

# The Effect of Informing Children Diagnosed with Acute Lymphoblastic Leukaemia and Their Families About the Disease and Its Treatment on Quality of Life

## Akut Lenfoblastik Lösemi Tanılı Çocuklar ve Ailelerini Hastalıkları ve Tedavileri Hakkında Bilgilendirmenin Yaşam Kalitesine Etkisi

Şenay ÇETİNKAYA,<sup>a</sup>  
Ayşe SONAY KURT<sup>b</sup>

<sup>a</sup>Paediatric Nursing,  
School of Health, University of  
Çukurova, Adana

<sup>b</sup>Paediatric Nursing,  
School of Health, University of Selçuk,  
Konya

Geliş Tarihi/Received: 21.08.2008  
Kabul Tarihi/Accepted: 23.03.2009

*This study was presented at the 1<sup>st</sup> International Health Improvement and Health Education Congress (9-12 November 2006; Muğla, Turkey) as a poster presentation. Financial support was received from Research Fund of Selçuk University as project number 2004/053.*

Yazışma Adresi/Correspondence:  
Şenay ÇETİNKAYA  
Adana School of Health,  
Çukurova University,  
Paediatric Nursing, Adana,  
TÜRKİYE/TURKEY  
scetinkaya@cu.edu.tr

**ABSTRACT Objective:** This quasi experimental study was conducted to examine the effect of information about planned chemotherapy on the characteristics of their quality of life (QoL) given to children with Acute Lymphoblastic Leukaemia (ALL). **Material and Methods:** Forty seven children and their parents, who were already receiving chemotherapy in Selçuk University, Meram Faculty of Medicine, Paediatric Haematology-Oncology Clinic, and the applicants came for follow-up between the March 01<sup>st</sup> and April 30<sup>th</sup> 2005, have constituted the main set of samples of this research. The children and families were asked to complete a data collection form about their descriptive characteristics and the Kindl R quality of life tests were applied thereafter. They were given information about chemotherapy as they came to the polyclinic for medical controls, one day every week during one month of period. At the end of this period, the second scale application was performed during their next month's appointments, where a "chemotherapy information booklet" was also introduced to the families. During the data analysis, paired-sample test was used for determining the average values and percentages, one-way ANOVA test was applied when there were three or more parameters, and the Tukey test was used for advanced analysis. The analyses were conducted on a computer using SPSS 11.5 statistics program. **Results:** The life quality scores after information reported by both the children (t4-7= 19.640 p< 0.05, t8-12= 25.853 p< 0.05) and their families (t4-7= 12.762 p< 0.05, t8-12= 19.016 p< 0.05) were found to be increased comparing to that before information. An increase in the area of self respect was achieved for every age group informed about chemotherapy. **Conclusion:** It can be concluded that the information about chemotherapy, and related training programmes for the children with ALL and their families, would improve their life qualities.

**Key Words:** Child; quality of life; pediatric nursing; chemotherapy, adjuvant

**ÖZET Amaç:** Araştırma ALL' li çocuklara verilen kemoterapi ile ilgili bilgilendirmenin çocukların yaşam kalitesine etkisini araştırmak amacıyla yapılmıştır. **Gereç ve Yöntemler:** Yarı deneysel bir çalışmadır. 01 Mart-30 Nisan 2005 tarihleri arasında Selçuk Üniversitesi Meram Tıp Fakültesi Pediatrik Hematoloji-Onkoloji polikliniğine kontrol amaçlı başvuran ve hala kemoterapi alan 47 çocuk ve anne babası araştırmamın örneklemini oluşturmuştur. Çocuk ve ailelerine bilgilendirme öncesi tanıtıcı özelliklerini içeren veri formu ile Kindl R yaşam kalitesi ölçekleri uygulandı. Bir ay boyunca haftada bir gün poliklinik kontrolüne geldikleri zaman kemoterapi hakkında bilgi verildi. Bir aylık süreç sonrasında aileye kemoterapi hakkında bilgilendirme kitapçığı verilerek bir ay sonraki randevularında ikinci ölçek uygulaması yapıldı. Verilerin değerlendirilmesinde ortalama ve yüzdelere, paired-sample t testi, üç ve daha fazla sayıda değişkenler için one-way ANOVA testi, ileri analiz için Tukey testi kullanılmıştır. Değerlendirmeler bilgisayar ortamında (SPSS 11.5) istatistik programında yapılmıştır. **Bulgular:** Bilgilendirme sonrasında bilgilendirme öncesine göre hem çocuk (t4-7= 19.640 p< 0.05, t8-12= 25.853 p< 0.05) hem de aileleri tarafından bildirilen yaşam kalitesi puanının (t4-7= 12.762 p< 0.05, t8-12= 19.016 p< 0.05) yükseldiği bulunmuştur. Kemoterapi hakkında bilgilendirme her yaş grubunda özsaygı alanında artış sağlamıştır. **Sonuç:** ALL'li çocuk ve anne-babalarını kemoterapi hakkında bilgilendirme ve eğitim programlarının yaşam kalitelerini arttıracacağı söylenebilir.

