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Quality of Life for Children with Acute Lymphoblastic Leukemia

El-Shimaa El-Sayed Abd El-Latif [1], Madiha Amin Morsy [2],
Iman Ibrahim Abd El Moniem[3]

Pediatric Nursing Department, Faculty of Nursing -Ain Shams Universit -Cairo- Egypt

Abstract: **The aim of this study was to assess the impact of counseling on quality of life (QoL) and treatment adherence.**

Research designs: A quasi experimental research design.

Setting: The study was conducted at Pediatric unit in National Cancer Institute belonging to Cairo University .

Subjects: A purposeful sample composed of thirty children out of 90 children aged from 6 to18 years had eligible criteria which were newly diagnosed with Acute Lymphoblastic Leukemia, in the initial diagnosis period and received chemotherapy treatment at the first day of induction phases and had been accompanied by their mother and admitted to the previously mentioned setting.

Tools of data collection was a structure interviewing questionnaire to assess knowledge about Acute Lymphoblastic Leukemia disease process and treatment regimen and health related quality of life (HRQL) Scale to assess quality of life of children.

Results: The study results revealed that the children and their own mother had unsatisfactory knowledge about disease process and treatment regimen and declining deficits in health-related quality of life of children.

Conclusion: It could be concluded that the children had still lack of knowledge to Acute Lymphoblastic Leukemia disease process and treatment regimen that affect quality of life.

Recommendation: The study recommended for application of counseling session for all Acute Lymphoblastic Leukemia children and their mothers to improve adherence to treatment which lead to promote their quality of life.

Keywords: **Counseling, Adherence, Quality of Life. Children, Acute Lymphocyte Leukemia and Mothers.**

1. INTRODUCTION

Leukemia cells usually invade the blood fairly quickly. They can then spread to other parts of the body, including the lymph nodes, liver, spleen, central nervous system (brain and spinal cord), and testicles (in males). Other types of cancer also can start in these organs and then spread to the bone marrow, but these cancers are not leukemia **(American Cancer Society [ACS], 2016).**

Acute lymphocytic leukemia (ALL) is also called acute lymphoblastic leukemia is a cancer that starts from the early version of white blood cells called lymphocytes in the bone marrow **(American Cancer Society [ACS], 2014).**

Acute lymphoblastic leukemia is the most common malignancy in children, accounting for almost one third of newly diagnosed pediatric cancer cases. The annual incidence is approximately four cases per 100,000 children per year in the National Cancer Institute (NCI), Cairo University, Egypt. ALL constitutes 30% of all pediatric malignancies and 70% of pediatric leukemia. Cases show a male to female ratio of 2.3:1. The 2-10 years age group constitutes 68.5%. Currently **(National Cancer Institute [NCI], 2013).**

Acute lymphocytic leukemia could be fatal if children not treated treatment for childhood with ALL requires that the child passes through three phases which are induction, consolidation and maintenance phase. Each phase requires specific time for fulfillment the effect of the drugs. This need a good relationship between the parent and the health care team (**American Cancer Society [ACS], 2013).**

Children with ALL make use of complementary therapies in order to improve their qualities of life. Cancer and chemotherapy worsen quality of life and increase the need for complementary therapy **(Zencirci and Ustundag2015).** Early and effective treatment is essential for a successful cancer treatment and high (QoL) **(Bektas *et al.*, 2016).** 80% of children with ALL treated in modem centers are alive and disease-free at 5 years. The major contributors to this long-term survival are the improvements in anticancer therapies **(Ashaat *et al., 2010).***

In treatment

The purpose of cancer therapy is not only to cure the cancer and increase the survival but also to minimize the symptoms and alleviate the (QoL). In other words, better (QoL) increases patients' adaptation and desire for the therapy. Higher quality of life leads patients to complete therapy with the lowest harm, control experienced symptoms and overcome these symptoms **(Zencirci and Ustundag, 2015).**

Acute lymphocytic leukemia children are better response rates to treatment because of differences in childhood and adult ALL in the disease and treatment, the children's bodies can often handle aggressive treatment better than adult's treatment. **(American Cancer Society** [**ACS], 2015).**

