

## Impact of Parental Education on the Quality of Life of Children with Leukemia

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### ABSTRACT

*Background: The fear and anxiety of parents after diagnosis of their children with leukemia and a lack of knowledge about the disease, treatment, and care of the child adversely affects the quality of life of the leukemic children. Methods: In this interventional study, 43 parents with acute lymphoblastic leukemia children who met the inclusion criteria were selected using purposive sampling and were assigned to intervention and control group. The study tool included a valid and reliable questionnaire the Peds QoL inventory that was completed through interviews with the children and self-filled by the parents. The Peds QoL inventory included 8 dimensions containing questions related to quality of life specific to children with cancer. The intervention included interaction and classes that were composed of a lecture and question and answer session and accompanied by a booklet. Results: Before intervention, the quality of life score as perceived by the children themselves in the intervention and control group was  $49.59 \pm 15.8$  and  $50.57 \pm 10.56$ , respectively; after intervention, these values changed to  $59.31 \pm 15.04$  and  $50.15 \pm 20$  respectively. In the quality of life score as perceived by the children themselves the scores were  $51.91 \pm 12.77$  and  $51.55 \pm 13.80$  in the intervention and control group respectively; after the intervention, these changed to  $62.51 \pm 14.61$  and  $51.58 \pm 8.76$ , respectively. By paired-sample t-test, quality of life score increased significantly at  $p$  value  $< 0.05$  in the intervention group. Conclusion: Parental education successfully increased the quality of life of leukemic children, therefore parental consultation sessions and educational programmes are recommended.*

**Keywords:** education, leukemia, parents, quality of life

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### INTRODUCTION

Leukemia, cancer of the blood forming tissues, is the most common form of childhood cancer,[1] and is the second major cause of death among children aged 5 to 14 years.[2] Acute lymphoblastic leukemia (ALL) accounts for over 75 % of childhood leukemia.[3] It is a complex malignant disease characterized by the malignant proliferation of lymphoblasts that affect the normal process of maturation and differentiation of cells in the bone marrow tissue with cancerous cells.[2] Acute lymphoblastic leukemia

affects boys twice as frequently as girls and the peak prevalence is between 2 and 6 years of age.[1] The improvement in survival rate of acute lymphoblastic leukemia is one of the most dramatic among cancers[1,4,5] which can be attributed to the aggressive treatment protocols involving combination.[3,6] Current long term disease-free survival rates for children with acute lymphocytic leukemia is 80% in major cancer research centers,[1,4] although it is often less than 35% in developing countries. Chemotherapy typically involves a

sequence of stages: induction remission, consolidation and maintenance therapy. Prophylactic therapy is used to prevent central nervous disease, involving intrathecal chemotherapy and possibly cranial radiation for children with high risk disease[3].

Treatment of leukemia is prolong and patients suffers from many side effects of treatment [6] which adversely affects the child's quality of life[7,8]. Quality of life in children with acute lymphoblastic leukemia is now considered an important measure of treatment for this disease[2]. The concept of quality of life is generally considered as the perception of one's welfare, which originates from one's current life experience.[2] Several studies have shown a low quality of life in leukemic children.[5,9–13] Studies have also shown that enhancement of parents' apprehension about the problems and needs of their cancer children has an chief effect on family support, leading to a notable increase in the quality of life of these children [2,14]. Similar studies in other chronic diseases have confirmed that such interventions lead to improvement in the quality of life of children.[15–18] This study aims to determine the effect of educating the parents of leukemic children on the patients' quality of life.

