages, from adolescents to adults. The translation of the scale into Turkish and checking its validity analysis was conducted by Köker (1991). As a result of the item analysis, the correlation between the scores obtained from each item of the scale and the total scores was sufficient. The test-retest reliability coefficient of the scale was 0.85 (Köker, 1991). In the current study, the Cronbach's α reliability coefficient of this scale was 0.86.

Data analysis

Analysis of the data was conducted using SPSS V. 16. In order to examine the normality of the distribution of the data and the missing data related to the data set of the study group, the Kolmogorov-Smirnov test was applied. Frequencies and descriptive analyses were applied to determine the descriptive characteristics of the children with ALL and their parents. The scale was applied to calculate the Cronbach's α value of the caregiver burden and life satisfaction of the mothers.

In the current study, Kruskal Wallis-H analysis, used for nonparametric data, was performed to determine whether the life satisfaction scores of the mothers were significantly different according to their financial and educational status. Complementary comparison techniques were used to investigate the groups that determined these significant differences. There is no specific test technique for this purpose; however, the Tamhane test, which is a post-Hoc test for non-parametric data preferred in multi-comparisons was used (Otrar 2018). The non-parametric Mann Whitney-U test was used to determine the significance of the relationship between family type and the gender of the child with ALL, mothers' life satisfaction, and their caregiver burden scores.

One-way Analysis of Variance (ANOVA) was used to determine whether the mean caregiver burden scores of the subjects changed significantly according to their educational and financial status. Bivariate correlation (Pearson multiplication moment correlation) was used to determine the relationship between the mean life satisfaction and the caregiver burden scores of the mothers. Regression analysis was used as a further analysis since the result of bivariate correlation analysis was significant with regard to the mean score of caregiver burden according to the age of the mother and the child. In order to include the variables in the regression equation, the level of statistical significance was $P < 0.05$.

3. Results

Socio-demographic characteristics

The findings of the current study are shown in the following tables. As shown in Table 1, the socio-demographic characteristics of the parents of ALL children were analyzed. The mean age of the mothers of the children with ALL was 34.51 ± 7.48 (range=21-57), the mean number of children per mother was 4.77 ± 2.58 (range=1-15), the average age of the fathers was 39.22 ± 8.24 (range=23-80), 50.5% of the mothers were primary school graduates, 96.9% of them were housewives, 56.4% had a medium socio-economic status, 52.6% of them had a family affiliation with their husbands, 78.9% of them were in the nuclear family.

The mothers of children with ALL had a mean caregiver burden score of 42.68 ± 16.66 (range=9-83) while their mean life satisfaction score was 13.82 ± 7.00 (range=5-35). When the socio-demographic characteristics of children with ALL were considered, the mean age was 7.26 ± 3.78 years (range: 5 month-16 year), 53.6% of them were male (Table 1) and 64.4% of them were previously enrolled at school but could not continue to study due to their illness.

Differences

According to the results of Kruskal Wallis H test employed in order to determine the significance of the difference between the mean life satisfaction scores and the economic and educational status of the mother, the difference between the mothers with different economic status was statistically significant ($X^2=12.161$; $df=2$; $P=0.002$) (Table 2). A significant difference was observed between the mean life satisfaction score and economic status of the mother ($P < 0.005$). To determine which group was the source of this significant difference, subsidiary comparison techniques were used. The mothers with a medium income had higher life satisfaction than the mothers with a low economic level ($P=0.000$).

The Mann Whitney-U test was used to determine whether the mothers' life satisfaction and caregiver burden scale scores changed significantly according to the family type, and the gender of the child and a significant difference was observed between the groups $P < 0.05$ (Table 3). According to One-way Analysis of Variance (ANOVA), no statistically significant difference was observed between the mean caregiver burden scores of the mothers and their educational and economic status (Table 4).

Table 1. Correlation between the caregiver burden and the life satisfaction of mothers of children with ALL (N=194)

Parental Characteristic			
Characteristics	N	%	
Education level of the mothers	Illiterate	100	51.5
	Literate	20	10.3
	Primary school graduate	61	31.4
	High school	10	5.3
	University	3	1.5
Mothers' mean age: 34.51±7.48 (range=21-57)			
Mothers' total number of children: 4.77±2.58 (range=1-15)			
Education level of the father	Illiterate	35	18.0
	Literate	20	10.3
	Primary school graduate	98	50.5
	High school	30	15.5
	University	11	5.7
Fathers' mean age: 39.22±8.24 (range=23-80)			
Mother's job	Housewife	188	96.9
	Government employee	4	2.1
	Self-employed	2	1.0
Mother's caregiver burden score: 42.68±16.66 (range=9-83)			
Mothers' life satisfaction score: 13.82±7.00 (range=5-35)			
Father's job	State employee	16	8.3
	Self-employed	125	64.4
	Unemployed	53	27.3
Income status of family	Good	10	5.2
	Middle	106	54.6
	Bad	78	40.2
Relationship of mothers and fathers	Not in a relationship	92	47.4
	In a relationship	102	52.6
Family type	Nuclear family	153	78.9
	Extended family	41	21.1
Characteristics of Children			
Gender of ALL children	Female	90	46.4
	Male	104	53.6
Average age of children with ALL: 7.26±3.78 year (range=5 months)			
Total	194	100	

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Correlations

The mean score of caregiver burden (42.68±16.66) of the mothers was moderately high while their mean life satisfaction score was very low (13.82±7.00). Pearson product moment correlation analysis, showed a statistically significant negative correlation between the mean scores of life satisfaction and caregiver burden ($P < 0.05$) ($r = -0.420$, $P = 0.000$). As shown in Table 5, there was a negative correlation between the mean score of caregiver burden and the age of mother and child ($P < 0.01$).