Acute lymphocytic leukemia treatment is a long-term process that lasts two to three years of chemotherapy treatment aim to destroy the leukemia cancer cells that divide rapidly. And enable the bone marrow to work normally again. The ALL treatment is given in three main phases. The length of each phase is based on the intensity of treatment **(National Cancer Institute [NCI], 2014).**

The concept of (QoL), often used interchangeably with the term 'health related (HRQL)' is generally understood as a multi-dimensional construct concerning an individual's awareness of the impact of illness and treatment on his/her health, wellbeing or functioning in relation to physical, psychological, and social aspects of life **(Eman D et al., 2017).**

children with ALL face some psychological as problems -stress, anxiety and depression also some physiological side-effects – could occur as hair loss, pain, tiredness, nausea, vomiting; some social side effects as social isolation, role and function loss; and 3 eventually, a worsened (QoL) **(Zencirci and Ustundag, 2015).**

Children with ALL (QoL) can be affected by many factors such as problems in spouse and family relationships, changes in body image, difficulties in adapting to these changes, changes in social support systems, psychological problems and loneliness, isolation, financial difficulties and fatigue is one of the most common complaints which distracts people from daily activities by affecting all domains of the (QoL) in relation to the treatment applied and fear of death and recurrence of the disease **(Gungor et al., 2017).**

The Health-Related Quality of Life assessment is essential for health care professionals to make a reliable and accurate diagnosis, capable of sustaining an effective intervention for its improvement **(Batalha et al., 2015).**

Measurement of quality of life QoL in pediatric children with ALL is perceived that provides an important assessment of the welfare of children and families. Especially, by evaluating different QoL dimensions and in different treatment stages is supported that will assist in detecting children and families with an expected poorer QoL and guide health professionals with targeted interventions to improve it **(Vlachioti et al., 2016).**

Significance of the study:

The acute lymphoblastic leukemia is most common malignancy in children they experience declining deficits in (HRQL) during active treatment phases (QoL) refers to "global well-being," including physical, emotional, mental, social, and behavioral components. Outcomes of healthcare treatments as perceived by the children with cancer. (QOL) has considerable changes in overall dimensions for patient with cancer **(Furlong et al., 2012 and Arslan et al., 2013).**

Aim of the Study:

The aim of the study was to assess the quality of life for children with Acute Lymphoblastic Leukemia.

Research questions

1. What are the QoL for children acute lymphoblastic leukemia?
2. What are the factors affecting QoL for children acute lymphoblastic leukemia?
3. Is there a relation between illness dangerous and QoL for children with acute lymphoblastic leukemia?

2. SUBJECTS AND METHODS

I. Technical Design:

Research Design

A descriptive research design was used in this study.

Research Settings:

The study was conducted in inpatient and outpatient pediatric oncology units at National Cancer Institute [NCI] belonging to Cairo University.

Subjects:

A purposeful sample composed of 30 children out of 90 children aged from 6 to18 years had eligible criteria were newly diagnosed with Acute Lymphoblastic Leukemia, in the initial diagnosis period and received chemotherapy treatment at the first day of induction phases and had been accompanied by their mother and admitted to the previously mentioned setting.

Tools of Data Collection:

Data were collected by using the following tools**:**

I- Structured Interviewing Questionnaire

It was developed by the researcher after reviewing past and current related literature and was written in Arabic Language to suit the subject understanding. It is composed of the following two parts:

- **First part**: It concerns with characteristics of children and accompanied mothers such as the child's age, sex, rank, level of education and residence as well as mothers.
- **Second part:** It concerned with the children knowledge regarding to ALL and its management i.e. Definition, causes, risk factors, clinical manifestation, diagnosis, complications, care and treatment regimen) pre and post counseling.

Scoring system:

According to the respond of children for the questions about their knowledge the answers was categorized as satisfactory knowledge if grades have score>60% while unsatisfactory if grades have score>60.

II- KIDSCREEN Scale:

It was adopted from kids Screen Group Europe (2006) to assess Quality of Life. It has ten dimensions related to health-related quality of life (HRQOL).

