

Original Article

An Evaluation of the Changes Experienced by the Parents of Children with Cancer

Ilknur Kahriman, PhD

Associate Professor, Karadeniz Technical University, Faculty of Health Sciences, Nursing Department, Trabzon, Turkey

Birsel Canan Demirbag, PhD

Associate Professor, Karadeniz Technical University, Faculty of Health Sciences, Nursing Department, Trabzon, Turkey

Hacer Kobya Bulut, PhD

Associate Professor, Karadeniz Technical University, Faculty of Health Sciences, Nursing Department, Trabzon, Turkey

Correspondence: Ilknur Kahriman, Associate Professor, Karadeniz Technical University, Faculty of Health Sciences, Department of Nursing, 61080, Trabzon, Turkey E-mail: ilknurkahriman@hotmail.com

Abstract

Background: One of the most challenging aspects of being parents of a child diagnosed with cancer is to balance their normal family life with the child's health needs and treatment requirements. Cancer covers an important part of family life and gets ahead of other matters. Families mostly feel that everything has changed in their lives with the cancer diagnosis and are obliged to make a number of adjustments in their lives. Their normal family life suddenly begins to include treatments, hospital appointments and hospitalizations.

Objective: This study was conducted as a descriptive study to evaluate the changes that the parents of children with cancer experienced in this process.

Method: The study was carried out with 65 families of children aged 0-17 with cancer in a pediatric oncology clinic and outpatient clinic of a university hospital in Trabzon. The data were collected between August and November 2015 using a survey. Numbers, percentages and chi-square test were used in the evaluation of the data.

Findings: The mean age of the mothers was 35.33 ± 6.31 years, the majority of them had an education level below high school (60.0%) and they were housewives (89.2%). The mean age of the fathers was 39.30 ± 6.29 years (50.8) and they were self-employed (43.8%). It was determined that the majority of the children were male, their mean age was 7.74 ± 4.00 years and 90.8% of them had leukemia diagnosis. The mothers stated that their fears increased (87.5%), their workload at home increased (84.4%), they had more stressful lives (82.8%) and they felt physically tired (82.8%). They also indicated that their healthy children could not do the activities they used to do (56.5%), they did not feed their healthy children with their favorite food so that their sick children would not desire (52.3%) and their healthy children became more nervous (53.2%). As for the fathers, they reported that their work load at home increased (82.3%), they had more stressful lives (80.6%), and they could not find time for their hobbies and interests (77.8%). After the diagnosis, a statistical significance was found between age, educational status of the parents and changes occurred in their lives ($p < 0.05$). The study demonstrated that almost all of the mothers paid more attention to the order at home, laundry cleaning, food/drinks and bathing.

Conclusion: The study suggested that the parents of children with cancer had increased workload at home, more stressful lives, no time for social activities, increased fear, self-tiredness, the social activities of their healthy children decreased and they became more nervous.

Key words: Parent, cancer, child, oncology

Introduction

Cancer is a disease that affects the life style of an individual and his/ her family directly or indirectly due to its prognosis and treatment, causes serious stress in the patient's family as well as the patient from the diagnosis to the terminal stage and forces all their balances and adjustment (Kuzeyli, 2006). Families often suffer from stress because they are not ready for home care of their child while fulfilling roles such as controlling the symptoms of the disease, and providing medical care and comfort (Yaman, 2011; Ikeda et al., 2012). Therefore, cancer is a problem that concerns the whole family rather than only the patient (Kim and Given, 2008). The fact that the child in the family gets sick places a burden on his/her family with its symptoms, treatment method, prognosis, daily activity restriction and long term effects (Er, 2006). The family also carries out the care and treatment of the child at home outside the hospital. It has been reported that family members who care for cancer patients could experience conflicts related to their social roles, tension in their marriages and family relationships, new responsibilities regarding the child's home care, limitations in their daily activities, psychological problems such as anxiety, anger, depression and guilt, deterioration in their physical health, economic burdens due to medical expenses and uncertainties about the future of their children (Kim and Baker, 2006). For this reason, besides being a medical-physical disease, cancer is also known as a phenomenon involving many problems regarding psychological and psychosocial aspects.

