

## The Impact of Educating Parents of Leukemic Children on the Patients' Quality of Life

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### Abstract

**Background:** The quality of life of children with leukemia is reduced by the fear and anxiety of their parents after diagnosis and a lack of information about the disease, treatments, and care of the child.

**Patients and Methods:** In this interventional study, 60 parents of Acute lymphoblastic leukemia (ALL) children who met the inclusion criteria were selected using simple random sampling and assigned to experimental and control groups. The study tool included a valid and reliable questionnaire (TNO-AZL) that was completed through interviews with the parents before and 2 months after the intervention for both groups. The first part of the questionnaire included demographic items, and the second part (7 dimensions, each with 8 sections) contained questions related to quality of life. The scores could range between 56 and 280; higher scores represented a better quality of life. The intervention included 3 1-hour classes that were composed of a lecture and question-answer sessions, which were held for groups of 4-6 participants, accompanied by a booklet.

**Results:** Before the intervention, the quality-of-life score in the experimental and control groups was  $180.83 \pm 14.43$  and  $174.28 \pm 20/72$ , respectively; after the intervention, these values changed to  $226.9 \pm 11/76$  and  $174.41 \pm 20/42$ , respectively. By paired-sample t-test, quality of life increased significantly in the experimental group.

**Conclusions:** Parental education successfully increased the quality of life of leukemic children; therefore, parental consultation sessions and educational programs are recommended.

**Keywords:** Leukemia, Education, Parents

### Introduction

Leukemia is the most common malignancy in children, with a prevalence of 129 in 1 million, and is the second leading cause of death among children aged 5 to 14 years. Acute lymphoblastic leukemia (ALL) is the most common type of this disease, (1) accounting for 75 % of all leukemias and 30 % of all malignancies in childhood. ALL affects boys twice as frequently as girls (2). In the US, the incidence of ALL has risen from 1980 to 2002, and the current incidence is approximately 3-4 per 100,000 children aged under 15 years (3). ALL is also the most common malignancy in children of southwestern Iran, with

a prevalence of 44.5 % (4). The survival rate of children with ALL has increased in the past 30 years, based on a study in Canada (5). Occasionally, Total duration of chemotherapy (induction, consolidation and maintenance therapy) lasts 3 years (6) and the treatment is also effective and today, increasing life expectancy and rehabilitating patients to effect an appropriate quality of life are the cornerstones of therapeutic programs for children with hematological malignancies (3). The concept of quality of life is generally considered as the perception of one's welfare, which originates from his current life experience (7). Several studies have noted a decline in the quality of life in leukemic children (8-10). Studies have also indicated that enhancement of parents' knowledge about the problems and needs of their leukemic children has an important effect on family support, leading to a significant increase in the quality of life of these children (11, 12). Other studies have confirmed that such interventions affect the quality of life of children with oth-

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er chronic diseases (13-15). Until now, there has been no research on the impact of educating parents of leukemic children on the patients' quality of life in Iran. This study aims to determine the effect of educating the parents of leukemic children on the patients' quality of life.

## Patients and Methods

This interventional study was performed in Motahhari Clinic of Shiraz University of Medical Sciences and Afzalipoor Hospital of Kerman University of Medical Sciences, in the southern regions of Iran, in 2009. Sixty parents of ALL children were selected using simple random sampling and assigned to intervention and control groups (30 participants in each group). Inclusion criteria were parents with children with a diagnosis of ALL between 1 month and 2 years prior the study; the leukemic child was under maintenance therapy; no other chronic disease was present expect ALL; age between 7-10 years; and children with standard ALL (i.e., a white blood cell count less than 50000/fL, absence of chromosomal anomalies, and documented response to therapy in the first month of treatment) (1). Also, children with parents and siblings without any accompanying disease were included. The family had to be nuclear. The participating parents had to be literate and should not have used other consultation systems. The parents were required to give informed consent to join the study. The exclusion criteria were the participating child's death and a lack of interest of the parents in participation in the study. A previously validated reliable questionnaire (TNO-AZL: parent form) was used to assess the quality of life of the children before and 2 months after the intervention. This questionnaire was improved initially by Vogels et al. at the TNO Institute of Prevention and Health in the Netherlands. They conventionally called it TNO-AZL. The first part of the questionnaire included demographic items, and the second part contained questions on quality of life in 7 dimensions {physical (body) complaints, autonomous (auto), social, cognitive and motor functioning, positive and negative emotions}. Each dimension comprised 8 subgroups; each subgroup was scored between 1 and 5 on a Likert scale (representing the 5 levels "always," "most of the time," "sometime in the 2 most recent weeks", "rarely," and "never"). For the positive emotions dimension, choosing "always" was scored 5 and choosing "never" was scored 1; for other dimensions, "always" was scored 1 and "never" was scored 5. The scores could range between 56 (a score of 8 for each dimension) and 280 (a score of 40 for each dimension); higher scores represented a better quality of life (16). The content validity of this questionnaire was confirmed in studies by Landolt et al. in Germany and Soory in Iran. The reliability of the questionnaire was measured using Kronbach alpha and reported as 0.66-0.77 by Landolt et al. and 0.73 by Soori (10, 17). The participating parents were assisted by a researcher to complete the questionnaire at the beginning of the study. A coding system was used to ensure that the

