A Study to Assess the Awareness Regarding Neutropenia Home Care Needs among Caregivers of Children with Leukemia Attending Oncology Units, at Aims, Kochi

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Abstract:
Introduction: Leukemia is the most common malignancy of children with a prevalence of 129 in one million, and the second cause of death among children aged 5 to 14 years. Most of the children have chance to develop neutropenia during their treatment period.
Methods: The approach used for the study was quantitative approach using descriptive research design. The study was conducted among 30 caregivers of children with leukemia who met the eligibility criteria following non probability convenience sampling technique with an objectives to assess the awareness regarding neutropenia home care needs among caregivers of children with leukemia, and to find out association between level of awareness among caregivers and selected demographic variables.
Findings: The researcher found that most of the caregivers (86.7%) had average knowledge and 13.3% had good knowledge regarding neutropenia home care needs. Most of the caregivers have more knowledge in diet pattern (mean percentage 73.3%) such as preparing meal, storage, and do's and do not's consumption of food. Half of the caregivers had less knowledge among physical or physiological needs and personal hygiene. Duration of illness had shown statistically significant association at p<0.005 level (p= 0.017) with level of awareness regarding neutropenia home care needs among caregivers of children with leukemia.
Conclusion: Researcher concluded that most of the caregivers had average knowledge and each one had different views about their child's care.

Keywords: ALL: Acute Lymphocytic Leukemia, AML: Acute Myeloid Leukemia, Chronic myeloid leukemia

1. Introduction

Leukemia is the most common malignancy of children with a prevalence of 129 in one million, and the second cause of death among children aged 5 to 14 years. Acute lymphoblastic leukemia (ALL) is the most common type of this disease, accounting for 75% of all leukemia and 30% of all malignancies in childhood. ALL affects boys more than girls. Studies have also indicated that enhancement of the parents' knowledge about the problems and needs of their leukemic children has an important effect on family support, leading to a significant increase in the quality of life of these children. Most of the children have more chance to develop neutropenia during their treatment.

Infections are the major cause of mortality and morbidity in children. The risk of infections is principally related to the intensity and duration of the immune suppressive chemotherapy. Any child can get neutropenia. Some people are born with neutropenia or get it for no known reason. The most common cause in children is a temporary decrease in the number of white blood cells or an increase in the number being destroyed after a viral infection.

2. Material and Methods

Quantitative approach using descriptive design was adopted for the present study. The setting was Amrita institute of medical sciences, Kochi. The subjects for the study were caregivers of children who have leukemia, attending oncology units of Amrita institute of medical sciences, Kochi who were selected for the present study. Non probability convenience sampling technique was

used for the selection of subjects. Thirty parents were selected from oncology departments of AIMS who met with the inclusion criteria.

The data collection instrument includes a semi structured interview schedule to assess the socio-demographic and clinical data. The socio-demographic data of the caregivers consists of 8 items which includes age, relationship, education, occupation, family history of disease, no. of children, personal qualification, and socioeconomic status. Socio-demographic profile and clinical data of the child consists of 5 items which includes age of the child , sex, diagnosis, duration of illness, duration of leukemia treatment and history of neutropenia.

Structured interview to assess the awareness regarding neutropenia home care needs. Semi Structured interview questionnaire consisted of 30 closed ended questions with yes or no options. It was categorized into 3 headings about physical/psychological needs, personal hygiene and diet.

3. Findings

3.1. Section A: Sociodemographic Characteristic of Caregivers of Children with Leukemia

SL.	Sample characteristics no.	Frequency (f)	Percentage (%)
1.	Age of the care giver		
	18 – 30 years	8	26.7
	31- 40 years	16	53.3
	41-50 years	4	13.3
	Above 50 years	2	6.7
2.	Relationship with the child		
	Mother	15	50
	Father	15	50
3.	Educational Status		
	Illiterate	0	0
	primary	3	10
	secondary	10	33.3
	Higher secondary	6	20
	Graduate	7	23.3
	Post graduate	4	13.3
4.	Occupation		
	Government job	2	6.7
	Private job	9	30
	Self employee	1	16.7
	Daily wages	5	3.3
	unemployed	13	43.3
5.	Number of Children		
	One	19	63.3
	Two	11	36.7
	More than two	0	0

Table 1: Frequency and percentage distribution of subjects based on demographic characteristics

Table 1 shows that majority of the caregivers (53.3%) belong to the age group 31-40 years.
33.3% of caregivers were having secondary education. 63.3% caregivers have one child.