The diagnosis of cancer is a traumatic experience both for the individual and his/her family. Compared to other diseases, cancer can affect the individual and his/her family physically, psychologically, socially and economically by ruining the daily life balance of the individual. Cancer can have implications for the individual, such as influencing adaptation mechanisms, ruining the plans for the future, and loss of power. It causes anxiety in the patient and his/her family because its clinical prognosis is unclear and the treatment can not be fully guaranteed (Kuzeyli, 2006). Starting from this point, this study was conducted to evaluate the changes that the parents of children with cancer experienced in this process.

Methods

Study group

The study group of this descriptive study aimed to evaluate the changes in the lives of the families of children with cancer was conducted with 65 families of the children who were followed up at the Pediatric Hematology Clinic and Children's Chemotherapy Polyclinic of a university hospital serving a wide area in the Eastern Black Sea Region between August-December 2015.

The universe and sample of the study

The universe of the study comprised the mothers of 65 children aged 0-17 who were previously and newly diagnosed with leukemia and lymphoma and who came to hospital to receive chemotherapy either at polyclinic or outpatient clinic and discharged from the hospital at least once. The universe was small, so method of sampling was used and the whole universe participated in the study voluntarily.

Data Collection Tools

The data collection was carried out after the relevant permits were obtained from the relevant institution in accordance with the ethical rules. In order to conduct the research, written permission was obtained from the chief physician and written and verbal consent were obtained from the participants after giving them brief information before the application. The data was collected using a survey developed by the researchers.

The survey included the questions investigating the socio-demographic characteristics of the children and their parents such as the age, gender, educational status, occupation, the diagnosis of the child, the duration of the disease, the changes in the lives of family members and the children, the self-health perceptions of the parents in pre and post diagnosis period and the changes they made in their houses after the diagnosis of their children.

The data were collected from the parents face-to-face. The data were analyzed in SPSS 22.0 package program in the computer environment by using percentages, mean and the Chi square test. The results were evaluated at a confidence interval of 95% and at a significance level of $p < 0.05$.

Results

The majority of children were found to be male, their mean age was 7.74 ± 4.00 years old and 77% of them had ALL (Table 1).

The mean age of the mothers was determined as 35 years, most of them had an education level below high school and they were housewives. The mean age of the fathers was 39 years, most

of them had an education level below high school, and they were self-employed. Most of the families had 2 or more children, lived in the district and had a nuclear family structure (Table 2). The mothers indicated that their fears increased (87.5%), their work load increased (84.4%), their lives were more stressful (82.8%) and they felt physically tired (82.8%) (Table 3).

Table 1. The distribution of parental characteristics of children with cancer diagnosis

	n	%
Mean age	7.74±4.00	
Gender		
Girl	22	33.8
Boy	43	66.2
Diagnosis		
Leukemia	59	90.8
Lymphoma	6	9.2
Birth order of your child with cancer (n=65)		
1.child	22	33.8
2.child or more	43	66.2
Mean duration of the disease (month)	18.7±13.8	
Duration of the disease (Max:48; Min:1)		
0-12 months	33	50.8
13 months and over	32	49.2
Receiving radiotherapy		
Yes	6	9.2
No	59	90.8

Table 2. The distribution of parents according to their socio-demographic characteristics

	n	%
Mean age of the mother	35.33±6.31	
Age group of the mother		
≤ 35 age	35	53.8
≥ 36 age	30	46.2
Mean age of the father	39.30±6.29	
Age group of the father		
≤ 35 age	20	30.8
≥ 36 age	45	69.2
The number of children (n=63)		
1 child	8	12.3
2 children and more	57	87.7
Educational status of the mother		
Below high school	39	60.0
High school and above	26	40.0
Educational status of the father		
Below high school	33	50.8
High school and above	32	49.2
The occupation of the mother		
Housewife	58	89.2
Civil servant	2	3.1
Worker	3	4.6
Others	2	3.1
The occupation of the father		

