

Study of Acute Leukaemia in Children: Impact on Patients and their Families, Utilization and Satisfaction with Health Services in Alexandria - Egypt

Sherif R. Omar ^{*}, Ezzat M. Hassan ^{*}, Bayoumi A. Ghareeb [†], Ekram W. Abd El-Wahab ^{*}.

Abstract: Objectives: To assess impact of leukaemia on children and their families and to describe utilization and satisfaction with health services among acute leukaemic children. **Methods:** A descriptive study started Nov. 2004 for one year duration, included 163 cases (all acute leukaemic cases below the age of 15 attended in-and out-patient of University of Alexandria Paediatrics Hospital, either newly diagnosed or for follow up). Questionnaire sheet administered by interview with the patient's mother included questions about disease impact on the child and his parents. Answers to questions on utilization of health services were blotted to a total score for mother satisfaction. **Results:** Overall health services were free of charge, (83.4%) of mothers received financial aid, but (93.3%) of families were affected financially, as (65.6%) were of low socioeconomic level. Psychological upset was almost the rule in relation to the patient and his family members. The learning process deteriorated in (63.8%) of cases. Most mothers (83.4%) complained that only some drugs are available, but only (22.7%) said that investigations were incomplete. The child club in the hospital was the only recreational mean and utilized by (41.1%) of cases. Highest satisfaction score was with services offered by physicians (art of medical care); lowest score was for the amount of food presented to patients. **Conclusion:** The leukaemic health problem influences the patient and his family's quality of life in a serious way, the child educational progress is affected as well. Patient's mother satisfaction is crucial and her recommendations to improve the quality of service are to be considered.

Keywords: Egypt; Acute Leukaemia; Children; Impact; Health Service; Utilization; Satisfaction.

INTRODUCTION

Leukemias are the commonest form of malignancy among children below the age of 15.¹ They are due to arrest of maturation and unchecked proliferation of white blood cells precursors in the bone marrow, acute types constitute 75% of cases.² Diagnosis of leukemia is an enduring and important life stressor that can disrupt the lives of children and their families and put them at risk for

disturbances of emotional and social functioning that may be more disabling than the physical condition itself.³ This chronic illness increases the economic demand on the family by a sizable increase in the out of pocket costs.⁴ The learning process is usually affected due to frequent school absenteeism, affection of the scholastic achievements and school performance, inability to pass exams, leaving the school, and even inability to join the school.⁵

^{*} Tropical Health Department, High Institute of Public Health, University of Alexandria, Egypt

[†] Paediatrics Department, Faculty of Medicine, University of Alexandria, Egypt

Utilization of health services is a determinant of health and disease within a population.⁶ In Egypt; child health services are provided through the Ministry of Health, Health Insurance Organization, University hospitals, the curative organizations, as well as the private sector. Patient satisfaction with the health care is an important health care outcome; consumer or patient satisfaction is the degree of effective or emotional response to a specific consumption experience. It is expected when the consumption experience matches a standard.⁷ Surveys concerning this issue provide information to health care providers about the quality of their service, which is useful in program planning, evaluation, and quality assurance activities.⁸

The present study was carried out to describe the impact of leukaemia on the child and his family and to assess utilization and satisfaction with health services among acute leukaemic children in Alexandria – Egypt

MATERIAL AND METHODS:

A descriptive study was carried out over one year duration, started November

2004. The University of Alexandria Paediatric Hospital in Shatby was the study venue, it serves 4 different governorates. Study population encompassed all children below 15 years old, attended in- or out-patient over one year duration, either newly diagnosed or for follow up.

Collection of data was through a standardized questionnaire sheet, managed through interviewing patient's mother; it includes personal, demographic, and socioeconomic data. The social standard was assessed according to a score system modified after Fahmy and El-Sherbini.⁹

Questions concerning impact of the disease included impact on the child, change of life quality, dependency on mother, change in school performance and learning process, impact on parents, and the economic burden of the disease.

Questionnaire also included assessment of the health service utilization (medical and social services received in the University Paediatrics Hospital). Mother's

satisfaction with the health service was calculated through a total score using the weight average mean method; where each degree of maternal satisfaction with each variable is given a suitable weight as follows:

- Satisfied 3
- Satisfied to some extend 2
- Not Satisfied 1

The average mean satisfaction score is obtained by dividing the total score by the total number of the studied mothers, the average is then ranked according to the following scale (3-1) levels:

- Ranks (1-4) for average mean satisfaction score (3 - 2.5) → High score
- Ranks (5-7) for average mean satisfaction score (2.5 - 2) → Average score
- Ranks (8-10) for average mean satisfaction score (2 - 1) → Low score.