**Anahtar Kelimeler:** Çocuk; yaşam kalitesi; pediatri hemşiresi; kemoterapi, adjuvan

Leukaemia is a heterogeneous neoplastic disease group that develop due to malignant transformation of haematopoietic (blood building) cells.<sup>1</sup> Childhood leukaemia constitutes 35% of all malignancies in children under the age of 15,<sup>2,3</sup> and 30% of the childhood cancers.<sup>4</sup> In children, acute lymphoblastic leukaemia (ALL) is the most common type of leukaemia (75%).<sup>5-7</sup>

With the help of improvements in treatment, many patients can be cured or have their lives lengthened.<sup>8</sup> Because the cancer treatment is complex and is long-term, it can damage physical well-being besides the psychosocial aspects of life.<sup>9</sup> The physical, psychological and social effects of cancer on the patients and their families have led to discussions regarding to the quality of life (QoL) of these patients.<sup>10</sup> The healthcare staff determining the quality of life looks for relieving the disturbances of cancer itself while doing the very same about its symptoms therewithal.<sup>11</sup>

QoL is a broad concept, temporarily affected by disease diagnosis and treatment, has all aspects of life including but not limited to only health and illness matters. QoL is also affected by parameters like education, employment and environment. Therefore the term, "health related quality of life," implies that the patient is affected in almost all areas of life.<sup>12</sup>

The QoL of cancer patients has been getting more attention in the last two to three decades.<sup>13</sup> Various quantitative scales have been created to assess the health related quality of life.<sup>13,14</sup>

Evaluating the effect of cancer on QoL of the patient and that of the family can help choosing the most appropriate treatment program which would improve the functional abilities, happiness and the general health of patients. Therefore, the adaptation of patients and their families to the disease brings about improvements on QoL.<sup>15</sup>

In this study, an answer to the question of whether or not information about the disease, the chemotherapy and its side effects would result in any decline at the anxiety levels of the children diagnosed with ALL besides their families, thus, ac-

chieving improvements in their life qualities was sought.

## MATERIAL AND METHODS

This quasi-experimental study was conducted in order to determine the effects of giving chemotherapy information to the 4-to-12 years old children diagnosed with ALL on their life qualities. The patients were being treated in Selcuk University, Meram Faculty of Medicine, Paediatric Haematology-Oncology Outpatient Clinic in Konya, Turkey.

The research population was comprised of children and their families who came to Selcuk University Meram Faculty of Medicine, Paediatric Haematology-Oncology Outpatient Clinic. The research sample was comprised of 47 children who were already receiving chemotherapy and their families and who came for the follow up appointments between March 1 and April 30, 2005.

In the research, the researchers helped a variety of tests to be completed, namely a social-demographic questionnaire form, a questionnaire for the young children between ages of 4-7 years (Kiddy-Kindl<sup>®</sup>), questionnaire for the QoL of Small Children, 4-7 age group Family Form of Kindl<sup>®</sup>, questionnaire for the Children of 8-12 age group (Kid-Kindl<sup>®</sup>), questionnaire for the QoL of Children and Adolescents 8-16 age Group, Family Form of Kindl<sup>®</sup>.

The QoL scale form developed for small children (Kiddy Kindl<sup>®</sup>) is the only scale developed for 4-7 age group. It is difficult to evaluate the QoL of children, particularly children in the 4-7 year old age group. Participation of the families of the children increases the reliability. This scale can be used for both children with chronic diseases and healthy children. This scale was developed by Ravens-Sieberer in 2000.<sup>15</sup> Studies for validity and reliability for our country were conducted by Erhan Eser and colleagues in 2003.

Sociodemographic questionnaires were used in the first interview for the purpose of data collection, and QoL questionnaires and information booklet about chemotherapy for children and families were used in the first and last interviews. Data col-

lection forms consisted of 26 questions concerning information about the child, disease, and parents. The sociodemographic questionnaire used in the study was developed by the researchers in light of information in the literature.<sup>3,7,16-20</sup>

The information booklet about chemotherapy was also developed by the researchers in light of information in the literature.<sup>3,7,17-20</sup> The booklet consists of 29 pages, and contains information about ALL, chemotherapy and adverse effects of chemotherapy.

