International Journal of Health Sciences and Research
www.ijhsr.org ISSN: 2249-9571

Original Research Article

Descriptive Study to Assess the Level of Knowledge Regarding Leukemia among Caregivers of Leukemia Patients in Selected Hospitals of District Mohali, Punjab

Ms Rekha Rani Nar[1], Prof. Kanwaljit Gill MN[2]

[1]PhD Scholar Desh Bhagat University Mandi Govindgarh Punjab
[2]PhD Guide: Desh Bhagat University Mandi Govindgarh Punjab

Corresponding Author: Ms Rekha Rani Nar

ABSTRACT

In India hematological malignancies as a group were the sixth most common with 8.77% patients. Reason for India's low survival rates is patients do not fully comply with the treatment decided by the doctors and follow-up is also patchy, says A Nandakumar, director of the National Cancer Registry Programme. A diagnosis of leukemia dramatically affects the lives of caregivers and all others who have a relationship with the patient. The patient and the entire family experience an emotional, physical and financial impact. Both patient and caregiver usually need to rearrange daily activities to some degree changes that may not come easily. Care givers often feel unprepared to provide care because they receive little guidance from the formal health care providers. As a result, care givers are unfamiliar with the type of care they must provide because of the inadequate knowledge and skills to perform their work.

Quantitative approach using descriptive design was adopted for the present study. The sample for the present study was comprised of the caregivers of leukemia patients who were regularly attending OPD with patient in selected hospitals under study and is main family caregiver. One hundred fifty caregivers of patients suffering from leukemia were included in study. Paper and pencil techniques were selected to collect data regarding knowledge of caregivers of leukemia patients. Data collection was done using structured knowledge questionnaire to assess the knowledge of caregivers of leukemia patients regarding leukemia. Results shows that majority of caregivers of leukemia patients had poor knowledge. The study found that mean knowledge score was poor and thus required intervention. As observed in findings, maintaining and improving the health care status of the leukemia patients is very important and thus caregivers need information and support to take care of their near ones.

Key words: Caregiver, leukemia and knowledge

INTRODUCTION

Cancer in all forms is causing about 12% of deaths throughout the world. In the developed world, cancer is the second leading cause of death, next to cardiovascular disease, accounting for 21% (2.5 million) of mortality. An average about 15% of world's population is affected by different types of blood disorders. [8]

In India hematological malignancies as a group were the sixth most common with 8.77% patients. In males, these malignancies comprised fourth most common group forming 10.6% of all patients while in females, it was the seventh most common system involved with 6.2% cases.

As stated in various cancer registries, CML is one of the commonest adult leukemia in Indian population accounting for 30% to 60% of all adult leukemia. [11]

Reason for India's low survival rates is patients do not fully comply with the

treatment decided by the doctors and follow-up is also patchy, says A Nandakumar, director of the National Cancer Registry Programme at Bangalore who was associated with the study. "Accessibility, affordability, lack of awareness about the nature of the disease and the need for periodic checkups and several other socioeconomic factors could contribute (to the low survival rates in India)," Nandakumar said. [12]

A diagnosis of leukemia dramatically affects the lives of caregivers and all others who have a relationship with the patient. The patient and the entire family experience an emotional, physical and financial impact. Both patient and caregiver usually need to rearrange daily activities to some degree changes that may not come easily. [5]

Family caregivers are essential partners in the delivery of complex health care services and this case exemplifies the associated caregiver burden and stress during cancer treatment. Unlike professional caregivers such as physicians and nurses, informal caregivers, typically family members provide care to individuals with a variety of conditions, most commonly advanced age, dementia, and cancer. [1]

Care givers often feel unprepared to provide care because they receive little guidance from the formal health care providers. As a result, care givers are unfamiliar with the type of care they must provide because of the inadequate knowledge and skills to perform their work. Nurses are often the members of the treatment team with whom patients and their families have the most contact. Thus nurses bring extraordinary knowledge, experience, and expertise to patient care.

