

Quality of Life During Active Treatment for Pediatric Acute Lymphoblastic Leukemia

Hossain MM¹, Islam A², Hasan AD³, Parvez MM⁴, Ali MM⁵

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Abstract:

Background: Acute Lymphoblastic Leukemia (ALL) is the most common cancer in children with an improved outcome at present. Because of its increased cure rate (almost 80%), more emphasis has been placed on reducing the toxicities of therapy, improving quality of life (QoL) during treatment and minimizing the long-term effect of therapy. So, the study was aimed at understanding QoL during different phases of chemotherapy.

Methods: This cross-sectional study was conducted from 1st April, 2011 to 30th September, 2011 in the Department of Pediatric Hematology and Oncology, Bangladesh Medical University, Shahbag, Dhaka. Total 42 Children of 2-16 years with ALL were included in this study. QoL scores were collected using the Pediatric Quality of Life Inventory™ (PedsQL™) 4.0 Generic Scale and the Pediatric Quality of Life Inventory (PedsQL™) 3.0 Cancer Module proxy report. Medical and demographic data were collected from medical records and interviewing guardians. Data were processed and analyzed by using the SPSS (version 17.0).

Results: PedsQL overall 62.03 (range 58.28-64.69), physical score 67.22 (range 53.13-71.88), psychological score consisting of emotion, social and school score was 60.00 (range 56.67-60.00), emotional score 72.50 (range 70.00-80.00), social score 100 (range 90.00-100.00) and school score 2.5 (0.0-20.0). Social score was best but school score was worst. Here no predictor was found that significantly worsened QoL. Scores were similar in different phases of treatment.

Conclusion: QoL in children with ALL has been described and there are no predictors of worse QoL. QoL was also similar in different phases of treatment. School summary score was worst, so special attention should be provided to improve the schooling of children.

Introduction:

Acute Lymphoblastic Leukemia (ALL) is the most common cancer in children. Outcome of ALL have improved over time, and currently, almost 80% of children are cured of their disease primarily with outpatient chemotherapy¹. Aggressive treatment protocol involving combination chemotherapy have greatly influenced improvements in survival of children with ALL. Treatment typically involves a

sequence of stages: induction of remission, consolidation, and maintenance therapy. Prophylactic therapy is used to prevent central nervous system disease, involving intrathecal chemotherapy and possibly cranial radiation for children with high risk disease².

As cure rates have increased, more emphasis has been placed on reducing toxicities of therapy, improving quality of life (QoL) during treatment and minimizing

1. Dr. Md. Musharraf Hossain, Junior Consultant, Department of Pediatrics, Netrokona District Hospital, Netrokona, Bangladesh.
 2. Professor Dr. Afiquel Islam, Ex-Professor, Department of Pediatric Hematology and Oncology, Bangladesh Medical University, Dhaka, Bangladesh
 3. Dr. A.S.M. Didarul Hasan, Assistant Professor, Department of Pediatrics, US-Bangla Medical College, Rupganj, Narayanganj, Bangladesh
 4. Dr. Md. Masum Parvez, Lecturer, Department of Microbiology, Pabna Medical College, Pabna, Bangladesh
 5. Dr. Md. Miraz Ali, Assistant Professor, Department of Pediatrics, Netrokona Medical College, Netrokona, Bangladesh
- Correspondence:** Dr. Md. Musharraf Hossain, Junior Consultant, Department of Pediatrics, Netrokona District Hospital, Netrokona, Bangladesh. Email: musharraf1982@gmail.com Phone: +8801751778217

long term effect of therapy. Thus, more attention has been directed at understanding QoL during active therapy³. Implementing Health Related QoL (HRQOL) measurement in pediatric healthcare setting can improve communication between patients and health care provider (HCP), increase patient-parent satisfaction with HCP, identify hidden morbidities and assist in clinical decision making⁴.