The booklet was given to the children and their families after evaluating the QoL of the children recruited for the study. Chemotherapy information was provided in the weekly sessions in the form of questions and answers when the patients came to the outpatient clinic for a control visit. It was performed one day in a week for four weeks. The educational sessions were conducted in Meram Medical Faculty Primary School in a quiet and calm environment. After presenting the basic information about cancer and ALL, chemotherapy, possible adverse effects due to chemotherapy, precautions to prevent such adverse effects, what to do when such adverse effects occur, and subjects on general care such as nutrition, and hygiene were included in this information.

The purpose of the information given to the children and their families was to inform them about the disease and chemotherapy, side effects of this treatment, and what to do for these side effects. The expected result was to observe a decreased anxiety about the disease and the side effects and an increased QoL.

The final research data were collected by the researchers by re-administering the QoL scales when the children came in the next month for their appointment.

Averages and percentages were used for the evaluation of data. Paired-sample t test was used for coupled variables for the purpose of determining a change in QoL before and after the chemotherapy training sessions, one-way ANOVA test was used for three or more variables, and Tukey test was used for further analysis.

Approval by Selçuk University Meram Faculty of Medicine Ethics Committee was obtained to conduct the study. Written permission from the Directorate of National Education of Konya Province was obtained to use the Meram Faculty of Medicine Primary School as the physical setting. Participating children and their families were informed about the research and their verbal consent was obtained.

Our study was limited to the inclusion of only the children in the 4-12-year-old age group who had received and were receiving chemotherapy between the March 1 and April 30, 2005, with the diagnosis of ALL.

The financial support was obtained from Selçuk University Research Fund with the project no. 2004/053.

## RESULTS

In this study, 61.7% of the participants reported their financial statuses as “expenses exceeding the income”. The descriptive characteristics are given in Table 1. No differences were found in the distribution of positive family history for cancer among age groups ( $t=0.311$ ,  $p=0.757$ ). When positive cancer history in the family was considered together with QoL scores, although QoL scores increased, there were no significant differences in either the QoL scores reported by the child (pre test value:  $t=1.480$ ,  $p=0.146$ , post test 2:  $t=1.076$ ,  $p=0.288$ ) or in the QoL scores reported by the family (1  $t=0.948$ ,  $p=0.349$ ; 2  $t=0.417$ ,  $p=0.679$ ) ( $p>0.05$ ).

The majority (73%) of the mothers' educational level was primary school and 27% was middle school or higher, yet 80% of the fathers had a middle school or higher level of education and 20% primary school. The majority of the participating parents (78.7%) were unemployed and 21.3% were employed. All family members who were employed had a nuclear family structure.

The parents' employment status was not found to have an effect on children's QoL scores. Although the educational status did not seem to have an effect after the educational session, some effect was observed. Statistically significant differences were detected.

**TABLE 1:** Distribution of parents' descriptive characteristics.

Descriptive characteristics	n	%
<b>Age group</b>		
20-29 years	25	53.2
30-39 years	22	46.8
<b>Relationship with patient</b>		
Mother	34	72.3
Father	13	27.7
<b>Health Insurance</b>		
Bağ-kur	27	57.4
Pension Fund	10	21.3
Social Security Institution	10	21.3
<b>Income status</b>		
Expenses exceed income	29	61.7
Expenses equal income	18	38.3
<b>Place of residence</b>		
Village	26	55.3
Province- District centre	21	44.7
<b>Number of children in the family</b>		
1 child	15	31.9
2 children	24	51.1
3 or more children	8	17.0
<b>Cancer history in the family</b>		
Positive	8	17.1
Negative	39	82.9
<b>Changes in inter-family relationships</b>		
Increase in support and solidarity within family	21	44.7
Difficulties encountered related to stress	12	25.5
Social isolation	14	29.8
<b>Ideas about the disease</b>		
Requires long-term treatment	24	51.1
Disease will be cured	18	38.3
Disease will not be cured	5	10.6
<b>Ideas about chemotherapy</b>		
It will cure the disease	24	51.1
It will reduce the symptoms of the disease	18	38.3
It will stop the progression of the disease	5	10.6
Total	47	100.0

ted in the scores of parents with middle school education or higher ( $t= 3.253$ ,  $p= 0.002$ ) and in their children's scores ( $t= 2.717$ ,  $p= 0.009$ ).