4. Discussion

The diagnosis and treatment of cancer affects the family as well as the child. Children have difficulties to meet their own needs due to problems such as nausea, vomiting, weakness, fatigue and anorexia due to illness and treatment, and as a result their mothers need to perform many tasks to meet these needs (Kostak & Zafer 2012). The functionality of the whole family, role distributions and internal relationships are affected by this crisis. Cancer can be called a family disease (Bostanci et al. 2007; Neu et al. 2014). It is also observed in many studies that the females usually have

Table 2. Life satisfaction scores of the mothers of children with ALL according to economic and educational status

Life Satisfaction Scale					
Score	Group	N	Mean Range	Mean±SD	P
Economic status	Good	10	100.35	14.00±6.09	0.002
	Medium	106	109.66	15.44±7.33	
	Bad	78	80.61	11.61±6.05	
	Total	194	100.35		
Educational level of mother	Illiterate	100	91.87	13.23±7.16	0.353
	Literate	20	109.35	14.75±6.20	
	Primary school	61	100.40	14.13±6.71	
	High school	10	97.60	14.60±9.17	
	University	3	91.87	19.00±4.00	

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the role of caregiver (Kholasehzadeh et al. 2014; Chen et al. 2015; Erdem et al. 2013; Şahin, Polat & Ergüney 2009; Karahan & İslam 2013; Karahan & İslam 2013). Almost all of the caring and responsibility for the children are traditionally provided by the mothers from birth onwards (Boştancı et al. 2007). The mean age of the mothers in the current study was 34.51±7.48.

In the study conducted by Ghodsbin et al. (2014) in Iran, the mean age of the mothers of children with ALL was 34.1-34.8 years. It was observed that the mean caregiver

burden score (42.68±16.66) of the mothers in this study was moderately high while the mean life satisfaction score (13.82±7.00) was low. In the literature review, similar studies could not be found, either in Turkey or worldwide. Therefore, the findings of the current study were discussed here using the findings of studies conducted on the parents of children with other chronic diseases.

Karahan and İslam (2013) found the mean caregiver burden score of mothers of children with cerebral palsy to be 40.7±6.9. This findings of the current study were

Table 3. Relationship between mean life satisfaction and caregiver burden scale scores for different family types and genders

Scores	Life Satisfaction Scale	N	Mean±SD	Mean Range	U	Z	P
Family type	Nuclear	153	14.15±7.08	99.81	2783.500	-1.110	0.267
	Extended	41	12.63±6.62	88.89			
Gender of the child	Female	90	14.31±6.99	101.21	4346.00	-0.860	0.390
	Male	104	13.41±7.01	94.29			

Scores	Caregiver Burden Scale	N	Mean±SD	Mean Range	U	Z	P
Family types	Nuclear	153	42.62±16.26	97.51	3134.500	-0.006	0.995
	Extended	41	42.87±18.28	97.45			
Gender of the child	Female	90	40.93±16.30	91.63	4151.500	-1.356	0.175
	Male	104	40.19±16.90	102.58			

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Table 4. Caregiver burden scores according to the educational and economic status of the mothers of children with ALL

Caregiver Burden Scale				ANOVA Results				
Characteristics Economic Status	N	Mean±SD	Source of Vari- ance	Sum of Squares	df	Mean of Squares	F	P
Good	10	42.40±18.70	Intergroup	1065.63	2	532.81	1.93	0.147
Medium	106	40.63±17.10	Intragroup	52540.55	191	275.08		
Bad	78	45.50±15.56	Total	53606.18	193			

Caregiver Burden Scale				ANOVA Results				
Education Level of the Mothers	N	Mean±SD	Source of Variance	Sum of Squares	df	Mean of Squares	F	P
Illiterate	100	42.34±16.75	Intergroup	1396.99	4	349.24	1.26	0.286
Literate	20	36.25±14.43	Intragroup	52209.19	189	276.23		
Primary school graduate	61	44.96±17.28	Total	53606.18	193			
High school	10	46.60±14.99						
University	3	37.33±15.88						

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congruent with the literature. In a study on adults undergoing chemotherapy, there was a statistically significant difference in comparison of caregivers' perceptions about health before and after care giving (Şahin et al. 2009). In the current study, it was observed that the mean life satisfaction score was low (13.82±7.00). According to a study, it was determined that the life satisfaction of mothers of children with no mental retardation was higher than those of the mothers of children with mental retardation (Yavuz 2016).