HRQOL is defined as a multidimensional construction composed of the patients' perceptions of the impact of disease and treatment on his or her functioning in a variety of aspect of life, including physical, psychological and social health dimensions delineated by the World Health Organization (WHO)⁵. Pediatric patient self-report is considered to be standard for measuring HRQOL, however proxy reports may be the only available source of data when children are too young, too cognitively impaired or too sick to complete a HRQOL instrument³. Using both a generic and specific disease instrument is recommended to achieve a more comprehensive evaluation of patient HRQOL.

The Pediatric Quality of Life Inventory (PedsQL™) 4.0 Generic Core Scale and The Pediatric Quality of Life Inventory (PedsQL™) 3.0 Cancer Module are considered to be very promising HRQOL instruments for children and adolescent⁶. It is designed for pediatric patients between age of 2 and 18 years and available in a patient self-report version designed for children or adolescents and a proxy-report version for guardians. The PedsQL™ 4.0 Generic Core Scale (Generic scale) is a multidimensional instrument developed by Varni et al^{7,8}. It consists of 23 items categorized into 4 subscales: physical functioning (8 items), emotional functioning (5 items), social functioning (5 items) and school functioning (5 items).

The PedsQL™ 3.0 Cancer Module (Cancer Module) is a multidimensional instrument developed by Varni et al^{6,7} to assess the impact of disease treatment on the HRQOL of Pediatric cancer patients. It consists of 27 items distributed to 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, 13-18 years old as well as for parents of children aged: 2-4, 5-7, 8-12 and 13-18 years old.

As both short- and long-term toxicity of chemotherapy affect the quality of life of patients. At present, main goal of treatment in ALL is improving QoL and minimizing long term effect. So there have much scope of utilization of HRQOL measurement to improve communication between patient and Health Care Provider, increase patient-parent satisfaction and identify hidden morbidity to assist in clinical decision-making. So, this study was designed to assess the QoL in children with ALL receiving chemotherapy.

Materials and Methods:

This cross-sectional observational study conducted in the Department of Pediatric Hematology and Oncology, Bangladesh Medical University (BMU), Shahbag, Dhaka from 1st April 2011 to 30th September 2011. Total 42 samples were collected from inpatient & outpatient department via purposive sampling method from children of 2-16 years who diagnosed as ALL more than 1 month before enrollment into the study and already receiving chemotherapy. Data was collected from patients and their guardians in various phases of treatment using the Pediatric Quality of Life Inventory™ (PedsQL™) 4.0 Generic Scale and the Pediatric Quality of Life Inventory (PedsQL™) 3.0 Cancer Module. First, the instruments were translated from English version to Bengali version with the help of Bengali translator expert. This questionnaire was tested on five cancer patients to determine whether the translation (instruction, items and response choices) was acceptable, whether it was understood in the way it's supposed to be, and whether the language used was simple and appropriate. All patients were classified as either Preceding maintenance (induction, consolidation, re-induction) or maintenance. Risk group was high risk and standard risk according to treatment protocol. Demographic data regarding information about age, relationship of respondent to child, number of children in family, parental education status and socio-economic status were collected from guardian or parents. Medical data regarding diagnosis, treatment status, disease risk status, treatment protocol was obtained from the patients' Medical Record. Interviews of eligible guardians were performed individually. Before data collection informed written consent were taken from each participant without any force or pressure. They were assured that all information will be kept confidential and will only be used for research

purpose. Approval of the ethical review committee of Bangladesh Medical University was obtained for the study.

The Scale had five Likert response options: 0 = never a problem; 1 = almost never a problem; 2 = sometimes a problem; 3 = often a problem; 4 = almost always a problem. Items were reverse-scored and linearly transformed to a 0-100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0), so that higher PedsQL 4.0 score indicate better HRQOL⁹. To derive dimension and summary scores, more than half the items had to be completed for that dimension. A one-month recall period was used. All data were processed and analyzed by using the SPSS Windows (version 17.0) with the help of expert data analyst. Potential predictors of QoL scores

were determined using univariate linear regression analyses. For multiple regression modeling, demographic, disease-related and socioeconomic factors that were associated with QoL were entered into a forward selection model. Data was presented as β coefficients with their standard errors as derived from linear regression. Positive β coefficients meant that the predictor (or increasing values of the predictor) was associated with better QoL whereas negative β coefficients suggested that the predictor (or increasing values of the predictor) was associated with worse QoL. To compare QoL between children in phases of therapy preceding and during maintenance, the student's t-test was used. Statistical significance was defined as $p < 0.05$.