Types of health insurance of parents was found to have an effect on QoL ( $t= 2.545$ ,  $p= 0.016$ ), and results concerning Bağ-Kur (a national social security health insurance for self employed workers) had a much stronger correlation ( $p< 0.05$ ).

When the QoL scores and sociodemographic characteristics were compared, a generally significant difference was found ( $t= 3.560$ ,  $p= 0.001$ ), but no single factor was singularly influential ( $p> 0.05$ ).

Gender was not found to have an effect on QoL scores of the children; 51.1% of whom were females and 48.9% of whom were males. Two thirds (66.6%) of the girls were between four and seven years old; 33.4% were between eight and 12 years old. Almost half (47.8%) of the boys were between four and seven and 52.2% were between eight and 12. Statistically significant differences were found for children's QoL scores according to their age group ( $t_{\text{child}}= 2.413$   $p= 0.020$ ,  $t_{\text{family}}= 5.357$   $p= 0.000$ ). The children's age group had a positive effect on QoL scores after the education was provided, however it had a negative effect before the educational session.

Of all the children, 57.5% were in the four to seven year old age group and 42.5% were in the eight to 12 year old age group. Nine of the children (19.2%) were diagnosed with leukemia when they were between one and three years of age, 25 (53.2%) between four and six years, and 13 (27.6%) when they were over six year old. When mothers and fathers were asked whether they knew about the diagnoses of their children, none of them was found to be aware of it. When distribution of the age at ALL diagnosis was investigated, statistically significant differences were found ( $t= 6.884$ ,  $p= 0.000$ ). There were also statistically significant differences between age groups for parents' opinions about the disease ( $t= 2.727$ ,  $p= 0.009$ ).

The child's age at the diagnosis was found to be ineffectual on child's QoL score before the chemotherapy training. However, the age at the diagnosis had considerable negative effects on QoL after the training of children. The diagnosis age had a negative effect on the parents before the education, however it had a positive effect on the parents after the education (Table 2). Following the results of the Tukey's HSD advanced test, the age at diagnosis over six years old was found to be the source of the difference ( $p< 0.05$ ).

It was determined that 10 of the children (21.3%) were hospitalized one to three times, 25

(53.2%) four to six times, and 12 (25.5%) more than seven times. When the age groups of the children were compared with their number of hospitalization, no statistically significant differences were found ( $t= 0.573$ ,  $p= 0.569$ ).

The families were asked for the number of hospitalizations of their children. There were no significant differences in QoL scores for the child or for the family according to number of hospitalizations before chemotherapy education; yet, after education, differences found (Table 2). As a result of Tukey's HSD advanced test, the source of this difference was found to be the children hospitalized more than six times ( $p < 0.05$ ).

When the frequency of hospitalization was examined, it was seen that 25 (53.2%) came every two weeks, 15 (31.9%) once a month, and seven (14.9%) every three months.

Although a significantly positive difference was observed between the hospitalization frequency and the children's QoL scores both before and after receiving information about chemotherapy, it was determined that there was no statistically significant difference between the families' QoL scores either before or after receiving information about chemotherapy (Table 2). In the Tukey's HSD

advanced test analysis, it was determined that the scores for the children hospitalized every two weeks were significantly different from the other groups ( $p < 0.05$ ).

When the effect of the ideas of parents about the disease on QoL scores was considered, the children's QoL scores before and after the education were not found to be statistically significant ( $F= 0.012$ ,  $p= 0.998$ ;  $F= 0.472$ ,  $p= 0.703$ ), however a statistically significant negative difference was found between the families' QoL scores before and after the education ( $F= 3.029$ ,  $p= 0.040$ ). In the Tukey's HSD advanced test analysis, it was seen that the QoL scores for parents expecting cure were found to be significantly different from other groups ( $p < 0.05$ ).

When the relation between the economic status and the QoL scores was analysed, it was found that the children gave themselves negative scores before the education ( $t= 4.658$ ,  $p= 0.036$ ) and after the education ( $t= 7.253$ ,  $p= 0.010$ ), and on the scores the family gave the child before being informed about the chemotherapy ( $t= 5.783$ ,  $p= 0.020$ ); however, it was not found to have an effect on QoL scores the family gave the child after being informed ( $t= 0.217$ ,  $p= 0.643$ ).

**TABLE 2:** QoL scores according to age of onset, number of hospitalizations and frequency of hospitalizations (average  $\pm$  SD).