3.2. Section B: Sociodemographic and Clinical Data of Children with Leukemia

Sl. No.	Sample characteristics	Frequency (f)	Percentage (%)
1	**Age of the child**		
	Up to 3 years	5	16.7
	4-7 years	15	50
	8-11 years	9	30
	12-17 years	1	3.3
2.	**sex**		
	Male	17	56.7
	Female	13	43.3
3.	**Duration of illness**		
	Less than 6 Months	14	46,7
	6 - 12 Months	9	30
	12 - 24 Months	7	23.3
	More than 24 Months	0	0
4.	**Duration of leukemia treatment**		
	Less than 1 Year	2	6.7
	1 - 2 Years	9	30
	2 - 3 Years	19	63.3
	More than 3 Years	0	0

Table 2: Distribution of children with leukemia based on sociodemographic characteristics and clinical data

Table 2 Shows that the most of the children (50%) were in the age group of 4-7 and (30%) 8-11 years. Majority of the children were male. Duration of illness for most of the subjects (46.7%) is in less than 6 months. Majority of the children (30%) are taking treatment for 1-2 yrs.
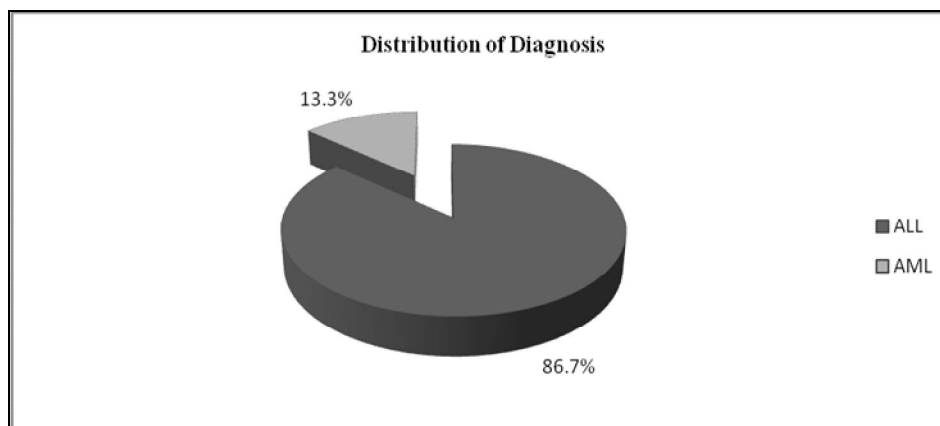

Figure 1: Pie diagram showing types of leukemia among children n=30

Pie diagram shows that 86.7% of the children had Acute Lymphoblastic Leukemia and 13.3 % of children Acute Myeloid Leukemia**.**
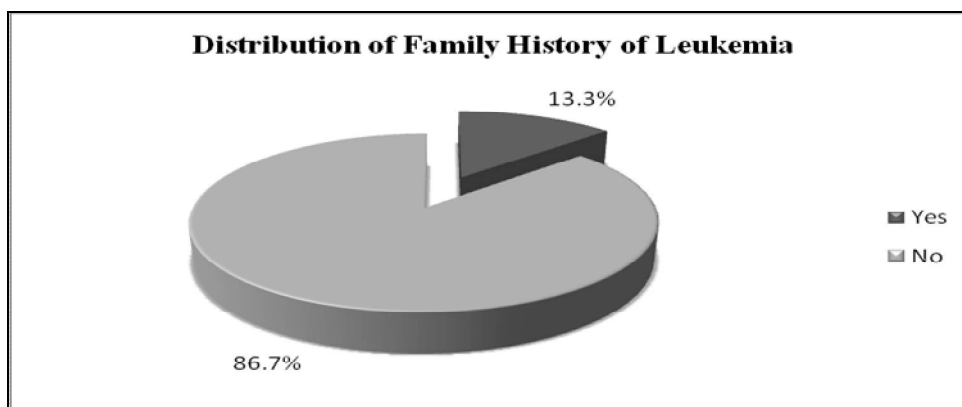