Results:

Table-I:

Demographics and summary scores in 42 children with acute childhood leukemia

Variable	Value
Child factors	
Median child age in years (range)	5 (2.0 – 12.0)
Median months since diagnosis (range)	6 (1.0 – 60.0)
No. male child (%)	29/42 (69.0)
No. with high-risk ALL (%)	11/42 (26.2)
No. received radiation (%)	4/42 (9.5)
Parent factors	
No. female parent respondent (%)	39/42 (92.9)
No. single parent (%)	0/42 (0.0)
No. first parenting experience (%)	15/42 (35.7)
No. female parent undergraduate degree (%)	5/42 (11.9)
No. female parent working (%)	2/42 (4.8)
Household factors	
No. monthly household income $\leq$ 10,000 taka (%)	36/42 (85.7)
Quality of life summary scores	
Median overall summary score (95% CI)	62.03 (58.28-64.69)
Median physical summary score (95% CI)	67.22 (53.13-71.88)
Median psychological summary score (95% CI)	60.00 (56.67-60.00)
Median emotional summary score (95% CI)	72.50 (70.00-80.00)
Median social summary score (95% CI)	100.00 (90.00-100.00)
Median school summary score (95% CI)	2.5 (0.0-20.0)

Table I demonstrates child, parents and demographic information. The median child age was 5 (range 2-12) years. When divided by age groups, 17(40%) were 2-4 years, 12 (28.5%) were 5-7 years, 13 (30.9%) were 8-12 years and 0 were 13-18 years of age. Median years since diagnosis are 6 months.

Among 42 children, 29 were male (69%), high risk ALL was 11 (26.2%), 4 patient received radiation (9.5%). Female parents respondent were 39 (92%), first child in family affected by ALL was 15 (35.7%). Monthly income >10,000 taka was 36 (85.7%) among 42.

In addition, Table I describes the PedsQL overall 62.03 (range 58.28-64.69, 95% Confidence Interval, CI), physical score 67.22 (range 53.13-71.88, 95% CI), psychological score which consists summation of emotion, social and school score was 60.00 (range 56.67-60.00, 95% CI), emotional score 72.50 (range 70.00-80.00, 95% CI), social score 100 (range 90.00-100.00, 95% CI), school score 2.5 (0.0-20.0). Here social score is best but school score is worst as 21(50%) children did not go to school for disease, among them 17(40%) patients were under 5 age group.

Table-II:

Multiple linear regression for overall, physical, psychosocial, emotional, social and school quality of life scores in 42 children with acute childhood leukemia

Variable	Adjusted β coefficient $\pm$ standard error	<i>p</i>
Overall summary score		
Child age	0.31 $\pm$.68	0.08
Male child	-0.11 $\pm$ 3.89	0.55
High-risk disease	-0.12 $\pm$ 4.13	0.47
Household income per 10,000 taka	0.12 $\pm$ 3.73	0.49
Physical summary score		
Male child	-0.19 $\pm$ 6.9	0.22
High-risk disease	0.01 $\pm$ 7.4	0.95
Radiation	0.08 $\pm$ 11.11	0.59
Household income per 10,000 taka	0.18 $\pm$ 6.74	0.29
Psychosocial summary score		
Child age	0.04 $\pm$.74	0.83
Male child	0.18 $\pm$ 3.77	0.25
High-risk disease	-0.13 $\pm$ 4.56	0.47
Household income per 10,000 taka	-0.05 $\pm$ 3.5	0.77
Emotional summary score		
High-risk disease	0.03 $\pm$ 6.6	0.83
Social summary score		
Male child	-0.27 $\pm$ 6.1	0.86
Time since diagnosis	0.20 $\pm$.29	0.20
High-risk disease	0.14 $\pm$ 6.4	0.37
Household income per 10,000 taka	-0.03 $\pm$ 5.9	0.88
School summary score		
Child age	0.62 $\pm$.85	0.01

Table II describes, the result of multiples regress analysis and consequently which variables were independently associate with QoL. Here no predictor was found that significantly worsen QoL, only child age predicts on school score positively.