Physical well-being (5 items): This explores the level of physical activity, energy and fitness of the child or adolescent, Psychological well-being (6 items): This examines the psychological well-being of the child/adolescent, including positive emotions and satisfaction with life, Moods and emotions (7 items): This covers how much the child/adolescent experiences depressive moods and emotions, and stressful feelings, Self-perception (5 items): This explores whether respondents perceive their bodily appearance positively or negatively; body image is explored by questions concerning satisfaction with looks as well as with clothes and other personal accessories, Autonomy (5 items): This looks at the respondent's opportunities to create social and leisure time, Parent relations and home life (6 items): This examines relationships with parents and the atmosphere at home, Social support and peers (6 items): This examines the nature of the respondent's relationships with other children/adolescents, School environment (6 items): This explores the perceptions of the child/adolescent about their cognitive capacity, learning and concentration, and their feelings at school, Social acceptance (3 items): This covers the aspect of feeling rejected by peers in school and Financial resources (3 items): This assesses respondents' perceptions of their financial resources.

Scoring system:

According to the answer for the questions from the child response about HRQOL dimensions (Not at all, Slightly, Moderately, Usually, Extremely) the total mean score for each item of HRQOL dimensions

Validity &reliability

Validity of the study tools were tested for their content by a jury of five experts in the field of pediatric nursing to ascertain relevance and completeness of the tools and the needed modifications were done. Reliability of these tools was tested by the researcher (test- retest) for the internal consistency by administration of the same tool to the same participants after two weeks and compares the results.

II. Operational design:

It includes preparatory phase, pilot study and field work.

Preparatory Phase:

The researcher was reviewed the past, current related literature covering various aspects of the research problem was done by using available articles, periodicals, magazines, and books to be acquainted with the research problem, develop the study tools and content.

Ethical Consideration:

The ethical considerations in this study included the research approval was obtained from ethical research committee/Faculty of Nursing/Ain shams University. The researcher clears the objective and aim of the study to each study subject and the study is harmless and take subjects oral and written acceptance. The researcher maintains anonymity and confidentiality and. secured ensured that subjects have the right to withdraw from the study.

Pilot Study:

A pilot study was carried out 10% of the total study subject to evaluate the feasibility, clarity and applicability of the study tools that used. result of the pilot study helped in necessary modifications of the used tools. All participant in the pilot study were included in the study subjects, where no radical modification was carried out in the tools as revealed from the pilot.

Field Work:

The actual work of this study carried out from June 2016 to September 2018, the research introduced the children and their mothers. Informed consent was obtained from children and their mothers who agreed to participate, after a brief explanation for the of the study they were assured about confederation of data collected that were used for the purpose of the study only. They were informed that they have the right to withdraw from the study at any time without giving any reason. The researcher attended the study settings for 3 days/week; the researcher was available from 9 am to 5 pm in each one of the previously mention settings; each children and their mothers were interviewed individually by using the questionnaire; for 3 days/week over 6 months; each child and her mother's interviewed individually to gather the necessary data of the study, the interview was managed below 30:45 minutes.

Administrative Design:

An Official letter to conduct the study was obtained from the Dean of Faculty of Nursing Ain Shams University, National Cancer Institute [NCI] affiliated to Cairo University that the study was conducted.

Statistical Design:

Data collected are organized, tabulated and analyzed, using electronic computer and statistical package for social sciences (SPSS) version 19. General characteristics of the children are presented in terms of percentage, mean and standard is deviation, and t-test is used to examine the relationship between pre, post counseling, chi-square test is used to study the relation between QOL and treatment adherence.

The appropriate statistical methods and tests are used for analysis of the results, and Quantitative data were expressed as mean and standard are deviation Qualitative data are expressed as number and percentage and analyzed. P value denoted level of significance where a p value <0.01 was considered as highly statistically significant, a p value <0.05 was considered as statistically significant whereas a p value > 0.05 was non-statistically significant.

3. RESULTS

Table (1): Shows that the mean age of the studied children was 10.80 ± 2.8 that and 66.7% male and 33.3% female. In regarding to children educational level, it was found that primary 56.7%, 26.7% prep, 16.7%, secondary, regarding to children ranking 3 0.0% first, 56.7% second, 10.0% third, 6 3.3% forth, regarding to children residence 46.7% rural and 53.3% urban of the studied sample.