Statistical analysis: Collected data were coded, tabulated, and organized. Analysis was done using the Statistical Package for Social

Sciences, version 11.5 (SPSS, 2002). Data were presented using frequency distribution, means and standard deviations (SD), bivariate association between the dependant variables and the independent variables, chi-square test (χ^2), and Fisher's Exact Test (FET) when (χ^2) is not valid for qualitative variables, and t-test for the difference between mean values for quantitative variables, with a p-value <0.05 is considered as a level of significance.

RESULTS:

The study population included 163 children with acute leukaemia (**Table 1**); the age group 4- <7 years and 7- <10 years were the most frequently encountered age group (33.7, 23.3%), respectively. Overall mean age (7.6±3.5) years, 58.3% were males. Two-thirds (69.3%) were from rural areas, 65.6% belonged to the low socioeconomic level, and 49.7% attended primary schools, while 36.2% were below the school age.

Regarding disease impact on the child (**Table 2**); most cases expressed feelings of fear, anxiety, and sadness (83.4, 95.1, and 69.9%), respectively. The disease mostly

changed their life quality, e.g., decrease physical activity (91.4%), stop playing with others (84.6%), and more dependency on their mothers. The school performance deteriorated in 63.8% of cases, e.g., frequent absenteeism, low scholastic achievements, and performance (97.1, 91.3, and 70.2%), respectively.

Psychological impact on parents is dramatic in all aspects, their quality of life is significantly changed (**Table 3**). Both parents experienced same negative effects but more pronounced on the mother. The influence of the disease on their economic stability was highly evident (**Table 4**), only 6.7% of mothers denied any economic drawback. Most parents attributed the burden to the expenses of medications, investigations, and transportation (84.4, 58.5, and 63.1%), respectively.

Concerning services delivered by the University Hospital (**Table 5**), it is evident that overall health services and admission are free of charge. On the other hand; 83.4% of mothers complained that they have to purchase some medications which are

unavailable. Few mothers (22.7%) had to do some investigations in the private sector. More than half of the mothers complained also from unavailable recreational mean for children and from the long time they have to wait in the chemotherapy room (58.9 and 53.4%), respectively. In contrast; many services were offered through social workers; 83.4% of mothers received financial aids, 43.5% get external aids from NGOs, and 38% were supplied with some deficient drugs.

Mother's satisfaction with health services provided by the University Hospital was ranked into an average mean satisfactory score (**Table 6**) ranged between 1 (low) and 3 (high satisfactory score). Highest score was for the services offered by the physicians, adequate length of hospital stay, and interpersonal relationship with medical staff (scored 2.88, 2.66, and 2.59, respectively). Lowest score was for amount of food presented (1.45). Mothers got several recommendations to improve services in the hospital (**Table 7**), three-quarters of them (73.6%) recommended regular supplies of

medications, on the other hand, 25.2% of them got nothing to recommend.

DISCUSSION:

Acute childhood leukemia is a spectrum of diseases, they enforce enormous amount of stresses on the child and his family. This study included 163 cases; the majority of children experienced anxiety (95.1%) and fear (83.4%). On the same trend; Sawyer¹⁰ mentioned in his study that immediately after diagnosis, children with leukaemia reported the same emotions, reflecting impact of hospitalization, chemotherapy, and other invasive medical procedures. The child's quality of life is disturbed; Hicks *et al.*¹¹ in their research allowed children to describe their quality of life in their own words; a decreased physical, psychological, social, and spiritual well-being were identified. This goes with results of the current study where 91.4% of cases suffered decreased physical activity and easy fatigue, 84.6% stopped playing with others, and this may be attributed to the effect of medications, lack of energy, even to the effect of hair loss.