Table III illustrates that no significant correlation to worse QoL in high-risk ALL.

Table IV showed no significant variables that predict reduced QoL in standard risk ALL. Here noticed that child age negatively correlates in emotional scores and positively correlates in school scores.

Table-III :

Multiple linear regression for overall, physical, psychosocial, emotional, social and school quality of life scores in high-risk acute childhood leukemia (n = 11)

Variable		Adjusted β coefficient $\pm$ standard error	p
Overall summary score	Child age	0.09 $\pm$ 1.35	0.79
	Male child	0.14 $\pm$ 7.70	0.70
	Household income per 10,000 taka	0.20 $\pm$ 7.23	0.58
Physical summary score	Child age	-0.50 $\pm$ 1.52	0.25
	Household income per 10,000 taka	0.21 $\pm$.07	0.84
Psychosocial summary score	Child age	0.18 $\pm$ 1.29	0.61
	Male child	0.11 $\pm$ 7.33	0.77
	Household income per 10,000 taka	0.24 $\pm$ 6.91	0.50
Emotional summary score	Child age	-0.22 $\pm$ 2.51	0.52
	Male child	-0.16 $\pm$ 14.46	0.63
	Household income per 10,000 taka	-0.07 $\pm$ 16.67	0.85
Social summary score	Child age	-0.07 $\pm$ 2.09	0.84
	Male child	0.15 $\pm$ 11.90	0.69
	Household income per 10,000 taka	0.27 $\pm$ 10.40	0.45
School summary score	Child age	0.56 $\pm$ 2.05	0.07
	Household income per 10,000 taka	0.21 $\pm$ 16.11	0.57

Table IV :

Multiple linear regression for overall, physical, psychosocial, emotional, social and school quality of life scores in standard risk acute childhood leukemia (n = 31)

Variable		Adjusted β coefficient $\pm$ standard error	p
Overall summary score	Child age	-0.30 $\pm$ 1.22	0.17
	Household income per 10,000 taka	-0.03 $\pm$ 4.4	0.91
Physical summary score	Male child	-0.27 $\pm$ 8.6	0.13
	adiation	0.15 $\pm$ 15.93	0.38
Psychosocial summary score	Household income per 10,000 taka	0.21 $\pm$ 8.69	0.29
	Child age	-0.27 $\pm$ 1.00	0.22
Emotional summary score	Household income per 10,000 taka	-0.19 $\pm$ 4.14	0.36
	Child age	-0.50 $\pm$ 1.65	0.02
Social summary score	Household income per 10,000 taka	-0.03 $\pm$ 5.39	0.89
	Male child	-0.07 $\pm$ 7.63	0.71
School summary score	Household income per 10,000 taka	-0.09 $\pm$ 7.34	0.66
	Child age	0.68 $\pm$.91	0.01
	Household income per 10,000 taka	-0.22 $\pm$ 6.63	0.27

Table-V :
Comparison of quality of life scores during phases preceding maintenance compared with maintenance phase

