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Prevalence of Leukemia among Children and Guidelines for Parents on Leukemia - A Systemic Approach

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Abstract: ***Children are a unique population to care for because the decision about their management affects not only the children but also the entire parental unit and require amount of sensitivity. This study aims to provide guidelines to the parents of children with leukemia under the age of 19 years. Method: A quasi experimental research approach with non-equivalent control group design was adopted and a sample of 60 relatives of patients admitted in leukemic units of Safdarjang Hospital, Delhi were selected for the study. Result: In experimental group maximum 16(53.3%) of the respondents were having ALL, followed by 12(4%) AML, and a few 2(6.6%) had CML. In control group 18(60)% were having ALL followed by 9(33%)% AML and a few 3(7%) were having CML. Conclusion: Parents of children with leukemia had high learning need and high desire to learn. The maximum numbers of children suffering from leukemia were male and maximum of the children were diagnosed as Acute Lymphoblastic Leukemia.***

Keywords: Children with leukemia, Parents, Evaluating, Guidelines

1. Background

Children are the most precious blessings given to family. There is nothing in this world that can be more important than own baby. The lives of the parents completely adjust upon the arrival of their child. A child's chronic illness affects the lives of all family members emotionally and physically. Roles and routine change and the demands of care giving must be negotiated. Financial recourses may be strained. Leukemia is the most common malignancies in children with a prevalence of 129 in one million and the second cause of death among children aged 5-14 years. Parents who have a child suffering from cancer face distress in regard to multiple hospitalizations, chemotherapy side effects (hair loss, nausea, vomiting and infections). World Cancer Day which was led by union of international cancer control (UICC) based in Geneva, supported by Pan-American Health Organization and WHO promoted ways to ease the global burden of cancer, preventing cancer and raising quality of life for cancer patients. According to National Cancer Control Program me current status & strategies in India Cancer has become one of the ten leading causes of death in India. It is estimated that there are nearly 2-2.5 million cancer cases at any given point of time. Over 7 lakh new cases and 3 lakh death occur annually due to cancer. Data from population based registries under National Cancer Registry Program me indicate that the leading sites of cancer are oral cavity, lungs, oesophagus and stomach amongst men and cervix, breast and oral cavity amongst women.

Table 1: Comparison of Paediatric Oncology cases in India and USA as per Executive Summary India Paediatric Oncology Initiative Meeting- Feb-2-2009 status of Paediatric Oncology cases

S.No.	Area	India	U.S.A
1.	New cases per year	40,000	12,400
2.	Treatment, curative intent	50%	100%
3.	Overall cure rate	25%	70%
4.	Treated on-op groups	5%	98%

Table 1 indicates that new cases of paediatric oncology is greater in India as compare to U.S.A., whereas treatment & curative intent is also 50% in India which is 100% in U.S.A, overall cure rate is 25% in India which is 70% that is much higher in U.S.A. And treated an op- group is 5% in India which is 98% in U.S.A.Cancer therapy evaluation program, Division of cancer control population sciences, National Cancer Institute[12]discussed that childhood cancer incidence rate increased significantly from 1975 through 2006, with increasing rate of ALL most notable. Childhood cancer mortality rate declined by more than 50 % between 1975 and 2006.

American Cancer Society, cancer facts found that an estimated 52,380 new cases of leukemia are expected in 2014. Leukemia is a cancer of the bone marrow and blood and is classified into four main groups according to cell type and rate of growth: acute lymphocytic (ALL), chronic lymphocytic (CLL), acute myeloid (AML), and chronic myeloid (CML). The majority (91%) of leukemia cases is diagnosed in adults 20 years of age and older, among whom the most common types are CLL (35%) and AML (32%). Among children and teens, ALL is most common, accounting for 75% of leukemia cases (see special section on childhood and adolescent cancers, page 25).From 2006 to 2010, overall leukemia incidence rates increased slightly (by 0.5% per year). Pillitteri, A. stated that the higher incidence of ALL is in children between 2-6 years. The prognosis is in children younger than 2 years or older than 10 years at the time of first occurrence is not as good as in those between 2-10 years. The prognosis in children who have more than 20,000 white blood cells per millimeter is not good as in those with a lower white blood cell count and fewer 1.2 cells at first diagnosis. The incidence of ALL is slightly higher in boys than girls. Lack of literature on teaching leukemic patient and their parents exists at the moments. Bajel, A. et al stated that the current population of India is over a billion people including 340 million children (33%) younger than 15 years and treatment will be required for 8160 new cases of childhood ALL every year. A learning package has significant positive influence on retention of knowledge. The

result of study conducted by Bhagyamma indicates a similar direction.