The objective of the study was:

1. To assess level of knowledge regarding leukemia among caregiver of leukemia patients.

MATERIALS AND METHODS

Quantitative approach using descriptive design was adopted for the present study. The study was conducted at selected hospitals of district Mohali, Punjab, they were, Fortis Hospital, Max Super specialty Hospital, IVY hospital, Sri Guru Harkrishan Sahib multi-specialty Hospital. The population for the present study was comprised of the main/primary caregivers leukemia patients who were taking care for last three months and are accompanying leukemia patients to OPD of selected Mohali Hospitals. The sample for the present study was comprised of the caregivers of leukemia patients who were regularly attending OPD with patient in selected hospitals under study and is main family caregiver i.e. father, mother, spouse, daughter or son. One hundred fifty caregivers of patients suffering from leukemia were included in study. Written consent was taken from the caregivers of leukemia patients. Caregivers were assured of the confidentiality of their data. Five caregivers of leukemia patients were interviewed per day. Data collection from one patient took on an average of 50-60 minutes. The researcher gathered data between 9am to 5pm in OPD of selected hospitals.

Data Collection Techniques and Tools: Paper and pencil techniques were selected to collect data regarding knowledge of caregivers of leukemia patients. Data collection was done using structured knowledge questionnaire to assess the knowledge of caregivers of leukemia patients regarding leukemia.

The structured knowledge questionnaire consists of two sections:

Section I: comprised of eleven items information seeking on demographic variables of leukemia caregivers such as age, gender, marital status, educational status, religion, type of family, occupation, total family income per month, residence and time since care has been provided.

Section II comprised of twenty four items on knowledge regarding leukemia. Covering the following content areas:

1. Concept of cancer, leukemia and anatomy of blood
2. Risk factors and diagnosis
3. Sign and symptoms

4. Treatment of leukemia
5. Side effect of treatment and dietary intervention

Criterion measure:

Level of knowledge	Range of scores
Excellent (>80%)	20-24
Good (65-80%)	16-19
Average (50-64%)	12-15
Poor (<50%)	0-11

The reliability coefficient for structured knowledge questionnaire was calculated by using Kuder-Richardson -20 (KR-20) formula. The reliability coefficient was found to be 0.76.

RESULTS

TABLE 1: Frequency and Percentage Distribution of Caregivers of Leukemia Patients According to Demographic Variables N=150

Sr.no	Demographic Variable	n	(%)
1	**Age in years**		
	20-30	30	20
	31-40	33	22
	41-50	46	31
	>50	41	27
2	**Gender**		
	Male	57	38
	Female	93	62
3	**Marital Status**		
	Single	33	22
	Married	90	60
	Widow/Widower	21	14
	Divorced/Separate	6	4
4	**Education status**		
	Illiterate	0	0
	Primary	15	10
	Matric	39	26
	Sr. Secondary	63	42
	Graduate & above	33	22
5	**Religion**		
	Hindu	78	52
	Sikh	48	32
	Christian	15	10
	Muslim	9	6
6	**Type of family**		
	Nuclear	87	58
	Joint	63	42
7	**Occupation**		
	Unemployed	27	18
	Labor	24	16
	Business	45	30
	Government job	24	16
	Private service	30	20
8	**Total family income**		
	< 10,000	15	10
	10001-20,000	33	22
	20,001-30,000	42	28
	> 30,000	60	40
9	**Residence**		
	Rural	84	56
	Urban	66	44
10	**Duration as Caregivers**		
	3-6 month	21	14
	6-12 month	60	40
	1-3 years	48	32
	>3years	21	14

Table 1 depicts frequency and percentage distribution of caregivers of leukemia patients according to demographic variables. Among 150 caregivers of leukemia patients 46(31%) were in the age group of 41-50 years, followed by 41(27%) in the age group of above 50 years, 33(22%) in the age group of 31-40 years and 30(20%) were in age group of 2-30 years. When differentiated on the basis of gender it was found that majority of caregivers of Leukemia Patients were female 93(62%).On the basis of marital status, majority of caregivers of leukemia patients 90(60%) were married.