Two-thirds of the current study cases (63.8%) had learning process difficulties. Similarly; several studies^{12,13} mentioned that these children face risk of school adjustment difficulties for number of reasons like frequent absenteeism, change of social interactions, and school phobia. They also may have difficulties in the cognitive functioning, poor scholastic achievements, and decreased learning disabilities.¹⁴

Regarding the psychological impact on parents; both experienced same stressful feelings but significantly more on the mothers, as they are the child care givers during the whole period of hospital admission. Zebrack *et al.*,¹⁵ evaluated this issue and stated that mothers were more likely to have symptoms of depression and post-traumatic stress disorder (PTSD) than fathers. On contrary; Rocha-Garcia *et al.*,¹⁶ mentioned that this experience may strengthen family bond in 82.4% of the families they studied, but the next common response (78.4%) was worries about the expenses they have to cover and the time to be dedicated caring for the sick child.

As 65.6% of the families in this study belonged to the low socio-economic level, 93.3% suffered an economic burden, and 83.4% accepted financial aids. On the same trend, Cohn *et al.*,¹⁷ explored impact of out-of-pocket expenses on five domains of family lifestyle: social, assets, credit, utilities, and charity. Parents of cancer children reported 80% lifestyle change to meet related expenses, area of the greatest impact was social domains, as canceling vacations, giving up recreational pleasures, and social expenditure. Among the lower income people; effect may extend to more crucial needs and requirements.

In Egypt, progress has been made in the development of successful treatment programs for children with cancer. Improvements were possible due to the availability of University hospitals with a collective expertise in the clinical management, and existence of experienced investigators.¹⁸ The importance of comprehensive, multidisciplinary treatment in improving patient outcome in a cost-effective

manner has been well documented for children with acute leukemia. Almost 80% of these children can be treated successfully if modern diagnostic and therapeutic approaches are initiated early. The role of specialized nursing and paramedical personnel, and the access to increasingly complex equipment and facilities, are critical in diagnosis, treatment, and long-term follow-up.¹⁹ This comprehensive approach medically and socially is seen to some extent in the University of Alexandria Paediatrics Hospital, once the child is admitted; complete confirmatory investigations were done for all cases, they received treatment both chemotherapy and radiotherapy free of charge. Diagnostic X-ray was done for 17.8% of the cases if chest infection is suspected, bronchopneumonia, or mediastinal mass. Abdominal ultra-sonography was done for 12.9% of cases to assess liver and spleen condition. Unfortunately; 83.4% of mothers have to purchase some medications, 22.7% considered doing some investigations outside the hospital. Recreational activities for the children are available only in one form of "child

club” which is only utilized by 41.1% of cases, there was no enough education about it, and it is closed in most hours of the day.

On the other hand, social services offered through social worker inside the hospital were popular. It was found that 84% of mothers received financial aids, 43.5% received external aids from NGOs, and supplies of some deficient drugs were given to 38.0% of cases. Only 16.6% didn't receive any social services as they said that they were not in need. Awareness about the need for a psycho-social service directed to pediatric oncology patients and their families has increased greatly in the last decades. However; it is currently unknown to what extent these services are available in the Egyptian hospitals.¹⁸ A survey was conducted in the United States to determine availability of some services helping children with cancer, e.g., psychological and social work consultation, support groups for patients and family members, as well as, pain and anxiety management. Results suggested that most centers offer social work consultation and

support groups to parents, fewer support groups are offered to patients, fewer services to assist patients coping with medication side effects.²⁰

In the current study, mothers were very satisfied with the medical team technical quality and art of care throughout the period of the study, as expressed by the highest mean satisfaction score (2.88). Average score was for satisfaction with services offered by the nurses, room cleanliness, hospital beds, cleanliness of the rest rooms, and number of beds inside the room. This could be attributed to improper cleanliness of the inpatient rooms, improper control of insects and cats, dirty walls and floors, in addition to the bad room odor. Mothers were told that they are responsible for the cleanliness of their rooms, beds, and rest rooms. Some also told us that number of inpatient beds is above the capacity of the room, beds are uncomfortable with dirty linen, and blankets were insufficient in the winter. Some were dissatisfied with the food service which may be attributed to lack of confidence about the degree of containers

cleanliness, the way of cooking and presentation. Low score was only for the amount of food presented which was considered not sufficient for many mothers (67.5%).

Patient's Mothers had several recommendations to improve the service; although 25.2% had no recommendations. Similarly, Soh²¹ reported that satisfaction was not associated with the patient's feeling of improvement in their medical problem or having their specific requests granted. 83% had specific requests, most commonly prescription of drugs (45%) or investigations (19%). However, only 37% actually expressed these requests to the doctor. These findings

suggest the importance of encouraging patients to express their requests, to provide health givers with information about patient's wishes, health beliefs, and expectations. In addition, encouragement of verbalization of requests will result in more effective physician-patient communication and thus greater compliance in the utilization of health services.