2. Method

A **Quantitative Experimental approach** was selected. Research design used for the study is **Quasi experimental (non equivalent control group pre test post test design)** was used. In present study the independent variable is the guidelines on the care of children with leukemia given by the researcher. The study was conducted in Safdarjang Hospital of New Delhi. The population for the current study is comprised of parents of children with leukemia under the age of 19 years. **Convenient sampling** technique was used to select the subjects for the study. A total of 60 subjects; 30 in experimental and 30 in control group to identify the learning needs of the parents on care of children with leukemia. The following tools were used for the purpose of data collection:

1) Leukemia learning need questionnaire
2) Structured knowledge questionnaire
3) Guidelines for parents of children with leukemia on care of children with leukemia.

The leukemia learning need questionnaire was prepared to assess the learning needs of the parents on care of children with leukemia. It consists of two sections:-

Section I contained items on demographic data of child and parents and leukemia related information.

Section II contained 40 questions in the area like leukemia, its definition, diagnosis, causes, sign and symptoms of leukemia, Complication of leukemia and management of these complications, Management of children with leukemia ,Dietary management ,Rest and sleep ,Recreational therapy. Each question had several answer and a score of 1 was given for every correct response. The maximum possible score was 144.

According to the percentage of scores the following criteria of interpreting the scores were developed.

- Good : 120-144 (90% and above)
- Average: 80-119 (70-80%)
- Poor : 50-79 (below50%)

Table 2: Blue print on content and distribution of the items in leukemia learning need questionnaire to assess learning need of the parents of children with leukemia

Content Area	Domains of objectives			Total no of items	Percentage %
	Knowledge	Understanding	Application		
LEUKEMIA: definition, diagnosis, causes, sign and symptoms of leukemia	3	-	-	3	20%
Treatment of leukemia in children, Side effects of chemotherapy drugs , Management of side-effects	2	-	2	4	26.66%
Complication of leukemia and management of these complications, Management of children with leukemia, Dietary management ,Rest and sleep ,Recreational therapy	5	2	1	8	53.33%
TOTAL	66.66	13.44	20	15	100

Jamia Hamdard Institutional Review Board (IRB) has approved the study.

3. Result

Table 3: Comparison of demographic variables of children with leukemia in control and experimental group based on their frequency-percentage distribution, n1+n2=60

Demographic variables	Control group (n1=30)		Experimental group (n2=30)		Test used	p value
	F	%	f	%		
Age (in years)					Fisher exact	0.558
6-10	12	40%	16	53.33%		
11-15	9	33.33%	9	33.33%		
16-19	8	26.66%	5	13.33%		
Sex					Chi square test, df(1)	0.602
Male	18	60%	16	53.33%		
Female	12	40%	14	46.66%		
Diagnosis					Fisher exact	0.729
ALL	16	53.30%	18	60%		
AML	12	40%	9	33.33%		
CML	2	6.60%	3	7.70%		
Birth order					Fisher exact	0.36
First	21	71%	25	75%		
Second	9	29%	5	25%		
Duration of illness					Fisher exact	0.073
Less than 1 year	16	53.30%	18	60%		
1-2 yr	9	33.30%	12	40%		
3-4 yr	5	13.30%	0	0%		
Admission to the hospital					Fisher exact	0.795
First time	0	0%	0	0%		
Second time	0	0%	0	0%		
Third time	16	53.30%	18	60%		
More than 3 times	14	46.60%	12	40%		
Informant					Chi square, df(1)	0.584
Mother	19	57%	21	63%		
Father	11	43%	9	37%		

Data presented in Table 3 shows that Maximum of children in control group 12 (40%) were in the age group of 6-10 years, followed by age group 11-15 years which includes 9 (33%) of children with leukemia, 8(26.6%) were in age group of 16-19 years and in experimental group 16(53%) were in the age group of 6-10 years, followed by 9(33%) in the age group of 11-15 years and 5(13%) were in 16-19 years age group. The groups were compared using Fishers Exact test for age which was not significant. In the experimental group 40% were females and 60% were males. In the control group 53.33% were males and 46.66% were females. Both the groups were compared using Chi-square test (p=0.602) which was found not significant. In experimental group maximum 16(53.3%) of the respondents were having ALL, followed by 12(4%) AML, and a few 2(6.6%) had CML. In control group 18(60)% were having ALL followed by 9(33%)% AML and a few 3(7%) were having CML. No respondents had CLL. Both the groups were compared using Fishers Exact which was not significant. In experimental group 21(71%) were having first birth order followed by9(29%) which belongs to second birth order. In control group 25(75%) were having first order and 5(25%) had second order. No respondent belongs to others category. Both the groups were compared using fisher exact which was not significant. In experimental group majority of respondents were 16(53%)were admitted to the hospital less than one year, followed by respondents who were admitted since1-2 yrs 9(33%), 5(13%% were since 3-4 yrs. In control group 18(60%)% were admitted to the hospital less than one year, 12(40%)% since 1-2 yrs. No respondent found to be admitted more than 4 years in the hospital. Both the groups were compared using Fishers Exact which was not significant. In experimental group majority of respondent admitted third time 16(53.33%) followed by 14(46%) admitted more than third time In control group also majority of respondent admitted third time 18(60%) followed by 12(40%) who were admitted more than third time. Both the groups were compared using fisher exact which shows not significant. In experimental group (19)57% of informant were mother and 11(43%) were father. In control group 21(63%) were mother and 9(37%) were father. Both the groups were compared using Chi square at df(1) which was not significant.