QoL score according to age of onset	1-3 years	4-6 years	> 6	F	P
Children's pre-education score	50.00 $\pm$ 5.51	40.00 $\pm$ 11.33	42.55 $\pm$ 5.34	1.737	0.188
Children's post-education score	84.72 $\pm$ 6.58	76.67 $\pm$ 7.85	68.59 $\pm$ 4.05	4.917	0.012
Families' pre-education score	53.80 $\pm$ 8.31	50.90 $\pm$ 10.11	42.20 $\pm$ 5.23	3.212	0.050
Families' post-education score	69.75 $\pm$ 3.16	70.05 $\pm$ 4.97	71.79 $\pm$ 4.18	4.562	0.016
<b>QoL score according to number of hospitalizations (average <math>\pm</math> SD)</b>					
	1-3 times	4-6 times	> 6 times	F	P
Children's pre-education score	39.17 $\pm$ 11.32	44.50 $\pm$ 10.86	41.58 $\pm$ 3.40	3.903	0.054
Children's post-education score	76.67 $\pm$ 9.46	77.29 $\pm$ 7.99	72.66 $\pm$ 9.13	6.555	0.014
Families' pre-education score	50.49 $\pm$ 4.47	50.00 $\pm$ 11.40	45.67 $\pm$ 8.25	1.950	0.169
Families' post-education score	67.28 $\pm$ 3.01	70.15 $\pm$ 5.09	70.47 $\pm$ 4.32	4.225	0.046
<b>QoL score according to hospitalization frequency (average <math>\pm</math> SD)</b>					
	Every two weeks	Once a month	Every 3 months	F	P
Children's pre-education score	43.25 $\pm$ 7.01	43.68 $\pm$ 12.48	38.10 $\pm$ 11.53	6.712	0.013
Children's post-education score	75.75 $\pm$ 8.79	79.24 $\pm$ 7.49	69.79 $\pm$ 7.80	6.540	0.014
Families' pre-education score	48.64 $\pm$ 9.15	52.17 $\pm$ 10.84	43.83 $\pm$ 6.27	3.985	0.052
Families' post-education score	69.85 $\pm$ 4.25	68.70 $\pm$ 5.30	70.77 $\pm$ 4.64	1.739	0.194



Changes occur in family relationships after diagnosis. The QoL scores the child got before and after being informed about the chemotherapy was considered. The difference between the QoL scores given to the child by the family was not found to be significant ( $F= 3.985, p= 0.052$ ;  $F= 1.739, p= 0.194$ ), yet there were significant differences in the QoL scores the children gave to themselves ( $F= 6.712, p= 0.013$ ;  $F= 6.540, p= 0.014$ ). As a result of the advanced analysis of QoL with Tukey's HSD test, the scores of children receiving family support were found to be significantly higher than of those experiencing social isolation ( $p < 0.05$ ).

When the opinions of families regarding the chemotherapy and the average of the QoL scores the child got before and after chemotherapy training were investigated, the difference between QoL scores children gave to themselves ( $F= 0.120$ ;  $p= 0.887$ ;  $F= 0.509, p= 0.605$ ) and the scores the family gave to children ( $F= 0.564, p= 0.573$ ;  $F= 0.799$ ;  $p= 0.456$ ) were not found significant ( $p > 0.05$ ).

A close relationship was found between the children's QoL scores before and after chemotherapy training, and sociodemographic characteristics ( $B= 31.252, t= 2.174, P= 0.038$ ). When the relationship between the gender of the child and the QoL score of the child was examined, it was seen that the differences in both genders were similar (Girls:  $(78.82 \pm 9.03)-(45.14 \pm 8.15)$ ; Boys:  $(73.01 \pm 7.27)-(39.99 \pm 10.64)$ ).

QoL scores reported by children in the 4-7 year old age group and 8-12 year old age group and their families before and after education about chemotherapy are given in Table 3. There were statistically sig-

nificant positive differences in the scores before and after education for both age groups ( $p < 0.05$ ).

The QoL scores given by the 4-7 year old and 8-12 year old age group children before and after chemotherapy training and the QoL scores given by the families about their children before and after training are shown in Tables 4 and 5.

All parents of the children participating in this research stated that they did not have enough information about chemotherapy. A positive significant relationship was found between opinion about the effect of chemotherapy and QoL scores. The QoL scores were higher for those who thought that chemotherapy would heal their child.