In conclusion, the impact accompanies childhood leukaemia diagnosis on the child and his family is enormous, we tried to clarify that among the Alexandria cases, and to document services delivered to these patients by the University hospital, their satisfaction with it, and their recommendations to improve it in the future

Table 1: Case distribution according to the socio-demographic characteristics.

Character	n=163	%
<u>Age group:</u>		
1-	32	19.6
4-	55	33.7
7-	38	23.3
10-	26	16.0
13- <15	12	7.4
Mean±SD = 7.6±3.5		
<u>Gender:</u>		
Males	95	58.3
Females	68	41.7
<u>Residence:</u>		
Rural	113	69.3
urban	50	30.7
<u>Socioeconomic level:</u>		
High	16	9.8
High middle	15	9.2
Low middle	25	15.4
Low	107	65.6
<u>Educational Level:</u>		
Below school age	59	36.2
Illiterate	10	6.1
Primary school	81	49.7
Preparatory school	13	8.0

Table 2: Distribution of the studied sample according to disease impact on the child and his school performance

Variable	n=163	%
<u>Psychological impact of the disease on the child:</u>		
• Fear	136	83.4
• Anxiety	155	95.1
• Sadness	114	69.9
• Excessive crying	33	20.2
• Lack of appetite	47	28.8
• Lack of interest	14	8.6
<u>Change in child quality of life:</u>		
• Stop practice of school activities and sports	99	60.7
• Does not share his siblings or friend in playing	138	84.6
• Decreased physical activity, become easily tired from the least effort	149	91.4
<u>Dependency on mother in the daily life activities:</u>		
• Washing	147	90.2
• Wearing clothes	97	59.5
• Going to the bath room	82	50.3
• Getting off bed	64	39.3
• Feeding	62	38.0
<u>Effect of the disease on the learning process:</u>		
- Below the educational age	59	36.2
- Yes	104	63.8
<u>How the disease affects the learning process</u>		
	n=104	%
- Frequent school Absenteeism	101	97.1
-Affect scholastic achievement & school performance	95	91.3
- Does not pass the examinations	73	70.2
- Leave the school (not able to go on with studying)	11	10.5
- Could not join the school	8	7.7

Table 3: Distribution of the studied sample according to disease impact on the parents

Variable		Mother		Father		Test of significance	
		n=163	%	n=163	%	χ^2	p-value
I - Psychological impact of the disease on the parents:							
- Fear	Yes	138	84.6	49	30.1	99.3	0.000*
	No	25	15.3	114	69.9		
- Anxiety	Yes	140	85.9	118	72.4	8.9	0.003*
	No	23	14.1	45	27.6		
- Sadness	Yes	144	88.3	131	80.4	3.9	0.047*
	No	19	11.7	32	19.6		
- Lack of appetite	Yes	45	27.6	24	14.7	8.1	0.004*
	No	118	72.4	139	85.3		
- Lack of interest	Yes	87	53.4	70	42.9	6.5	0.011*
	No	76	46.6	93	57.1		
- Sense of guilt	Yes	114	69.9	94	57.7	5.3	0.021*
	No	49	30.1	69	42.3		
-Sense of weakness, hopeless, and helpless	Yes	67	41.1	34	20.9	15.6	0.000*
	No	96	58.9	129	79.1		
- Frustration, depression	Yes	97	59.5	58	35.6	18.7	0.000*
	No	66	40.5	105	64.4		
- Sleep disturbance	Yes	44	27.0	24	14.7	8.1	0.004*
	No	119	73.0	139	85.3		
II - Changes in the quality of life of the parents:							
- Leave their jobs	Yes	15	9.2	3	1.8	8.4	0.004*
	No	148	90.8	160	98.2		
- Effect on the job performance	Yes	8	4.9	25	15.3	9.7	0.002*
	No	155	95.1	138	84.7		
- Effect on the social relations and sharing in the social events.	Yes	133	81.6	96	58.9	20.0	0.000*
	No	30	18.4	67	41.1		

*p is significant if < 0.05

Table 4: Distribution of the studied sample according to the economic impact on the family and its relation to the socio-economic level.