Table (2): Shows that the characteristics of children mother's studies, it reveals that 66.7% of them from >30 years, 33.3% of them from <30

Years with mean score were 1.3333 ±.47946, was more than half 53.3% of them had secondary school and 50% of studied mothers were working equal housewives.

Table (3) Shows that total mean score knowledge children's regarding to their knowledge to disease process was 4.63±1.34.

Table (4) Shows that there was high statistical significance difference in total mean score knowledge children's regarding to their knowledge treatment regimen was 10.78±55. 62.

Table (5): Shows that the total means of children regarding to quality of life domains was 105.13 ±22.73.

Table (1): Distribution of the studied children according to their Socio-demographic characteristics (N =30).

Age in year	No	100%
6:<12	21	70.0%
12:18	9	30.0%
Mean ± SD	10.80±2.8	
Gender		
Male	20	66.7%
Female	10	33.3%
Educational level		
Primary School	17	56.7%
Preparatory	8	26.7%
Secondary school	5	16.7%
Children ranking		
First child	9	30.0%
Second child	17	56.7%
Third child	3	10.0%
Forth child	1	3.3%
Residence		
Rural	14	46.7%
Urban	16	53.3%

Table (2): Distributing of the studied children's mothers related to age, Level of education and job (N =30).

Characteristics of children's mothers	N=30	100%
Age in years		
>30	20	66.7
<30	10	33.3
Total No	30	100
1.3333 ±.47946 Mean ± SD		
Level of education		
Secondary school	16	53.3%
University education	14	46.7%
Total	30	100%
Job		
Working	15	50%
Housewives	15	50%
Total	30	100%

Table (3): Distribution of the studied children's knowledge regarding to acute lymphoblastic leukemia disease process (N =30).

Items	Mean	SD
Meaning of ALL (2).	1.03	0.18
Site of ALL disease (2).	1.12	0.36
Causes and risk factors of ALL disease (2).	0.78	0.25
Signs and Symptoms of ALL disease (2).	0.75	0.25
Diagnosis of ALL disease (2)	0.95	0.30
Total (10).	4.63	1.34

Table (4): Distribution of the studied children's knowledge regarding to acute lymphoblastic leukemia treatment regimen (N =30).

items	Mean	SD
Aim of treatment (6).	1.07	0.25
Type of treatment (6).	1.57	1.55
Number of treatment phases (6).	1.13	0.51
Time needed for treatment (6).	1.10	0.40
healing Rat (6).	1.08	0.46
Methods of drug administration's (5).	1.03	0.18
Side effects of medications (5).	1.00	0.00
Type of nutrition (5).	1.32	1.04
vaccination Dosages (5).	1.48	0.74
Total (50)	10.78	55.62

Table (5): Distribution of the studied children regarding to quality of life domains.

Items	Mean	SD
Physical well –being dimension (25)	7.93	3.24
Psychological well –being dimension (30)	10.23	4.67
Moods and Emotions dimension (35)	11.77	7.03
Self-perception dimension (25)	9.80	4.21
Autonomy dimension (25)	10.67	3.15
Parent Relations and Home Life dimension (30)	16.23	5.20
Social Support and Peers dimension (30)	9.20	3.67
School Environment dimension (15)	11.97	5.12
Social Acceptance/Bullying dimension (30)	9.57	1.57
Financial Resources dimension (15)	7.77	2.40
Total scale of Quality of Life 260	105.13	22.73

4. DISCUSSION

Pediatric oncology nurses are critical members of the oncology team, collaborating with colleagues and using an evidence based approach to reduce the burden of cancer and meet the needs of patients and families, at all levels will continue to play critical roles in the care of children with cancer as new diagnostic and treatment techniques become available Through persistence, vigilance, and dedication, nurses will shape the development and modification of practice standards that promote safe and effective pediatric cancer care **(Branowicki *et al.*, 2015).**

Quality of life refers to the social, emotional, and physical outcomes of healthcare treatments as perceived by the children and adolescents with cancer. It has considerable changes in overall QoL and dimensions in cancer patients **(Hansson *et al.*, 2013).**

Assessment of QoLis also important. In cancer, it should be done at the time of diagnosis and at multiple points during diagnosis, investigations, pre- and post-treatment, and later during follow-up irrespective of whether the treatment has been successful or not **(Chaturvedi &Muliyala 2016).**

Measurement of QoL in pediatric patients with cancer is perceived that provides an important assessment of the welfare of children and families. Especially, by evaluating different QoL dimensions and in different treatment stages is supported that will assist in detecting children and families with an expected poorer QoL and guide health professionals with targeted interventions to improve it **(Vlachioti *et al.*, 2016).**

Therefore, the present study is a descriptive study aimed to assess QoL for children with ALL and their mothers.