data were collected blindly. The intervention included a combination of 3 1-hour classes, composed of a lecture, question-answer sessions—which were held for groups of 4-6 participants, each lasting 45-60 minutes—and review of a booklet (18). The first class focused on the nature of leukemia, the basic therapeutic approaches, the effect of the disease on a patient's family, and coping strategies. The second class centered around techniques to communicate with the suffering child, the effects of the disease on various aspects of a patient's life, and solutions for increasing his quality of life. The third session was dedicated to patient care in the hospital and at home. Depending on the education level of the participating parents, learning assistance tools, such as posters, were used to ensure that the learning material was absorbed by the participants. The participants could also review the contents of the sessions using the booklets. Two months after the completion of the interventions, the quality-of-life questionnaire was completed again by the parents with the assistance of a researcher. The data were analyzed using SPSS, version 11.5, and a  $P < 0.05$  was considered statistically significant. This study was approved by the ethics committees of the affiliated universities.

## Results

The mean age of the mothers was 36.1 years in the experimental group and 36.33 years in the control group, and the mean age of fathers was 42.66 years in the experimental group and 40.86 years in the control group. The mean age of the children was 8.45 years in the intervention group and 8.13 years in the control group. Seventy percent of patients in the experimental group and 80 % in the control group were boys. While 53.3 % of the fathers in the experimental group and 46.7 % in the control group worked in the private sector, 96.7 % of mothers were unemployed housewives. The majority of fathers (73.3 % in both arms) and mothers (76.7 % in the intervention group and 80 % in the control group) were educated only at the primary school level. By t-test and chi-square test, there was no difference in the aforementioned characteristics between the 2 arms of the study. Before the intervention, the quality-of-life score in the experimental and control groups was  $180.83 \pm 14.43$  and  $174.28 \pm 20.72$ , respectively; after the intervention, these values changed to  $226.9 \pm 11.76$  and  $174.41 \pm 20.42$ , respectively. T-test revealed a significant increase in the quality of life in the experimental group ( $P < 0.001$ , Table 1). Quality-of-life scores for each dimension before and after intervention and between-group differences are compared in Table 2. Scores on all dimensions increased after the intervention, with the maximum increase observed in the negative emotions dimension ( $9.23 \pm 3.19$ ) and the smallest change noted in the motor functioning dimension ( $3.33 \pm 1.53$ ). According to the results, there was no change in the control group scores on the negative emotions dimension ( $0/00 \pm 0/45$ ), and the scores for autonomous and motor functioning decreased over time ( $-0/03 \pm 0/61$  and  $-0/06 \pm$

2/82). The change in quality-of-life score before and after 2 months of intervention in the experimental group was  $46.06 \pm 10.26$  and  $0.13 \pm 1.37$  in the control group. Paired t-test confirmed a significant rise in quality-of-life scores on all dimensions in the intervention group ( $P < 0.001$ ). However, such changes in the control group were not significant. t-test showed a significant difference in quality-of-life score before and after 2 months of intervention in the experimental group (for all 7 individual dimensions and total score) ( $P < 0.001$ ).