As per education status of the caregivers of leukemia patients 63(42%) was having secondary education, 39(26%) had passed matric, 33(22%) were graduate and above, 15(10%) had primary education. When caregivers of leukemia patients were divided on basis of religion, majority of caregivers of leukemia patients belonged to Hindu religion 78 (52%). The data also shows that out of 150 caregivers of leukemia patients 87(58%) were living in nuclear family and 63(42%) were living in joint family. Apart from it, 27(18%) caregivers of leukemia patients were unemployed, 24(16) were labor, 45(30%) were in business, 24(16%) were doing government job and 30(20%) doing were private service. 60(40%) had family income per month >30,000 and 15 (10%) caregivers of leukemia patients had total family income per month <Rs10,000. Most of the caregivers of leukemia patients in were residence of rural area 84(56%) were and 66(44%) were living in urban area. majority of caregivers of leukemia patients 60(40%) had duration as caregivers for 6-12months, while 48(32%) had duration as caregivers from 1-3years, 21(14%) were taking care from 3 to 6 months and same number of caregivers were taking care from more than three years.

Table 2: Mean, Median, Standard Deviation, Mean Percentage of Knowledge Score of Caregivers of Leukemia Patients N=150

Mean	Mean %	S.D.	Median	Maximum	Minimum
8.04	33.50	2.66	8	17	3

Maximum score: 24; Minimum Score: 0

The data presented in the Table 2, indicates that caregivers of leukemia patients had mean knowledge score (8.04) and mean percentage (33.50%). The median of the distribution of caregivers of leukemia patients was (8).

Table 3: Frequency and Percentage Distribution of Caregivers of Leukemia Patients in Terms of Level of Knowledge N=150

Level of knowledge	F	(%)
Excellent (20-24)	0	0
Good (16-19)	1	0.7
Average (12-15)	15	10
Poor (0-11)	134	89.3

Maximum score: 24, Minimum Score: 0

Table 3 shows 89.3% caregivers of leukemia patients had poor knowledge (0-11), followed by average knowledge (12-15) by 10% caregivers of leukemia patients. Further data shows that only 0.7% of caregivers of leukemia patients had good knowledge (16-19). The data further shows that no caregivers of leukemia patients had excellent knowledge regarding leukemia. Thus, it is evident that majority of caregivers of leukemia patients had poor knowledge.

Table 4: Area Wise Mean Score, Mean Percentage and Ranking of Knowledge Score of Caregivers of Leukemia Patients. N=150

Areas	Max Score	Mean score	Mean %	Rank
Concept of cancer and leukemia, anatomy of blood	8	2.81	35.08	II
Risk factors , diagnosis, Sign and symptoms	7	2.04	29.14	IV
Treatment of leukemia	6	1.92	32.00	III
Side effect of treatment and Dietary interventions	3	1.27	42.44	I
Total	24	8.04	33.50	

The data presented in Table 4, shows the area wise mean of knowledge score of caregivers of leukemia patients. The data shows that Side effect of treatment and Dietary interventions secured highest mean score 42.44% was ranked as I. Followed by concept of cancer and leukemia, anatomy of blood was ranked as II, mean percentage obtained was 35.08% and mean percentage score obtained in Treatment of leukemia was 32% ranked as III. Lowest mean percentage score obtained in area of Risk factors, diagnosis, Sign and symptoms was 29.14% was ranked as IV. Hence it is concluded that caregiver of leukemia patients in have poor knowledge in all the areas.

Table 5: Association of Level of Knowledge of Caregivers of Leukemia Patients with Demographic Variables. N=150