After the chemotherapy training, the QoL scores given by both the children ( $t_{4-7}= 19.640 p < 0.05, t_{8-12}= 25.853 p < 0.05$ ) and their families ( $t_{4-7}= 12.762 p < 0.05, t_{8-12}= 19.016 p < 0.05$ ) were found to have increased compared to their scores before the training. In order to minimize the anxiety of children with ALL and their families, helping them to have the trust in healthcare staff, and to be on good terms with them proved to be crucial. Thus, it can be concluded that informing them about chemotherapy by training programs given by the staff working with cooperation can improve their quality of lives.

## DISCUSSION

The word "cancer" is seen as a negative concept inducing negative feelings like anxiety or fear. Other members of the family are also affected by the disease because the difficulties encountered by the patient, increased expenses, and worsening of social status because of the obligation of giving care to the patient.<sup>16,17</sup>

**TABLE 3:** QoL scores of the children before and after education about chemotherapy (average  $\pm$  SD).

	Before education about chemotherapy		After education about chemotherapy		t	P
	Score (average $\pm$ SD)	% (average $\pm$ SD)	Score (average $\pm$ SD)	% (average $\pm$ SD)		
4-7 year old children	22.30 $\pm$ 2.89	42.90 $\pm$ 12.05	31.37 $\pm$ 1.90	80.70 $\pm$ 7.94	19.640	0.000
Parents of 4-7 year old children	144.07 $\pm$ 17.58	53.30 $\pm$ 9.56	171.81 $\pm$ 8.26	68.38 $\pm$ 4.49	12.762	0.000
8-12 year old children	64.55 $\pm$ 5.15	42.24 $\pm$ 5.36	90.80 $\pm$ 4.26	69.58 $\pm$ 4.44	25.853	0.000
Parents of 8-12 year old children	65.59 $\pm$ 5.88	43.32 $\pm$ 6.13	92.45 $\pm$ 4.16	71.30 $\pm$ 4.33	19.016	0.000

**TABLE 4:** QoL scores of 4-7 year old children before and after the education about chemotherapy (average  $\pm$  SD).

Children's QoL scores				
	Pre-education $\pm$ SD	Posteducation $\pm$ SD	t	P
Bodily well-being	1.26 $\pm$ 0.44	2.17 $\pm$ 0.60	0.641	0.431
Emotional well-being	1.95 $\pm$ 0.54	2.15 $\pm$ 0.47	0.045	0.834
Self-respect	1.91 $\pm$ 0.39	2.82 $\pm$ 0.38	6.019	0.021*
Family	2.26 $\pm$ 0.46	2.77 $\pm$ 0.42	2.357	0.137
Social relationships	1.57 $\pm$ 0.44	2.15 $\pm$ 0.49	5.556	0.027*
School	1.25 $\pm$ 0.56	2.59 $\pm$ 0.44	0.791	0.382
Questions regarding the long-term illness	2.07 $\pm$ 0.57	2.26 $\pm$ 0.57	2.643	0.092
Families' QoL scores				
	Pre-education $\pm$ SD	Posteducation $\pm$ SD	t	P
Bodily well-being	2.33 $\pm$ 0.54	2.74 $\pm$ 0.59	2.156	0.154
Emotional well-being	2.72 $\pm$ 0.55	2.87 $\pm$ 0.86	2.647	0.116
Self-respect	2.97 $\pm$ 0.76	3.72 $\pm$ 0.69	0.517	0.001*
Family	3.29 $\pm$ 0.71	3.41 $\pm$ 0.62	7.258	0.012*
Social relationships	2.77 $\pm$ 0.82	2.84 $\pm$ 0.64	2.516	0.102
School	2.50 $\pm$ 0.86	3.83 $\pm$ 0.57	5.643	0.010*
Some important questions	2.74 $\pm$ 0.64	2.81 $\pm$ 0.91	0.000	1.000
Questions regarding the long-term illness	2.86 $\pm$ 0.67	3.35 $\pm$ 0.87	2.451	0.108

\* Difference between pre and post-education scores is significant (P<0.05)