## MATERIALS AND METHODS

This interventional study was performed in Advanced Pediatric Centre, PGIMER, Chandigarh, in 2014. Forty parents of children with ALL were selected and assigned to intervention and control groups (20 participants in each group). Inclusion criteria were parents with children with a diagnosis of ALL between 5 and 16 years; the leukemic child had no other chronic disease except acute lymphocytic leukemia; child was in induction phase of chemotherapy. The exclusion criteria included a lack of interest of the parents in participation in the study; children with other type of leukemia; child was in other

phase of chemotherapy. A previously validated reliable questionnaire (Peds QoL inventory: parent form and child form) was used to assess the quality of life of the children before and 4 weeks after the intervention. This questionnaire was developed by James Verni [19,20]. QoL inventory instrument includes 27 items with 8 subscales: pain and hurt (2 items), nausea (5 items), procedural anxiety (3 items), treatment anxiety (3 items), worry (3 items), cognitive problems (5 items), perceived physical appearance (3 items), and communication (3 items). Both instruments were available for children aged: 5–7, 8–12 and 13–18 years old; as well as for the parents of children aged: 2–4, 5–7, 8–12 and 13–18 years old. The participants evaluated how often a certain problem occurred in the past 2 weeks. Five to 7 years aged children; a Face Scale with 3 pictures differ from a smiling face to a sad face was used. The mean scores could range between 0 and 100; higher scores represented better quality of life. The intervention included teaching on major aspects of care of children with leukemia, composed of a lecture, question-answer sessions – each lasting 45–60 minutes – and review of a booklet. The participants could also review the contents of the sessions using the booklet. Four weeks after the completion of the interventions, the quality-of-life was again assessed. The data were analyzed using SPSS, version 16, and a  $P < 0.05$  was considered statistically significant. This study was approved by the institute ethics committees of the institution.

## RESULTS

The mean age of the children was 7.25 in the intervention group and 7.54 in the control group. Of the total sample 76.19% of patients in the interventional group and 63.63% in the control group were boys. While 4.76% of the children in the intervention group and 4.54% of children in control group belonged to upper class, 28.57% in intervention group and 27.27%

in control group belonged to middle class; 66.66% in intervention group and 68.18 in control group belonged to lower class. By t-test and chi-square test, there was no difference in the aforementioned characteristics between the two groups. Before the intervention, the mean total quality of life score in the intervention and control group as perceived by the parents was 49.59±15.8 and 50.57±10.56, respectively; after intervention, these, values changed to 59.31±15.04 and

50.15±20, respectively. The mean total quality of life score in the intervention and control group as perceived by the children themselves before intervention was 51.91±12.77 and 51.55 ±13.80, respectively; after intervention, these, values changed to 62.51±14.61 and 51.55±8.76, respectively. t-test revealed a significant increase in the quality of life scores in the intervention group (p>0.05, Tables 1 and 2).

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

	Before intervention (Mean ± SD)			After intervention (Mean ± SD)		
	Intervention group	Control group	P value <sup>a</sup>	Intervention group	Control group	P value <sup>a</sup>
Pain and hurt	60.7±28.5	62 ±24.5	<0.05	68.7±27.0	62.3 ± 26.6	0.07
Nausea	60.7±22.4	60.5±21.4	<0.05	70.5±22.6	60.2 ± 21.4	0.22
Procedural anxiety	36.6±28.2	38.1 ±28	<0.05	48.3±33.9	38.0 ± 25.9	0.63
Treatment anxiety	47.4± 32.1	46.6±32.3	<0.05	56.6±26.1	46.9 ± 1.3	0.11
Worry	52.9±29.8	51.8±27.6	<0.05	62.4±28.5	50.2 ± 24.6	0.45
Cognitive problems	52.6±23.4	48.3±17.7	<0.05	61.5±23.5	49.3 ± 18.3	0.39
Perceived physical appearance	44.1±27.8	43.76±22.8	<0.05	56.6±26.2	43.1± 13.1	0.07
Communication	49.5±32.8	49.1±30.6	<0.05	60.8±30.8	50.9 ± 30.1	0.33

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

**Table 2.** Comparison of the quality of life scores as perceived by the children themselves before and after intervention in the two study groups.