Table 4: Mean and standard deviation of pre test knowledge scores of parents in experimental and control group, n1+n2=60

Group	Knowledge Score						
	Mean	SD	Mean D	SE_M	df	't' value	Table value (t)
Experimental (n_1=30)	25.68	4.72	1.82	0.77	58	1.63	2
Control (n_2=30)	27.5	5.39					

*t(58)=2, p>0.05, not significant

The data presented in table 4 show that mean pre test knowledge scores of control group (27.5) was higher than the mean pre test knowledge score of experimental group (25.68) with a mean difference of 1.82. It was not found to be statistically significant as evident from 't' value of 1.63 for df(58) at 0.05 level of significance which was less than the table value of 't', which was 2.00. This indicates that initially parents in the each group i.e, control and experimental group did not differ in their level of knowledge.

Table 5: Mean, standard deviation, mean difference, standard error, and 't' value of pre test and post test knowledge scores of experimental group, n1=30

Experimental group (n_1=30)	Mean	SD	Mean D	SE	df	't' value	Table value (t)
Pre test	25.86	4.72	24.57	1.3	28	18.47*	2.05
Post test	50.43	5.94					

*t (28)=2.05, p<0.05, significant

The data in table 5 show that the mean post test (50.43) of experimental group was higher than their mean pre test knowledge score (25.86) with a mean difference of 24.57. The't' value of 18.47 for df(28) was found to be statistically significant at 0.05 level as the table value for 't' was 2.05. This shows that the obtained mean difference of 24.57 was a true difference and not by chance.

Table 6: Mean difference, standard error of mean, and 't' value of post test knowledge scores between experimental and control group, n1+n2=60

Group	Post test Knowledge score					
	Mean	Mean D	SE	df	't' value	Table value (t)
Experimental (n_1=30)	50.43	21.1	0.79	58	16.01*	2
Control (n_2=30)	31.41					

*t(58)=2, p<0.05, significant

The data presented in table 6 show that the mean post test knowledge scores of experimental group, was higher than the mean post test knowledge scores of control group. The obtained mean difference was found to be statistically significant as evident from 't' value of 16.01 for df(58), Hence it can be inferred that guidelines were more effective in enhancing knowledge of parents of children for care of children with leukemia.

4. Conclusion

Maximum of children in control group 12 (40%) were in the age group of 6-10 years, followed by age group 11-15 years which includes 9 (33%) of children with leukemia, 8(26.6%) were in age group of 16-19 years and in experimental group 16(53%) were in the age group of 6-10 years, followed by 9(33%) in the age group of 11-15 years and 5(13%) were in 16-19 years age group. The groups were compared using Fishers Exact test for age which was not significant. In the experimental group 40% were females and 60% were males. In the control group 53.33% were males and 46.66% were females. Both the groups were compared using Chi-square test (p=0.602) which was found not significant. In experimental group maximum 16(53.3%) of the respondents were having ALL, followed by 12(4%) AML, and a few 2(6.6%) had CML. In control group 18(60)% were having ALL followed by 9(33%)% AML and a few 3(7%) were having CML. No respondents had CLL. Both the groups were compared using Fishers Exact which was not significant. The mean post test (50.43) of experimental group was higher than their mean pre test knowledge score (25.86) with a mean difference of 24.57. The't' value of

18.47 for df(28) was found to be statistically significant at 0.05 level as the table value for 't' was 2.05. This shows that the obtained mean difference of 24.57 was a true difference and not by chance. The mean post test knowledge scores of experimental group, was higher than the mean post test knowledge scores of control group. The obtained mean difference was found to be statistically significant as evident from 't' value of 16.01 for df(58), at 0.05 level of significance. Hence it can be inferred that guidelines were more effective in enhancing knowledge of parents of children for care of children with leukemia.

Analysis of data revealed that:

1) Parents of children with leukemia had high learning need and high desire to learn.
2) The maximum numbers of children suffering from leukemia were male.
3) There are areas of self care deficit, and according to priority, they are related to problem diseases, treatment, rest and comfort, follow-up care, personal hygiene and diet.
4) The guidelines were found to be effective in increasing the cognitive behavior of the parents of children with leukemia.

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