Figure 2: Pie diagram showing family history of leukemia among children

Figure 2 shows that 13.3% children had family history of leukemia, 86.7% of the children had no family history of leukemia.
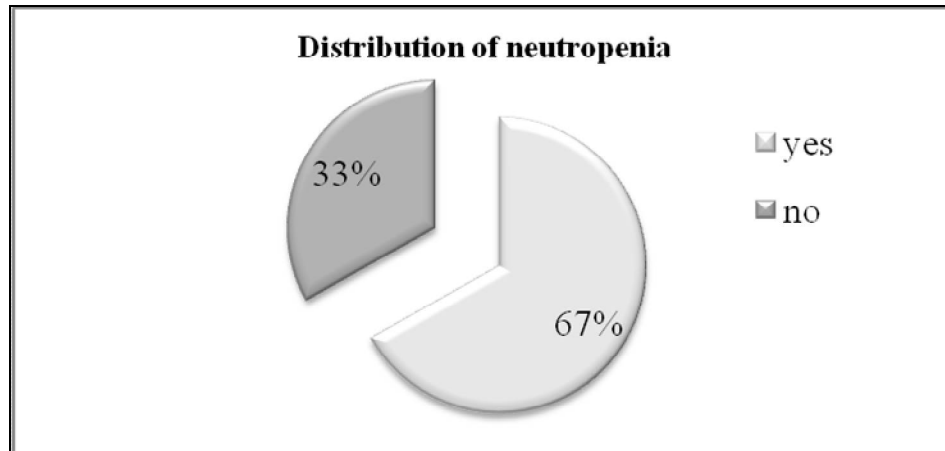

Figure 3: Pie diagram showing occurrence of neutropenia

Figure 3 shows that 67% children had history of neutropenia during their treatment and 33% have no history of neutropenia.

3.3. Section C; Assessment of Level of Knowledge among Caregivers Regarding Home Care Needs of Children Having Neutropenia

Level of knowledge	Frequency (f)	Percentage (%)
Poor	0	0
Average	26	86.7
Good	4	13.3

Table 3: Distribution level of knowledge of caregivers regarding home care needs of neutropenia

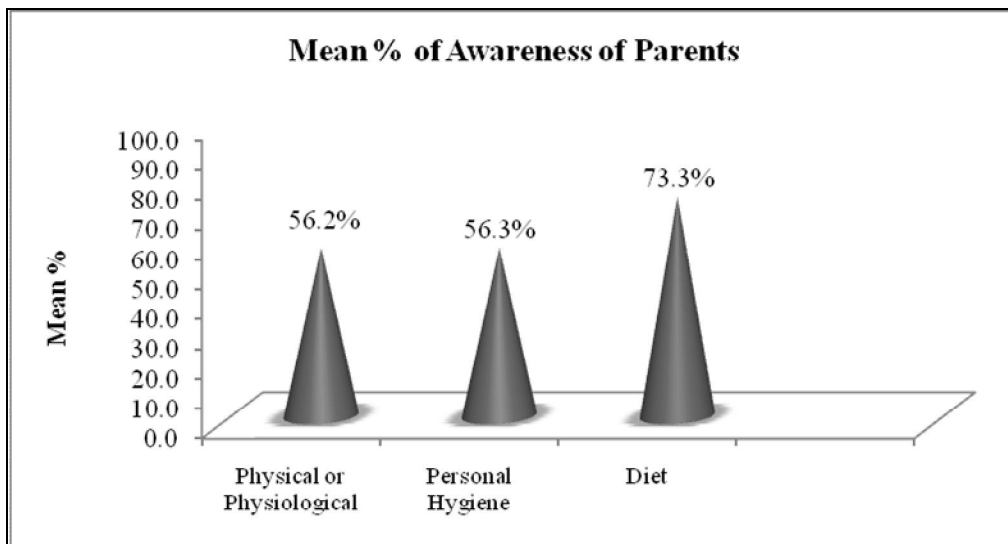Table 3 shows that most of the subjects 86.7% had average awareness and 13.3% had good knowledge.

Figure 4: Cone diagram Showing mean score percentage of caregivers regarding home care needs

Figure 4 shows that most of the parents have more knowledge about the diet to be followed (mean =73.3%) than the personal hygiene (mean percentage 56.3%) and physical or physiological needs (56.2%).