Civil servant	7	10.8
Worker	25	38.5
Self-employed	28	43.8
Others	5	7.7
Family income level before the diagnosis of the child		
Income less than expenditure	21	32.3
Equal income and expenditure	41	63.1
Income more than expenditure	3	4.6
Family income level after the diagnosis of the child		
Income less than expenditure	37	56.9
Equal income and expenditure	18	27.7
Income more than expenditure	10	15.4
Place of residence		
City	25	38.5
Province	28	43.1
Village	12	18.5
Family type		
Nuclear	57	87.7
Extended	8	12.3

Table 3. The distribution of the changes in the lives of mothers who had children with cancer

Changes	Yes		No	
	n	%	n	%
My fears have increased (n=64).	56	87.5	8	12.5
My workload at home has increased (n=64).	54	84.4	10	15.6
I have a more stressful life (n=64).	53	82.8	11	17.2
I feel physically tired (n=64).	53	82.8	11	17.2
I am unable to spend time with my relatives as much as I used to (n=64).	51	79.7	13	20.3
I am unable to spend time with friends (n=64)	48	75.0	16	25.0
I have more financial difficulties (n=63)	48	76.2	15	23.8
I sleep less than before (n=64)	47	73.4	17	26.6
I am unable to spend time for past hobbies and interests (n=64)	45	70.3	19	29.7
Since my child got sick I have been paying more attention to my other children and observing them in terms of cancer symptoms (n = 64)	45	70.3	19	29.7
My child's care and treatment takes all my time. (n=64)	41	64.1	23	35.9
I have a stressful life (n=64)	40	61.5	24	37.5
I am unable to allocate time for housework (n=64)	38	59.4	26	40.6
I am unable to take care of my other children enough (n=64)	35	54.7	29	45.3
My marriage relationship with my partner is better (n=63)	31	49.2	32	50.8
The communication with my healthy children has been adversely affected (n=62)	26	41.9	36	58.1
My communication with my healthy children has improved (n=62)	25	40.3	37	59.7
My marriage relationship with my spouse has been adversely affected (n=64)	24	37.5	40	62.5
I spend more time with my other children (n=63)	20	31.7	43	68.3
I have started to use psychiatric medication (n=63)	19	30.2	44	69.8
I get permission and medical permission more often and I am unable to allocate time for my work (n=62)	7	11.3	55	88.7
I have started to outsleep (n=63)	7	11.1	56	88.9
I have left my work (n=62)	4	6.5	58	93.5

Table 4. The distribution of changes in the lives of fathers who had children with cancer

Changes	Yes		No	
	n	%	n	%
My workload at home has increased (n=62)	51	82.3	11	17.7
I have a more stressful life (n=63)	50	80.6	12	19.4
I am unable to spend time for my hobbies and interests (n=63)	49	77.8	14	22.2
I am unable to spend time with my relatives as much as I used to (n=63)	47	74.6	16	25.4
I am unable to spend time with my friends (n=63)	44	69.8	19	30.2
I feel physically tired (n=62)	43	69.4	19	30.6
Since my child got sick I have been paying more attention to my other children and observing them in terms of cancer symptoms (n = 60)	42	70.0	18	30.0
I have a stressful life (n=61)	39	63.9	22	36.1
We have more financial difficulties (n=61).	39	63.9	22	36.1
I sleep less than before (n=63)	38	61.3	24	38.7
My fears have increased (n=62).	37	59.7	25	40.3
I am unable to take care of my other children enough(n=62)	29	46.8	33	53.2
My communication with my healthy children has improved (n=61)	27	44.3	34	55.7
I get permission and medical permission more often and I am unable to allocate time for my work (n=62)	26	41.9	36	58.1
My child's care and treatment is taking all my time(n=63)	24	38.1	39	61.9
I spend more time with my other children than before (n=61)	24	39.3	37	60.7
My marriage relationship with my spouse has been adversely affected (n=63)	21	33.3	42	66.7
The communication with my healthy children has been adversely affected (n=62)	19	30.6	43	69.4
I have started to outsleep (n=61)	18	43	29.5	70.5
I have started to use psychiatric medication(n=61)	18	29.5	43	70.5