According to the rate of admission the number of children were selected according to the previously determined criteria, total thirty children their age ranged from six to eighteen years old.

The present study lights that point of interest the male children with ALL represent more than half compared with female children who account less than half this result not in accordance with **Mohammed (2014)** who study the nutritional status of children having ALL and under chemotherapy find that females higher than males. The higher percent of the children those represent sixty-six and seven percent point severe belonging to primary one followed by primary school. The present study results indicated that more than half of the studied children their ranking was the second child in his family. Regarding to the present study results indicated that more than half of the studied children mother their age were more than thirty years old in this age, the mothers should have experience in caring for their children.

This finding was in agreement with **Hasan et al., (2010)** in research titled assessment of home care management for adolescent patient having leukemia in Erbil city. The present study revealed that most of children's mother educational level was either secondary school certificate or university certificate this result disagreed with **Hasan *etal.* (2010)** who reported that the majority of children's mother were not educated.

The results of the present study revealed that more than half of the studied children and the mothers were belonging to the urban residence. This finding was in accordance with **Mohammed (2014)**.

The present study results suggested that children having ALL still had lack of knowledge about the concept of the diseases, symptom as well as children mother unaware with the disease sing or its causes. This result was in accordance with results of **Michel et al., (2015),** in the study titled Hematological cancer and quality of life: A systematic literature review who show that in the general findings the hematological disease has negatively affects overall QoL. Compared with the general population, fatigue, pain or vitality were the more exposed aspects of QoL, which were specifically deteriorated during an advanced stage of hematological cancer.

Regarding to the aim of treatment the majority of children and their mothers did not known what the aim is but regarding to types of treatment, method of drug administration and the side effect.

Children with ALL QoL can be affected by many factors such as problems in spouse and family relationships, changes in body image, difficulties in adapting to these changes, changes in social support systems, psychological problems and loneliness, isolation, financial difficulties and fatigue is one of the most common complaints which distracts people from daily activities by affecting all domains of the QoL in relation to the treatment applied and fear of death and recurrence of the disease **(Gungor *et al.*, 2017).**

The current study finding revealed that all studied children from six to eighteen years old have total mean score for QoL lees than 50 for each domains of Physical well-being, Psychological well-being, Moods and emotions, Self-perception, Autonomy, Parent relations and home life, Social support and peers, School environment, Social acceptance and Financial resources indicated that children had deficit QoL.

This results agreed with **Eman et al.,(2017),** in research titled of **"**Factors affecting quality of Life in Patients with Pediatric Leukemia during Induction Chemotherapy**"** she found that QoL scores are lower in children receiving treatment for ALL compared to children with ALL 12 months off therapy and lower compared to healthy children. 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.

5. CONCLUSION

The finding of this study can be concluded that the ALL male and female children have lack knowledge of disease and treatment regimen that affect QoL domains related to Physical well-being, Psychological well-being, Moods and emotions, Self-perception, Autonomy, Parent relations, Social support and peers, School environment, social acceptance/bullying and Financial resources.

6. RECOMMENDATIONS

In the light of these results of the present study the following recommendations are suggested:

- Application of counseling sessions for all Acute Lymphoblastic Leukemia children and their mothers to improve knowledge to treatment which lead to promote the quality of life.
- Periodical continuous counseling programs for children and their mothers regarding ALL and treatment of ALL.
- Psychosocial counseling programs for children and their mothers in order to manage the challenges that they face in their QoL during and post treatment.
- Regular clinical assessment for children to monitor treatment adherence for improving their QoL.
- Further studies should be done on large numbers of ALL in different age groups and in other oncology units.

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