3.4. Section D; Association between Awareness of Caregivers with Selected Demographic Variables
Table 3; shows the association of awareness score regarding neutropenia home care needs among parents of children with leukemia with selected demographic variable**.**

Sl no	Demographic variable	Awareness score				x^2	df	Table value
		Average		good				
		f	%	f	%			
1.	**Age of the parents**							
	18 - 30 Years	8	100	0	0			
	31 - 40 Years	13	81.3	3	18.8			
	41 - 50 Years	4	100	0	0			
	Above 50 Years	1	50	1	50	3.825	1	0.290[ns]
2.	**Relationship with the Child**	13	86.7	2	13.3			
	Mother	13	86.7	2	13.3			
	father					0.000	1	1.000[ns]
3.	**Educational Status**							
	Primary	3	100	0	0			
	Secondary	8	80	2	10			
	Higher Secondary	6	100	0	0			
	Graduate	6	85.7	1	14.3	2.316	1	0.870[ns]
	Post Graduate	3	75	1	25			
4.	**Duration of Illness**							
	Less than 6 Months	14	100	0	0			
	6 - 12 Months	8	88.9	1	11.1			
	12 - 24 Months	4	13.3	3	42.9	6.191	1	0.017[**]
5.	**Duration of Leukemia Treatment**							
	Less than 1 Year	2	100	0	0			
	1 - 2 Years	7	77.8	2	22.2			
	2 - 3 Years	17	89.5	2	10.5	1.193	1	0.682[sn]

Table 4
**p<0.005.significant

The demographic data of duration of illness had shown statistically significant association at p<0.005 level (p= 0.017) with level of awareness regarding neutropenia home care needs among parents of children with leukemia. However, other demographic variables did not have any significant association.

4. Discussion
Objectives of the study were to,
The first objective was to assess the awareness regarding neutropenia home care needs among caregivers of children with leukemia.
The present study result shows that most of the caregivers 86.7% had average awareness and 13.3% had good knowledge. Most of the caregivers have more knowledge in the diet pattern (mean =73.3%) than the personal hygiene (mean percentage 56.3%) and physical or physiological needs (56.2%). Most of the subjects have more knowledge in diet pattern (mean percentage 73.3%) like preparing meal, storage, and do's and donot's consumption of food.
The present study finding supported by Hasan SS, Hussein KA, Hashim M, conducted a study on assessment of Home Care Management for caregiver's having leukemic adolescent patient in Erbil city. The study shows the majority of caregiver had deficit knowledge regarding cause of leukemia and nutrition to reduce fatigue for adolescent leukemic, and shows the majority of caregivers had poor practices regarding preparing meals, with poor practice regarding oral hygiene. This study shows that the caregivers who are having adolescent leukemia patients had deficit in knowledge and low practices regarding home care management.
D.Gelession, L. Y. Hiraishi, L. A. Ribeiro conducted a descriptive study on neutropenia and home care needs of children with leukemia among caregivers in Brazil 2009. Result indicates changes in the physical environment, people and human relationships,

evidencing crises and transition towards stability. The following care procedure raised doubts, hypothermia, body, food, environmental hygiene, risk of interpersonal contact and special care.

The second objective was to find out association between level of awareness among caregivers and selected demographic variables.

The present study shows that demographic data of duration of illness had shown statistically significant association at $p<0.005$ level ($p= 0.017$) with level of awareness regarding neutropenia home care needs among caregivers of children with leukemia. However, other demographic variables did not have any significant association.

A descriptive study conducted by Khames B.O, Zaid W.A and Ali Hussein on mothers' knowledge concerning leukemic children undergoing chemotherapy treatment in oncology units at Baghdad city. The present study findings supported that, there is significant association between mothers knowledge and duration of illness of their children (p-value = 0.05).

The present study result contradicted with Hasan SS, Hussein KA, Hashim M, conducted a descriptive study on assessment of home care management for caregiver's having leukemic adolescent patients in Erbil city and the study revealed a significant association between caregiver's knowledge and level of education (p-value 0.025), residency areas, and a highly significant association between caregivers' knowledge and practice with their socio-economic status.

5. Conclusion
The final conclusion reached from the study was that caregivers who participated in the study had average knowledge. From the findings of the study and in the light of available literature it can be concluded that the parents have lack of knowledge regarding care of neutropenia child in their personal hygiene and physical or physiological needs.

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