Table 5. The distribution of the changes in the lives of other children at home

Changes	Yes		No	
	n	%	n	%
They are unable to do the social activities they used to do anymore (n=62)	35	56.5	27	43.5
I do not feed my healthy children with their favorite food of so that my sick child would not desire (n=61)	34	52.3	28	45.2
They are more nervous (n=62)	33	53.2	29	46.8
They are unhappier (n=62)	31	50.0	31	50.0
They are more introverted (n=62)	26	41.9	36	58.1
Their school success has not been affected (n=61)	26	42.6	35	57.4
Healthy children have had to take more responsibilities at home (n=62)	26	41.9	36	58.1
The communication between my healthy children and sick child has been affected positively (n=61)	25	41.0	36	59.0
The communication between my healthy children and sick child has been affected negatively (n=62)	23	37.1	39	62.9
Their school success has worsened (n=62)	17	27.4	45	72.6

Table 6. The self-health perceptions of parents in the pre and post-diagnosis period

Self-health perception	Self-health perceptions of the mothers				Self-health perceptions of the fathers			
	Good		Bad		Good		Bad	
	n	%	n	%	n	%	n	%
In the pre-diagnosis period	58	90.6	6	9.4	57	91.9	5	8.1
In the post-diagnosis period	32	49.2	33	50.8	29	46.8	33	53.2

Table 7. The distribution of the changes made at home by the family members after the children's cancer diagnosis

Changes	Yes		No	
	n	%	n	%
I change the bed clothes/linens once/ twice a week.	62	95.4	3	4.6
I often ventilate my child's room.	62	95.4	3	4.6
The curtains and other covers in the sick child's room are washed more often.	61	93.8	4	6.2
We clean the bathroom, bathtub, shower, washbasin and closet with bleach thoroughly.	58	89.2	7	10.8
I wash the clothes through a machine or hand wash with hot water.	58	92.1	5	7.9
We clean the ceilings, heating pads, floors and windows.	56	86.2	9	13.8
I do not put potted plants or dry flowers in her/his room.	56	86.2	9	13.8
I certainly wash her/his new clothes before they are used.	56	87.5	8	12.5
The room is swept and wiped at least once a week.	55	84.6	10	15.4
My child has his/her hand towel which is changed every day.	54	85.7	9	14.3
I have been using special cushions, towels, clothes and bedclothes.	50	76.9	15	23.1
I do not use a spray or perfume in his/her room the dark.	47	72.3	18	27.7
I reduced the furniture at home as much as I could.	47	73.4	17	26.6
I iron everything that belongs to my child before he/she uses them.	46	71.9	18	28.1
Toilets are cleaned after each use.	46	70.8	19	29.2
I have bought washable fiber pillows and quilts.	45	70.3	19	29.7
I do not allow people to visit his/her room.	42	65.6	22	34.4
I do not accept guests at home.	39	60.9	25	39.1
The carpet in the room was removed or covered completely.	39	60.0	26	40.0
S/he has a TV in his/her room.	21	32.8	43	67.2
S/he has a computer in his/her room.	19	29.7	45	70.3

The main changes that occurred in the lives of the fathers of children with cancer were found to be the increased workload at home (82.3%), a more stressful life (80.6%) and their inability to spend time for their hobbies and interests (77.8%) (Table 4). According to table 5, regarding the other children at home the mothers stated that they could not do the social activities they used to do anymore (56.5%), she did not feed her healthy children with the favorite food so that the sick child would not desire (52.3%) and they were more nervous than before (53.2%). It was determined that the self-health perceptions of most of the mothers and fathers were good and bad in the pre and post diagnosis period respectively (Table 6). Regarding the changes they made at home, the parents stated that most of them changed the bed clothes/linens once/ twice a week (95.4%), they often ventilated their child's room (95.4%) and the curtains and other covers in the sick child's room were washed more often (93.8%) (Table 7).