### Discussion

At baseline, there was no difference in quality-of-life scores between two studied groups, and both groups received a moderate score on all dimensions, consistent with the baseline scores reported by Landolt *et al.* in Germany, Santos *et al.* in Brazil, and Redalli *et al.* in Italy (10, 19, 20). Speechly *et al.* also reported a lower quality-of-life score for leukemic children compared with analogous healthy children (5) So we considered interventions aimed at a better quality of life. Our findings indicate a higher quality of life in children 2 months after the intervention with their parents on all 7 measured dimensions ( $P < 0.001$ ). In another study in Iran, Allahyari *et al.* (2006) noted a significant increase in the quality of life of children with thalassemia after establishment of a family-centered improvement model for the quality of life of school-aged B-thalassemic children (14). Iconomou *et al.* reported similar outcomes after a booklet containing information about chemotherapy was given to Greek adult patients with malignant diseases (21). Our findings were also in accordance with those of Lorenzo *et al.* in Italy. They showed that a combination of lectures, booklets, and videos improved the quality of life of adult patients with malignant diseases after their first round of chemotherapy (18). We noted the largest increase in score on the negative emotions dimension and the smallest increase on motor functioning. This implies that our educational intervention for parents effectively reduced negative emotions in leukemic children, such as sadness, aggressiveness, anger, restlessness, jealousy, de-

pressed mood, and anxiety, and had a minimal effect on motor functions, such as running, walking, and playing. It is also possible that we observed few changes in motor function because of the short time span of our study (2 months) or because children undergoing chemotherapy had fewer chances to improve the quality and quantity of their motor skills (i.e., motor functions improved after completion of a course of chemotherapy and resolution of its side effects). Nevertheless, the improvement in scores on all 7 dimensions was statistically significant ( $P < 0.001$ ). Based on the information in Table 2, there was a slight increase in quality-of-life scores on the physical complaints, social and cognitive functions and positive emotions dimensions in the control group, although it was not statistically significant. This can be attributed to the fact that parents in the control group could also have acquired information from informal sources during the study, including contact with physicians and parents in the experimental group who were involved in the study, through experiences gained by the sick children, and their parents by coping with the critical circumstances related to the disease. There was no change in control group scores for the negative emotions dimension, and the scores on autonomy and motor function decreased over time. This might have been due to the nature of the disease, its side effects, the prolonged courses of treatment with repeat chemotherapy sessions, and a lack of formal education in the parents of the control group. A related study by Barrera *et al.* aimed to evaluate the role of social support in the emotional coping of siblings of children with malignant diseases. Their study showed that the siblings of children with malignant diseases who benefited from greater social support presented with signs and symptoms of anxiety, depression, and behavioral problems less frequently, consistent with our results. (22) Also, the improvement in social activities in the case group of our study resembles that of Sidhu *et al.* (2006). In the Sidhu study, social competency of siblings of children with cancer improved significantly after establishing a peer support camp for them (23). Furthermore, the results of the study by Packman *et al.* on the effect of psychological interventions on the signs and

**Table 1.** Comparison of the quality of life scores before and after intervention in the two study groups

	Before intervention (Mean ± SD)		P value <sup>a</sup>	After intervention (Mean ± SD)		P value <sup>a</sup>
	Experiment	Control		Experiment	Control	
<b>Physical (Body) complaints</b>	25.66 ± 4.89	23.5 ± 5	0.09	31.83 ± 3.47	23.53 ± 4.74	< 0.001
<b>Autonomous functioning</b>	28.26 ± 4.75	28.26 ± 5.21	0.95	34.7 ± 3.30	28.20 ± 5.35	< 0.001
<b>Social functioning</b>	24.36 ± 4.01	24.2 ± 3.80	0.92	31.1 ± 3.40	24.26 ± 3.67	< 0.001
<b>Motor functioning</b>	30.53 ± 2.60	30.16 ± 3.71	0.63	33.86 ± 2.04	30.13 ± 3.64	< 0.001
<b>Cognitive functioning</b>	25.36 ± 5.18	24.50 ± 3.70	0.45	31.13 ± 3.85	24.53 ± 3.71	< 0.001
<b>Positive emotions</b>	26.26 ± 3.99	24.36 ± 3.69	0.07	33.96 ± 2.20	24.46 ± 3.73	< 0.001
<b>Negative emotions</b>	20.76 ± 3.29	19.30 ± 4.38	0.14	30 ± 2.66	19.30 ± 4.53	< 0.001
<b>Total score</b>	180.83 ± 14.43	174.28 ± 20.72	0.16	226.9 ± 11.76	174.41 ± 20.42	< 0.001