**TABLE 5:** QoL scores of 8-12 year old children before and after education about chemotherapy (average  $\pm$  SD).

Children's QoL scores				
	Pre-education $\pm$ SD	Post-education $\pm$ SD	t	P
Bodily well-being	2.02 $\pm$ 0.54	2.91 $\pm$ 0.54	1.238	0.281
Emotional well-being	2.50 $\pm$ 0.57	3.43 $\pm$ 0.69	0.456	0.508
Self-respect	2.59 $\pm$ 0.69	3.80 $\pm$ 0.62	5.326	0.033*
Family	3.18 $\pm$ 0.53	3.21 $\pm$ 0.56	1.838	0.189
Social relationships	2.70 $\pm$ 0.69	3.38 $\pm$ 0.60	0.094	0.762
School	3.13 $\pm$ 0.61	3.20 $\pm$ 0.59	1.615	0.228
Some important questions	3.19 $\pm$ 0.68	3.59 $\pm$ 0.49	0.321	0.578
Families' QoL scores				
	Pre-education $\pm$ SD	Posteducation $\pm$ SD	t	P
Bodily well-being	2.44 $\pm$ 0.52	2.89 $\pm$ 0.58	0.169	0.686
Emotional well-being	2.46 $\pm$ 0.49	3.35 $\pm$ 0.74	10.800	0.004*
Self-respect	2.65 $\pm$ 0.67	4.00 $\pm$ 0.53	0.514	0.482
Family	3.11 $\pm$ 0.60	3.28 $\pm$ 0.71	0.071	0.794
Social relationships	2.66 $\pm$ 0.78	3.05 $\pm$ 0.47	2.184	0.157
School	2.95 $\pm$ 0.63	3.18 $\pm$ 0.62	0.017	0.898
Some important questions	2.83 $\pm$ 0.50	3.67 $\pm$ 0.61	0.831	0.374

\* Difference between pre and post-education scores is significant (P<0.05)

When the changes of family relationships as reported by the parents are considered, it is seen that there is an increase in solidarity inside the fa-

mily in 44.7%, difficulties related to stress in 25.5%, and social isolation is experienced in 29.8%.

When ideas of the relatives of the patient are considered, 24 individuals (51.1%) regarded this disease as one requiring long-term treatment. None of the parents of the patients thought that they had adequate knowledge about chemotherapy. A study by Meredith et al indicated that cancer patients expected more information about cancer (96%), changes of therapy (91%), and the possible adverse effects of the therapy.<sup>21</sup> Despite the cultural differences, the similarity of the patient expectations is interesting.

An important issue for the intervention on the patients is medical information of the patients. It has been reported that patients need more communication and information. Such information will reduce the uncertainty, fear, and losses of the patients.<sup>22</sup>

A relation can be found between the ages of the parents and their levels of anxiety. Studies indicate that anxiety level can increase with the decrease of the ages of parents.<sup>3,15</sup> It was found that the age group of parents did not affect the QoL scores. It is suggested that the closeness of the age groups may be the reason for this.

Half (51.1%) of the children were girls, and 48.9% were boys. Gender of the children did not affect the QoL scores. Similarly, Kızılcı reported that gender did not affect the QoL scores.<sup>17</sup> However, Ravens-Sieberer et al found that QoL scores of girls were lower than those of boys.<sup>15</sup>

In this study 57.5% of the children were in 4-7 year old age group, and 42.5% were in the 8-12 year age group. When the age of the children at the onset of leukemia signs was considered, it was seen that 9 (19.2%) were between 1 and 3 years of age, 25 (53.2%) were 4 to 6, and 13 (27.6%) were over 6 years old. The fact that the age of onset of the disease is under 7 years age is supported by the literature.<sup>6,23,24</sup>

Children with negative experiences related to hospitals display more anxiety. Families with relatives with cancer experience more anxiety. The role of the nurse is to recognize these needs and meet them.<sup>25</sup>

When the frequency of hospitalization of the children included in the study was examined, it was seen that 25 (53.2%) came every two weeks, 15 (31.9%) came once a month, and seven (14.9%) came every 3 months. These results suggest that both the children and their families have a lack of information.

Long-term diseases affect the lives of children and their families. It affects the job activities and performances of parents, the financial status of the family and their relationships with the society. According to the study of Çavuşoğlu, it was seen that in about half of the families, business life and social life of the family are affected from the disease of the child.<sup>26</sup> Cancer is a long-term disease and exclusion of some of the required drugs and medical items from the social security health insurance pave the way to financial difficulties in the family and worsening of the quality of life. It has also been found in literature reviews that financial difficulties are the most intensely encountered problems in the families of the children with chronic diseases.

When the relation between the financial status and QoL score was examined, it was seen that it negatively affected the QoL scores reported by the child before and after ( $t= 4.658$ ,  $p= 0.036$ ) and reported by the family after ( $t= 7.253$ ,  $p= 0.010$ ) the information about chemotherapy was given ( $t= 5.783$ ,  $p= 0.020$ ); however, it did not affect the QoL score reported by the family for the child after the information ( $t= 0.217$ ,  $p= 0.643$ ).