In the study, compared with the mothers under 35 (%52.9), the mothers over 35 (76.7%) stated that the care and treatment of their children took

all their time more and there was a statistically significant difference between maternal age and the total time spent for the care and treatment of children ($X^2 = 3.897$; $p = 0.04$). Most of the mothers who stated that their communication with their other children was positive were in the age group of 35 and over (62.1%) ($X^2 = 10.708$; $p = 0.01$). It was found that compared with the mothers with an education level below high school (28.2%), those with high school education and above (59.1%) could not spend time with their children. The fathers who could not spend time with their children had a high school education and above (60.5%) and there was a statistical difference between the education levels of the mothers ($X^2 = 5.622$, $p = 0.01$) and fathers ($X^2 = 8.961$; $p = 0.00$) in terms of their status of spending time with their other children.

The marriage relationship with the spouses has been adversely affected more in the mothers with high school education level and above (%79.3) compared with those with lower education level (41.0%) and a significant difference was found between the groups ($X^2 = 7.324$, $p = 0.02$).

The study demonstrated that mostly mothers with high school and below education level (66.7%) could no longer do social activities they used to do and that there was a statistically significant difference between the groups ($X^2 = 4.462$, $p = 0.03$). Most of the fathers (90.3%) with high school and above education level stated that they could not spend time on their hobbies and interests ($X^2 = 4.102$, $p = 0.04$). Most of the fathers with high school and below education pointed out that they had very stressful lives (77.4%) and had to take more responsibilities at home (54.5%). There was a significant difference between these groups ($X^2 = 4.971$, $p = 0.02$, $X^2 = 4.607$; $p = 0.02$ respectively)

Discussion

Cancer is known to have negative effects on family life. It affects the lives of all family members and causes severe stress. The social activities of family members may decrease, family members may experience social isolation, and it is difficult to organize family activities. The fact that the family members are responsible for their sick children 24 hours a day increases the burden of care and can be overwhelming (Ak, 2013). One of the most challenging aspects of being a parent of a cancer-diagnosed child is to balance between the his/her treatment needs and a normal family life. Cancer can form an important part of family life and can be prior to the other issues. Once their children are diagnosed with cancer, families mostly feel that everything in their lives will change and they have to make a series of adjustments in their lives. The normal family life suddenly starts to include hospital appointments and hospitalizations. In addition, in the families in which both parents work, one of the parents may have to leave work to look after the sick child. This situation may lead to financial problems, deteriorate family relationships and reduce tolerance to each other at the end (Ak, 2013). Providing care for the sick child brings various dimensions such as a restriction of social life and daily activities, difficulties in family and marital relations, economic difficulties and insufficient time for other family members (Ozdemir et al., 2009). The study findings indicated that the families of cancer-diagnosed children mostly experienced negative changes, which is consistent with the related literature. The data demonstrated that the mean ages of the mothers and fathers were 35.33 ± 6.31 and 39.30 ± 6.29

respectively, the education level of the majority of the mothers and fathers were below high school, most of the mothers were not employed, the fathers were mostly self-employed, the income and expenditures of most of the families were equal, they lived in the district and had nuclear families. The average age of the children who were diagnosed with cancer was 7.74 ± 4.00 , the majority of them were male, their diagnosis was leukemia, all of them received chemotherapy and the duration of their disease was 18.7 ± 13.8 months.

It may be difficult and frightening for parents to care for a child with a life-threatening disease (Toruner and Buyukgonenc 2013). The top changes influencing the parents' lives were the limitation of enjoyable and relaxing leisure activities, a reduction in self-care role, creating an additional burden for costs not covered by social security and reduced work hours (Yesil et al., 2016). It is also stated that the family members begin to have feelings such as sadness, anxiety, fear, loneliness, unhappiness, to think of nothing but the disease and to stay away from social activities (Yesil et al., 2016). Mothers participate more in child care during the disease and working mothers may have to leave their work. The fact that they cannot spend time for their social activities increases their care load (Er 2006). Consistent with the literature, our study also showed that the parents had increased fears and workload, their life became more stressful, they could not spend time with their relatives and friends and they had more financial difficulties after their child was diagnosed with cancer. Yesil et al. found that the major social and psychological problems resulting from care was a reduction in their relationship to other people (colleagues, social friends, etc.) (53.9%) and fear (48.3%) respectively.