Variable	Preceding maintenance (n =29)	Maintenance (n = 13)	p
Summary scores*			
Overall summary score	60.78 (50.31-66.87)	63.91 (55.00-70.94)	0.16
Physical summary score	65.63 (46.88-78.13)	68.75 (50.00-93.75)	0.29
Psychosocial summary score	58.33 (51.67-60.00)	60.00 (56.67-71.67)	0.13
Emotional summary score	75.00 (60.00-80.00)	70.00 (60.00-90.00)	0.89
Social summary score	100.00 (80.00-100.00)	100.00 (90.00-100.00)	0.24
School summary score	0.0 (0.00-20.00)	20.00 (0.00-45.00)	0.08
Cancer-specific scores*			
Pain and hurt	87.50 (75.00-100.00)	100.00 (75.00-100.00)	0.44
Nausea	70.00 (55.00-80.00)	50.00 (40.00-80.00)	0.16
Procedural anxiety	33.33 (.00-50.00)	25.00 (0.00-83.33)	0.61
Treatment anxiety	83.33 (66.00-100.00)	83.33 (33.33-100.00)	0.81
Worry	100.00 (100.00-100.00)	100.00 (100.00-100.00)	0.76
Physical appearance problems	100.00 (91.67-100.00)	100.00 (100.00-100.00)	0.05
Communication problems	33.33 (.00-66.67)	33.33 (25.00-91.67)	0.53
Cognitive problems	75.00 (60.00-100.00)	70.00 (50.00-100.00)	0.84

* All scores represent median (95% confidence interval)

Table V illustrates that overall, physical, emotional, social and school QoL score were qualitatively and statistically similar for those receiving treatment during preceding maintenance and during maintenance therapy.

When examining cancer specific score, nausea, procedural anxiety, treatment anxiety, worry, physical appearance, cognition, all were similar between these two time periods, but only physical appearance score improved significantly at maintenance phase.

Discussion:

In this study, QoL of 42 children with ALL in first remission during active treatment described. Relative to healthy children, scores from this cohort were lower. More specifically, Varni et al.⁵ surveyed 717 healthy children via PedsQL Generic Core Scales 4.0 proxy-report and mean $\pm$ SD scores were as follows: overall score 87.61 ± 12.33 , psychosocial health 86.58 ± 12.79 , physical health 89.32 ± 16.35 , emotional functioning 82.64 ± 17.54 , social functioning 91.56 ± 14.20 and school functioning 85.47 ± 17.616 . Consequently, our median QoL scores were one to two standard deviations below the healthy population for all

summary scores and dimension except social summary scores. These findings are concordant with others³ who have found that QoL scores are lower in children receiving treatment for ALL compared to children with ALL e"12 months off therapy¹⁰ and lower compared to healthy children¹¹⁻¹³. These findings are also concordant with qualitative studies of children receiving treatment for ALL that have noted problems with fatigue, detrimental effects of disease and treatment on physical activities as well as difficulties with social interactions^{14,15}.

Second objective was to describe predictors of poor QoL during treatment for non-relapsed ALL. Little previous work has showed that, for high risk ALL, older child and girl had worse QoL, whereas for standard risk ALL, those living in household with lower income and unmarried parents had worse QoL across several dimension³. Few studies have demonstrated that age and gender were predictors of QoL¹⁴. So, any predictor was not constant to worsen QoL among different study.

But in this study no predictors were found for worse QoL. It is explained by small sample size, small number of high risk patient, different cultural

background and low median months since diagnosis (6 months). Further study need to evaluate this finding among large sample in Bangladesh.

Third objective was to describe how QoL changes during different phase of therapy. Here found very similar QoL score across different phases for many aspects of QoL. This finding correlates the previous study done in Canada³ and in Indonesia⁴.

The strength of this study is the similarity of finding in overall, physical and psychological score to other studies that done in both developed and developing country. This is the first study to assess QoL in children with ALL in Bangladesh. So there is no scope to compare all findings of QoL considering similar cultural, social and economic background of patient. However no standard Bengali translated modules were available to assess QoL in children. So, there is more scope to validate and standardize PedsQL scale in Bangladesh.

Conclusion:

QoL in children with ALL have been described and found no predictor to worse QoL, QoL also similar in different phases of treatment. School summary score was worst, so special attention should provide in schooling of children. Further efforts should focus on longitudinal studies that describe QoL over time within individual patients both during and after completion of therapy in a large cohort in Bangladesh.

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