In the current study, as the caregiver burden of the mothers increased, the life satisfaction of the mothers decreased. Many mothers had to stay in hospital for days and months and therefore had to constantly change their lifestyles in order to support their children. They may not have time for

their own social activities and may not see their friends for a long time. During this period, mothers experience stress, anxiety, and depression (Elcigil & Conk 2010). However, when social support increases, the negative effects of care giving and the possibility of depression decreases and life satisfaction increases (Grant et al. 2004).

In the current study, the mean life satisfaction score of the mothers with a higher income was higher compared to those of the mothers with a low income. A healthy financial situation means that some needs can be met more easily. This situation can often lead to an increase in subjective well-being (Diener & Oishi 2000). It is observed that the parents with financial difficulties have higher levels of stress.

Table 5. Correlation between the caregiver burden and the life satisfaction of mothers of children with ALL (N=194)

Variable	B	Standard Error B	B	t	P
Age of mother	-0.496	0.157	-0.223	-3.169	0.002*
Age of child	-1.019	0.309	-0.231	-3.296	0.001**

Score	N	r	P
Life Satisfaction Scale	194	-420***	0.000

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*Model R²=0.050; Adjusted R²=0.045; F=10.044; P<0.005; **Model R²=0.054; Adjusted R²=0.049; F=10.863; P<0.001; ***P<0.001

The reason is the prolonged treatment of the disease, any recurrences that occur, and long term hospitalization when it cannot be treated. The families experience emotional and social problems and economic losses (Eiser & Upton 2007), since cancer puts a major burden on both the family budget and a country's economy.

In the current study, it was observed that with the age increase in care giving mother and the child, the burden of care decreased. In contrast, in the low age mothers and children, the burden of care increased. In a comparative study on caregivers caring for patients with cerebral palsy and geriatric hemiplegic disease, the mean caregiver burden score in the ones caring for geriatric hemiplegic patients was 50.9 ± 5.7 , while the mean caregiver burden score in the ones caring for cerebral palsy patients was 40.7 ± 6.9 (Karahan & İslam 2013).

It may be thought that mothers gain experience and learn to be more patient in their later ages. Another reason is that growing children need increasingly less input from the mother in order to meet their self-care and other needs. In the current study, it was found that 64.4% of the children had previously attended school, but they could not continue studying because of the disease. The life of a school-age child may be completely changed by the diagnosis of cancer. The issues that develop following the diagnosis and treatment of cancer, which affect the child's school attendance or academic achievement, can be divided into physical, psychosocial, and cognitive aspects.

The latter may not be the mother's priority, because the priority of the mother is to save the child's life. Children with cancer may also sometimes not be able to return to school because their parents may want to protect them from negative reactions and loss of confidence, even after the treatment. Informing the school about the situation may only come to mind after some months. Planning to return the child to school and having a positive experience of school requires good teamwork. For this, the child, family, school officials, friends and health personnel should work together and be in constant contact. The person who maintains the communication among the hospital, school, and family can be a hospital nurse, social worker, or school nurse belonging to the medical team (Elçigil 2007).

In conclusion, it was found that the caregiver burden and the life satisfaction of the mothers of children with ALL were negatively correlated; the life satisfaction of the mothers was low, the economic situation of the mothers affected the mean life satisfaction score, and the care burden and the age of mothers and children were negatively correlated.

Recommendations: Cancer affects all family members, but those most affected are the mothers. That is why mothers need physical, mental, and, in particular, social support. This social support should be provided primarily by the partner or spouse, other children, friends, neighbors, doctors, and nurses. The caregiver burden of the mother should be alleviated by dividing tasks between family members. In addition, nurses should help families by providing information about support systems and counseling services available in the community and facilitating the use of these resources.

Nurses should be able to put families in touch with the families of other children with same diagnosis. There is a need for large scale, comprehensive nursing studies covering the different problems involving the mothers of children with cancer in other regions and countries. It is also suggested that studies be conducted comparing the caregiver burden and life satisfaction of the mothers with healthy children and the mothers of children with leukemia.

Such studies should include the small-scale training programs given by nurses to help mothers to deal with diagnosis, treatment, and symptoms of the disease. Health care systems in all countries should provide services to improve the social and health conditions of both mothers and their children and support the home care for children with cancer. This would allow the mother to devote more time to herself, increase her quality of life, and, as a result, feel a greater sense of satisfaction. It was a cross sectional study. The study was conducted in one hospital and accordingly, the results should be interpreted with caution.

Ethical Considerations

Compliance with ethical guidelines

The study protocol was approved by the Ethics Committee for Non-invasive Clinical Studies of the Dicle University Medical Faculty (Date: 13.03.2017/Issue: 71). Verbal and written consents (04.04.2017) were obtained from the Children's Hospital of the university. Verbal and written consent was obtained from eligible mothers who agreed to participate in the study. An informed consent form containing information on the purpose, duration and application of the study, the collection of the data, voluntarily participation, the opportunity to leave the study at any stage, and confidentiality of personal data was used to obtain informed consent from the mothers.

Funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Acknowledgments

I convey my endless gratitude and respect to the devoted and self-sacrificing mothers who agreed to participate in this work and answered my questions with great patience in the Dicle University Child Hospital.

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