Demographic Variables	Knowledge Score			χ^2	P Value	df	Table Value
	Good	Average	Poor				
Age in years							
20-30	0	6	24	10.039	0.123	6	12.592
31-40	0	0	33				
41-50	0	4	42				
>50	1	5	35				
Gender							
Male	0	3	54	2.976	0.226	2	5.991
Female	1	12	80				
Marital status							
Single	0	3	30	30.877*	0.000	6	12.592
Married	1	3	86				
Widow/Widower	0	9	12				
Divorced/Separate	0	0	6				
Education status							
Illiterate	0	0	0	13.082*	0.042	6	12.592
Primary	0	0	15				
Matric	0	0	39				
Sr. Secondary	0	10	53				
Graduate & above	1	5	27				
Religion							
Hindu	0	6	72	6.310	0.389	6	12.592
Sikh	1	8	39				
Christian	0	1	14				
Muslim	0	0	9				
Type of family							
Nuclear	1	8	78	0.861	0.650	2	5.991
Joint	0	7	56				

Table 5 to be continued…							
Occupation							
Unemployed	1	8	18	28.514*	0.000	8	15.507
Labor	0	0	24				
Business	0	0	45				
Government job	0	1	23				
Private service	0	6	24				
Total family income							
<10,000	1	2	12	16.639*	0.011	6	12.592
10,001-20000	0	6	27				
20,001-30000	0	0	42				
> 30001	0	7	53				
Residence							
Rural	0	6	78	3.097	0.213	2	5.991
Urban	1	9	56				
Duration as Caregivers							
3-6month	1	5	15	14.222	0.027	6	12.592
6-12 month	0	7	53				
1-3 years	0	3	45				
>3years	0	0	21				

*significant (P< 0.05)

The obtained chi-square values of caregiver of leukemia patients shows association of knowledge with, marital status (30.877), educational status (13.082), occupation (28.514) and total family income (16.639) was found to be statistically significant at 0.05 level of significance. Hence, it can be deduced, that knowledge of caregiver of leukemia patients was dependent on their marital status, educational status, occupation total family income and duration as caregivers and was independent of other variables like age, gender, type of family, religion, residence and duration as caregivers.

DISCUSSION

Today, taking care of cancer patients is mostly done at home by caregivers. These caregivers are the primary source of support for cancer patients. Moreover, they provide psychological, physical, emotional, and financial support for the person with cancer. Evidence shows that following a leukemia diagnosis in a person, anxiety, depression, and stress are experienced by the family caregivers.

The above results were comparable to the studies done by various researchers. In terms of socio-demographic variables, study done by Manal M. El-Sawy et al(2013) shows that more than half (55.8%) of the caregivers aged from 35 to less than 45 with a mean age 37.46±6.56 years, about sixty percent (59.4%) of the caregivers were females and 41.4% had secondary school education, regarding marital status of the caregivers, the majority (90.1%) were married. [6] Saleem Hasan et al(2011) study results reveals that (31%) of caregiver's age were between (39-48) years. [4]

Regarding knowledge of caregiver of leukemia patients, results of current study indicates that 89.3% caregiver of leukemia patients poor knowledge regarding leukemia. The results were in consistent with the findings of other study that is Geetha. C (2015) reported that there was lack of knowledge among mother regarding leukemia. [2] Also, Marykutty PV et al (2014) who conducted study to assess the knowledge of parents of leukemic children about leukemia. [7] Ali Hussein Alek AL-Ganmi (2013) found that less than the half of the study participants have moderate of knowledge level. [9] These results were supported by Sameti Sedigheh et al (2013) who conducted a study to assess mother's educational needs about etiology of children's leukemia at health centers in Borujerd found that most of mothers had moderate or weak knowledge. [10] Similarly, Saleem Hasan et al (2014) carried out a study to assess caregivers' home care management regarding their adolescent leukemic patient and shows the majority of caregiver had deficit knowledge regarding leukemia. [3]

Implications

The finding of the study has implications for Nursing practice, Nursing administration, Nursing education, Community health practice, and Nursing research.

Nursing Practice

Knowledge of leukemia in nursing is absolutely essential for every nursing personnel to prevent the further complications in patients. Nursing personnel can update their knowledge by attending workshops and continuing education.

1. Nursing personnel can explain the importance of proper treatment and can help patients to avoid various complications during course of treatment.
2. Nurses can motivate the caregivers to complete the treatment regimen.

Nursing Education

1. Nurses and nursing students could increase their awareness on leukemia and toward all new strategies related toward prevention of further complication.