	Before intervention (Mean ± SD)			After intervention (Mean ± SD)		
	Intervention group	Control group	P value <sup>a</sup>	Intervention group	Control group	P value <sup>a</sup>
Pain and hurt	63.5±23.2	64.3 ± 18.7	0.14	76.8 ± 21.5	64 ± 29.04	0.04
Nausea	61.7±15.9	63.2 ± 16.2	0.22	74.5 ±14.7	63.1 ± 25.7	0.01
Procedural anxiety	37±28.9	38.3 ± 31.6	0.16	43.7 ± 27.5	38.02 ± 28.9	0.04
Treatment anxiety	49.1±21.7	48.3 ± 33.6	0.33	61.6 ± 30.7	50.4±32.94	0.05
Worry	55.8±21.9	53.3 ± 30.7	0.13	67.4± 21.2	53.5 ± 24	0.03
Cognitive problems	54±22.3	52.1 ± 28.1	0.12	61.8 ± 22.1	53.2± 25.92	0.05
Perceived physical appearance	46.2±23.1	44.5 ± 16.1	0.09	55.8 ± 26.5	44.5± 16.53	0.01
Communication	49.1±27.4	50.41 ± 32.94	0.02	55.8 ± 29.1	51.4± 25.44	0.03

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

Quality of life scores for each dimensions before and after intervention and between-group differences are compared in Tables 3 and 4. Scores on all dimensions increased after the intervention in both the child and the parent-proxy version in the intervention group. In the parent version

the maximum score was in the dimension of nausea, while in the children version the maximum score was in the dimension of pain. Paired t-test confirmed a significant rise in quality of life scores on all dimensions in the intervention group (P<0.05). However, such changes in the

control group were not observed, t-test showed a significant difference in quality of life score before and after 4 weeks of intervention in the experimental group for all the 8 measured dimensions and total score ( $P>0.05$ ).

## DISCUSSION

At baseline, there was no difference in the quality of life scores between the two studied groups, and both the groups received moderate score on all dimensions. The quality of life scores in the current study were found to be lower than those in study conducted by Verni *et al* (2002)[21] and Castillo-Martinez *et al* (2009).[4] So we considered interventions aimed at a

better quality of life. Our findings indicate a higher quality of life score in children 4 weeks after the intervention in all the 8 measured dimensions in both the parent and children version. In a similar study conducted by Hashimi F *et al* (2011)[2] in Iran reported increase in the quality of life scores of children with ALL after parental education. Someone study in Iran, Allahyari *et al* (2006) also observed a significant improvement in the quality of life of children with thalassemia after establishment of a family-centered improvement model for the quality of life of school-age b-thalassemic children.[15] Iconomou *et al*. (2006) reported similar outcomes after a booklet.

**Table 3.** Comparison of the quality of life scores as perceived by the parents and the change of scores before and after intervention in the two study groups.

	Intervention (mean $\pm$ SD)		P value <sup>a</sup>	Control (mean $\pm$ SD)		P value <sup>a</sup>	Change of score (mean $\pm$ SD)	
	Before	After		Before	After		Intervention	Control
Pain and hurt	60.7 $\pm$ 28.5	68.7 $\pm$ 27.0	<0.05	62 $\pm$ 24.5	62.3 $\pm$ 26.6	0.07	8.7 $\pm$ 1.3	0.3 $\pm$ 0.1
Nausea	60.7 $\pm$ 22.4	70.5 $\pm$ 22.6	<0.05	60.5 $\pm$ 21.4	60.2 $\pm$ 21.4	0.22	9.8 $\pm$ 2.4	-0.3 $\pm$ 0.2
Procedural anxiety	36.6 $\pm$ 28.2	48.3 $\pm$ 33.9	<0.05	38.1 $\pm$ 28.0	38.0 $\pm$ 25.9	0.63	11.7 $\pm$ 2.5	-0.1 $\pm$ 0.3
Treatment anxiety	47.4 $\pm$ 32.1	56.6 $\pm$ 26.1	<0.05	46.2 $\pm$ 32.3	46.9 $\pm$ 1.3	0.11	9.2 $\pm$ 1.6	0.7 $\pm$ 0.6
Worry	52.9 $\pm$ 29.8	62.4 $\pm$ 28.5	<0.05	51.8 $\pm$ 27.6	50.2 $\pm$ 24.6	0.45	9.5 $\pm$ 2.1	-1.6 $\pm$ 0.2
Cognitive problems	52.6 $\pm$ 23.4	61.5 $\pm$ 23.5	<0.05	48.3 $\pm$ 17.7	49.3 $\pm$ 18.3	0.39	8.9 $\pm$ 2.7	1 $\pm$ 0.7
Perceived physical appearance	44.1 $\pm$ 27.8	56.6 $\pm$ 26.2	<0.05	43.7 $\pm$ 22.8	43 $\pm$ 13.1	0.07	12.5 $\pm$ 2.4	-0.7 $\pm$ 0.5
Communication	49.5 $\pm$ 32.8	60.8 $\pm$ 30.8	<0.05	49.1 $\pm$ 30.6	50.9 $\pm$ 30.1	0.33	11.3 $\pm$ 4.2	1.8 $\pm$ 0.9