<sup>a</sup>Independent two-sample t-test

symptoms of stress disorder, anxiety, self-esteem, and quality of life in siblings of children with cancer indicated an improvement in self-esteem and quality of life and a decrease in stress and anxiety symptoms (24) These results are all consistent with our findings, which demonstrated an improved quality of life in leukemic children after educational intervention for their parents. Our findings are also consistent with those of another study by Golchin *et al.* (2008), which observed positive effects of educational and self-control programs on the quality of life of adult patients with leukemia (25). In a Dehkordi *et al.* study, education lead to the improvements of parents' awareness of children with beta-thalassemia major disorder (26). In short, our findings indicate that parental education successfully increases the quality of life of leukemic children to a greater extent than the potential gain of similar information from informal sources. Parental education leads to a better understanding of leukemia, chemotherapy, and its side effects, as well as the negative impact of this disease on a child's quality of life, (27) which in turn results in improved parental care in terms of communicating with the suffering child, providing appropriate care, and facing related problems. This improvement effects a higher quality of life in leukemic children.

Effective planning of educational interventions for parents leads to lower stress and higher quality of life in children with leukemia. This study explains the necessity of educating parents about the effects of leukemia on the quality of life of the affected children and their families and the appropriate methods to face the consequent problems. Members of the therapy team, especially nurses, should be trained in this regard to be able to meet the requirements of these parents. We recommend setting

up consultation clinics in centers that provide health care to leukemic children, where nurses offer education to the parents of these children and enable them to face and resolve the ensuing problems independently. Thus, the problems of such patients can be prevented, positively impacting their quality of life.

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### Conflict of Interest

None declared.

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**Table 2.** Comparison of quality of life scores and the change of scores before and after intervention in the two study groups.

	Experimental (Mean ± SD)		P Value <sup>a</sup>	Control (Mean ± SD)		P Value <sup>a</sup>	Change of score (Mean ± SD)		P Value <sup>b</sup>
	Before	After		Before	After		Experiment	Control	
	<b>Physical complaints</b>	25.66 ± 4.89	31.83 ± 3.47	< 0.001	23.5 ± 5	23.53 ± 4.74	0.80	6.16 ± 2.73	0.53 ± 2.82
<b>Autonomous functioning</b>	28.26 ± 4.75	34.7 ± 3.30	< 0.001	28.26 ± 5.21	28.20 ± 5.35	0.09	6.43 ± 3.23	-0.06 ± 2.82	< 0.001
<b>Social functioning</b>	24.36 ± 4.01	31.1 ± 3.40	< 0.001	24.2 ± 3.80	24.26 ± 3.67	0.44	6.73 ± 2.71	0.06 ± 1.33	< 0.001
<b>Motor functioning</b>	30.53 ± 2.60	33.86 ± 2.04	< 0.001	30.16 ± 3.71	30.13 ± 3.64	0.57	3.33 ± 1.53	-0.03 ± 0.61	< 0.001
<b>Cognitive functioning</b>	25.36 ± 5.18	31.13 ± 3.85	< 0.001	24.50 ± 3.70	24.53 ± 3.71	0.32	5.76 ± 2.84	0.20 ± 0.80	< 0.001
<b>Positive emotions</b>	26.26 ± 3.90	33.96 ± 2.20	< 0.001	24.36 ± 3.69	24.46 ± 3.73	0.08	7.70 ± 3.01	0.10 ± 0.95	< 0.001
<b>Negative emotions</b>	20.76 ± 3.29	30 ± 2.66	< 0.001	19.30 ± 4.38	19.30 ± 4.53	1.00	9.23 ± 3.19	0.00 ± 0.45	< 0.001
<b>Total score</b>	180.83 ± 14.43	226.9 ± 11.76	< 0.001	174.28 ± 20.72	174.41 ± 20.42	0.39	46.06 ± 10.26	0.13 ± 1.37	< 0.001

<sup>a</sup> Paired two-sample t-test

<sup>b</sup> Independent two-sample t-test

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