Nursing Administration

1. The nurse administrators should make sure that every new nurse before posting in ward should have proper orientation.
2. The nurse administrators could conduct various in-service education programmes / workshops to update the knowledge of nursing personnel's.

Community health nursing

1. Community health nurses can help in surveillance and epidemiological studies related to leukemia.

Nursing Research

1. Nurses can do extensive research in the area of leukemia and on caregivers.

CONCLUSION

The study found that mean knowledge score was poor and thus required nursing intervention. As observed in findings, maintaining and improving the health care status of the leukemia patients is very important and thus caregivers need information and support to take care of their near ones.

REFERENCES

1. Bevans M, Sternberg E. Caregiving Burden, Stress, and Health effects among Family Caregivers of adult cancer patients. JAMA [Internet]. 2012;307(4):398-403. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3304539/.
2. Geetha C. Knowledge on Leukemia, The Stress And Coping Stratagies of Mothers With Leukemic Children Undergoing Treatment in a Selected Cancer Institute, India. International Journal of Recent Scientific Research. 2015;6(5):4192-4196.
3. Hasan S, Kareema A, Mouroge H. Impact of Health Educational Program upon Caregivers' Know- ledge and Practices for Psychosocial Problems of Acute Leukemia Adolescent Patients. [Internet]. 2014 [cited 3 October 2018]. Available from: https://www.researchgate.net/publication/258222065_Impact_of_Health_Educational_Program_upon_Caregivers'_Know-_ledge_and_Practices_for_Psychosocial_Problems_of_Acute_Leuke-_mia_Adolescent_Patients.
4. Hasan S, Kareema A, Mouroge H. The Impact of Educating Parents of Leukemic Children on the Patients' Quality of Life. Iranian Red Crescent Medical Journal [Internet]. 2011 [cited 3 October 2018];13(8):550-555. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3371991/.
5. Kent E, Rowland J, Northouse L, Litzelman K, Chou W, Shelburne N et al. Caring for caregivers and patients: Research and clinical priorities for informal cancer caregiving. Cancer. 2016;122(13):1987-1995.
6. Manal M, El-Sawy, Gehan M, Ismail, Hebamagdy, Gehan A El-sam-man. Knowledge and Home Practices of Caregivers Having Children with Leukemia Attending National Cancer Institute Cairo University. Med J Cairo Univ [Internet]. 2018 [cited 3 October 2018];81(1):601-608,. Available from: http://www.medicaljournalofcairouniversity.net

7. Marykutty P, Rayaroth P, Soumya S. Knowledge and practice of parents of leukemic children. Journal of international academic research for multidisciplinary. 2014;2(9):10-13.
8. Mazkenzie J, Weller D, Knott V. Tackling the global burden of cancer. European Journal of Cancer Care. 2017;26(1):e12657.
9. Obaid, Khamees , Ajil, Zaid ,Hussen Alek Al-Ganmi, Ali. Mothers' Knowledge Concerning Leukemic Children Undergoing Chemotherapy: Treatment in Oncology Units at Baghdad City. Asian Academic Research Journal of Multidisciplinary. 2014:1:527 – 542.
10. Sedigheh S, Mitra G, Fariba F. Mother's Educational Needs about Etiology of Children's Leukemia. International Journal of Nursing Care. 2013;1(1):73.
11. Sharma R, Kapoor R, Bang B, Gurjar K. Spectrum of malignancies in Jaipur region (2004-2008). Indian Journal of Cancer. 2014;51(1):45.
12. Varma S. Cancer survival rate in India among the lowest in the world - Times of India [Internet]. The Times of India. 2018 [cited 3 October 2018]. Available from: https://timesofindia.indiatimes.com/india/Cancer-survival-rate-in-India-among-the-lowest-in-the-world/articleshow/45399391.cms.

How to cite this article: Nar RR, Gill MNK. Descriptive study to assess the level of knowledge regarding leukemia among caregivers of leukemia patients in selected hospitals of district Mohali, Punjab. Int J Health Sci Res. 2018; 8(11):137-143.

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