<sup>a</sup>Paired two-sample t-test, <sup>b</sup>Independent two-sample t-test.

**Table 4.** Comparison of the quality of life scores as perceived by the children themselves and the change of scores before and after intervention in the two study groups.

	Intervention (mean $\pm$ SD)		P Value <sup>a</sup>	Control (mean $\pm$ SD)		P-value <sup>a</sup>	Change of score (mean $\pm$ SD)	
	Before	After		Before	After		Intervention	Control
Pain & hurt	63.5 $\pm$ 23.2	76.8 $\pm$ 21.5	<0.05	64.3 $\pm$ 18.7	64 $\pm$ 2.0	0.41	13.3 $\pm$ 2.5	-0.3 $\pm$ 0.2
Nausea	61.7 $\pm$ 15.9	74.5 $\pm$ 14.7	<0.05	63.2 $\pm$ 16.2	63.1 $\pm$ 25.7	0.16	12.8 $\pm$ 3.5	-0.1 $\pm$ 0.3
Procedural anxiety	37.0 $\pm$ 28.9	43.7 $\pm$ 27.5	<0.05	38.3 $\pm$ 31.6	38 $\pm$ 28.9	0.41	6.7 $\pm$ 0.5	-0.3 $\pm$ 0.1
Treatment anxiety	49.1 $\pm$ 21.7	61.6 $\pm$ 30.7	<0.05	48.3 $\pm$ 33.6	50.4 $\pm$ 32.9	0.65	12.5 $\pm$ 1.7	2.1 $\pm$ 0.1

Worry	55.8±21.9	67.4±21.2	<0.05	53.3±30.7	53.5 ± 24	0.65	11.6±0.8	0.2±1.1
Cognitive problems	54 ±22.3	61.8±22.1	<0.05	52.1±28.1	53.2 ±25.9	0.57	7.8±0.6	1.1±0.2
Perceived physical appearance	46.2±23.1	55.8±26.5	<0.05	44.5±16.1	44.5±16.5	0.13	9.6±2.1	0±0.1
Communication	49.1± 27.4	55.8±29.1	<0.05	50.4±32.9	51.4±25.4	0.34	6.7±3	1±0.7

<sup>a</sup>Paired two-sample t-test, <sup>b</sup>Independent two-sample t-test.

Containing information about chemotherapy was given to Greek adult patients with malignant diseases [17]. Our findings were also in accordance with those of Lorenzo *et al* (2004) 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[22]. The findings of the present study were 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. In a study conducted by Dehkordi *et al.* (2008) in Pakistan, showed that education lead to the improvement of parents' awareness about problems of the children with beta-thalassemia major disorder [23]. These results are all consistent with the findings of the present study, which demonstrated an improved quality of life score in leukemic children after educational intervention for their parents. 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, 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.

## CONCLUSION

We suggest to initiate examination clinics in midpoint that provide health care to leukemic children, where nurses offer education to the parents of leukemia children and facilitate them to face and resolve the ensuing issue individually. Thus, the problems of such patients can be prevented, positively impacting their quality of life.

*The authors have no conflicts of interest to disclose.*

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