The changes such as financial problems, family support-related problems, the loss of physical strength and the changes in self-confidence affect the burden and life quality of families. Because the family allocates more time for the care of the sick child in this period, dependence develops and they end up with limited time for themselves and for each other (Yaman, 2011; Ikeda et al., 2012). Parents and healthy siblings may not have the same feelings about the changes in their lives. Healthy siblings at home are reported to experience depression, anger, anxiety, feelings of guilt, social isolation and limited family activities

as the unhappiest and emotionally neglected members of the family related to the disease. They may be anxious about the condition of their sick sibling or may feel jealous towards him/her due to the decreased interest on them. In addition, during the periods when their sick sibling is hospitalized, healthy siblings that are left to the neighbors may feel anger and insecurity (Ak 2013). Parents may not give priority to the needs of other healthy children, because most of their time and energy are allocated to their sick child. This situation was reported to lead to school problems, enuresis, depression, excessive speaking and antisocial behaviors in the healthy children (Cavusoglu, 2013). Moreover, parents' expectations from the healthy children such as housework, caring for sick sibling or younger siblings may lead to anger towards the sick sibling (Ak, 2013). Similarly, in our study the healthy children were reported to be unhappier and more nervous than before, they could not do their social activities anymore, and the mothers did not feed them with the favorite food so that their sick child would not desire.

The burden experienced by long-term caregivers of the child can lead to deterioration of physical health, psychiatric findings/ diseases and negative results in the health of the sick child (Atagun et al., 2011, Karaaslan 2013, Yesil et al., 2016). Similarly, in this study, it was observed that the perceptions of the parents whose self-health perceptions were good before changed after their child's diagnosis of cancer (Table 6). In a 2016 study by Yesil et al., it was determined that as the care load of the families increased, the levels of physical, social, emotional and mental health decreased. Schulz and Beash (1999) suggested that the mortality rates of individuals who provided care for four years were higher than those who did not by 63% and they had anxiety, worse self-health perceptions, and more depression symptoms.

An important part of cancer treatment requires effective use of home care services. The analysis of the changes that parents made in their homes demonstrated that most of them changed the bedclothes / linen once / twice a week, frequently ventilated the child's room and washed the curtains and other covers more frequently in the patient's room (Table 7). This result showed that the families took measures to protect their

children receiving chemotherapy from infections at home.

Compared with the others, the mothers at the age of 35 and over stated that the care and treatment took more time and their communication with other children was more positive than before. This result suggests that as the age increases the mothers become more experienced in care and they learn to balance their relationship with their other children. In addition, it is also thought that their workload increases due to their increased age and increased the number of children.

The study showed us that the mothers with high school education and above could spend more time with other children than before, had more positive relations with their husbands than the other group but could not do the social activities they used to do. Likewise, the related studies also reported that the caregivers whose family relationships were affected while caring faced problems such as stressful relationships in the family, discussion or separation from the spouse, tension in the family relations, paying less attention to spouse, children and housework (Beser ve Oz 2003, Kalav 2011).

In this study, the fathers with below high school education level spent more time with other children than before, had more stressful lives, had more positive communication with their sick children, took more responsibilities at home, could find time for their social activities. This result suggested that the fathers with a high level of education could not take responsibilities at home, could not spend time with their children due to the fact that they had good and permanent jobs and had more work intensity thanks to their high education level. Therefore, it can be concluded that the fathers with low education levels have more financial difficulties due to their lower income.

Conclusion

It was shown in this study that parents of children with cancer had changes in their attitudes at home such as paying more attention to nutrition, clothing, bathing, laundry selection and cleaning to provide infection control for chemotherapy. In addition, the parents were mostly found to suffer from both social and psychological aspects. Other children at home were found to be unhappier, more introverted and more nervous than before.

The difficulty of living with an individual with cancer diagnosis is known by everybody. However, this situation becomes more sensitive if the sick child is yours and if you have other children to look after. In the light of these results, we propose the necessity that the authorities in the country should urgently develop and implement programs which can improve the coping mechanisms of the families in this situation, support the family relations and prevent the deterioration of their health. In addition, it is suggested that government officials should conduct regular supervisions to increase the continuity and quality of these programs.

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