Family support is extremely important for the success of the cancer therapy. The family needs open communication starting from the first stages of the therapy. Families need a professional to ask questions and find answers. Effective information-giving allows families to plan their future.<sup>19,22</sup>

The differences in the QoL scores reported by children in the 4-7 year old age group and 8-12 age group and their families were found to be significant before and after the information about chemotherapy was given ( $p < 0.05$ ).

Adverse effects of therapies are important factors that can negatively affect the QoL of the child, and therefore of the family. In the treatment of



cancer, chemotherapy can worsen the QoL by requiring long-term hospitalizations because of infections, nausea-vomiting, and complications that may result because of the therapy. Information about these issues will reduce the uncertainty, fears, and losses of the patients. QoL will thus be improved.<sup>22</sup> Increases in QoL scores were found in both groups examined (Table 3). This increase also indicates that information has been effective. The greatest increase in scores was in the 4-7 year old age group. It has been suggested that the most important factor in this difference was that the questions asked in this age group had three choices for answers.

While the most significant increase among the QoL scores of the children in the 4-7 year old age group after the information about chemotherapy was given reported by the children were in self-respect ((2.82 ± 0.38)-(1.91 ± 0.39),  $t = 6.019$   $p = 0.021$ ) and social relationships ((2.15 ± 0.49)-(1.57 ± 0.44),  $t = 5.556$   $p = 0.027$ ), the scores reported by the families were in self-respect ((3.72 ± 0.69)-(2.97 ± 0.76),  $t = 0.517$   $p = 0.001$ ), family ((3.41 ± 0.62)-(3.29 ± 0.71),  $t = 7.258$   $p = 0.012$ ) and school ((3.83 ± 0.57)-(2.50 ± 0.86),  $t = 5.643$   $p = 0.010$ ) fields. Improvements in these fields improved the QoL also (Table 4).

The most significant increase among the QoL scores of the children in the 8-12 year old age group after the information about chemotherapy reported by the children were in self-respect ((3.80 ± 0.62)-(2.59 ± 0.69),  $t = 5.326$   $p = 0.033$ ) field, however the scores reported by the families were in emotional well-being ((3.35 ± 0.74)-(2.46 ± 0.49),  $t = 10.800$   $p = 0.004$ ) field. Improvements in these fields also improved the QoL. This finding indicates that information has had an effect in the desired direction (Table 5). The help of informing about chemotherapy was very important for increasing self respect in all age groups.

## CONCLUSION

Considering the initial thoughts of participating parents, more than the half of them (51%) believed the disease would require a long term therapy; they declined they were adequately informed.

Although the pre-training QoL scores of families and their sociodemographics characteristics were shown to be quite different, it was, however, further suggested that neither of these seemingly relational elements could be effective quality factors when alone. It was also determined that there was a statistically significant difference between the children's QoL scores before education and their sociodemographic characteristics.

The relationship between ideas about the effect of chemotherapy and the QoL score was found to be statistically significant. QoL scores of the optimistic individuals thinking that "chemotherapy cures" were found to be higher.

As a result, it was determined that the children's QoL scores both before and after the training ( $t_{4-7} = 19.640$   $p < 0.05$ ,  $t_{8-12} = 25.853$   $p < 0.05$ ) and that of the families' ( $t_{4-7} = 12.762$   $p < 0.05$ ,  $t_{8-12} = 19.016$   $p < 0.05$ ) had improved, while the difference between these two were found to be statistically significant. It can be said that for lowering the anxiety of child with ALL and the parents, to ensure their confidence in healthcare staff for establishing positive relationships, programmes for informing children along with their parents about chemotherapy provided by a cooperating healthcare team can improve their QoL score.

The efforts in the science of nursing leads us to a universe called "quality of life", letting us to discover why it is there, only to see the reasons that bind us to our lives; these special efforts are for improving the QoL wherever it already existed, and for restoring it while it does not. By helping others and the ones who need, we begin discovering the answers eventually; and to relieve their troubling distress and anxieties, we provide them with the proper care, not magic, when they needed. We, thus, help such distressful people improving the biological, psychological, and socio-cultural aspects of their lives during a very uneasy process.

Following this study, the parents of the children diagnosed with ALL will be informed about chemotherapy and any necessary educational programmes will be promptly administered. The effect

of these activities are later to be examined in larger groups.

### Acknowledgement

Financial support was received from Research Fund of Selçuk University as project number 2004/053. We also

want to thank Professor Dr. Sait Bodur for his part in the biostatistical section of this study. We wish to express our special gratitude to Kunter Ilalan and his colleagues from Mavitepe Translation Office in Ankara after their editorial contributions and the language support for this article.

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