Variable			Socioeconomic level									
			High		High - middle		Low - middle		Low			
	No.	%	No.	%	No.	%	No.	%	No.	%		
<u>Economic impact</u>												
Yes	152	93.3	9	5.9	11	7.2	25	16.4	107	70.4		
No	11	6.7	7	63.6	4	36.4	0	0.0	0	0.0		
FET = 37.7 p = 0.000*												
<u>Causes of the economic impact:</u>							n=152	%				
- Expenses of the medications							129	84.8				
- Expenses of the investigations							89	58.5				
- Expenses of the transportation							96	63.1				
- The mother left her job to stay with the sick child in the hospital							15	9.8				

*p is significant if < 0.05

FET: Fisher's Exact Test

Table 5: Distribution of the sample according to medical and social services received in the University Paediatrics Hospital.

Variable	n=163	%
<u>Medical service performed with the child:</u>		
- Complete confirmatory investigations	163	100
- Treatment (chemotherapy and radiotherapy)	163	100
- Diagnostic X-rays	29	17.8
- Diagnostic abdominal Ultrasonography	21	12.9
<u>The medication availability:</u>		
- Available	27	16.6
- Some drugs are available and the others are bought by the patient	136	83.4
<u>Place of doing the laboratory investigations:</u>		
- In the University Paediatrics Hospital	126	77.3
- Some are in the hospital and some are in private labs	37	22.7
<u>Means of recreation for the sick child during his admission:</u>		
- Child club	67	41.1
- None	96	58.9
<u>Waiting to receive chemotherapy and radio-therapeutic sessions:</u>		
- Long period	87	53.4
- Reasonable time	66	40.4
- Short period	10	6.1
<u>Convenience of the waiting place:</u>		
- Convenient	11	6.7
- Inconvenient	152	93.3
<u>Cause of inconvenience in the waiting place:</u>		
- Narrow, overcrowded place	117	76.9
- There are no enough seats	108	71.0
<u>Benefits from the social services offered by the hospital:</u>		
- Yes	136	83.4
- No	27	16.6
<u>Type of social services presented through social workers:</u>		
- Didn't receive	27	16.6
- Financial aids	136	83.4
- External aids from NGOs	71	43.5
- Supply of some deficient drug	62	38.0

Table 6: Distribution of the sample according to mother satisfaction with the health services provided in the University hospital.

Mother's satisfaction	Satisfied		Satisfied to some extent		Not satisfied		Score	Rank
	No.	%	No.	%	No.	%		
- Adequate length of hospital stay	114	69.9	46	28.2	3	1.8	2.66	2
- Room cleanliness	83	50.9	69	42.3	11	6.7	2.44	6
- Hospital beds	68	41.7	89	54.6	6	3.7	2.38	7
- Number of beds inside the room	61	37.4	70	42.9	32	19.6	2.18	9
- Amount of food presented	21	12.9	32	19.6	110	67.5	1.45	10
- Quality of food presented	97	59.5	55	33.7	11	6.7	2.53	4
- Cleanness of the bath rooms	59	36.1	90	55.2	14	8.5	2.28	8
- Satisfactory interpersonal relationship with the physicians and the nurses	106	65.1	47	28.8	10	6.1	2.59	3
- Services offered by the physicians (art of medical care) * Answer all questions and allow the mother to explain the child's complaints * Explain the prescribed drugs and its side effect.	149	95.1	8	4.9	6	3.7	2.88	1
- Service offered by the nurses	107	65.6	27	16.6	29	17.8	2.48	5

<u>*Rank</u>	<u>Average Mean Satisfaction Score</u>	<u>Level of satisfaction</u>
1-4	(3 - 2.5)	High satisfaction score
5-7	(2.5 - 2)	Average satisfaction score
8-10	(2 - 1)	Low satisfaction score

Table 7: Distribution of the studied sample according to mother's recommendations to improve services in the University hospital.

Mother's Recommendations	n=163	%
- Regular supply of the needed medications	120	73.6
- Availability of the needed investigations	83	50.9
- Improving the quality of food offered and increasing its amount	62	38.0
- Recreational means for the children	53	32.5
- Health education sessions	44	27.0
- Care of the cleanness of rooms and the water closets	14	8.6
- Social and financial supports	13	8.0
- No recommendations	41	25.2

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