



Effectiveness of information brochure on home management of side effects of chemotherapy among caregivers of children admitted at department of pediatric oncology units in selected hospitals at Lucknow, Uttar Pradesh, India

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Abstract

Aim: This study aimed to assess the effectiveness of information brochure on improving the knowledge and practices of caregivers regarding home management of side effects of chemotherapy in selected hospitals from Lucknow, Uttar Pradesh and to find out various factors associated with it.

Materials & Methods: A quantitative research approach with Pre-experimental one group pretest and posttest design and Non-probability convenience sampling technique was used to select 60 caregivers in selected hospitals from Uttar Pradesh. A self-structured knowledge questionnaire and practice checklist was used for assessing the knowledge and practice among the subjects. SPSS version 25 was used for data analysis.

Results: There was a significant difference between the pre and post intervention level of knowledge ($t = 16.1, p = 0.0001$) and practice ($t = 12.6, p = 0.0001$) regarding home management of side effects of chemotherapy among caregivers. There was an association between caregivers knowledge score with their demographic variable educational status ($\chi^2 = 21.5, p = 0.006$). There was an association between caregivers practice score with their demographic variables like education ($\chi^2 = 20.8, p = 0.008$), occupation ($\chi^2 = 15.1, p = 0.05$) and previous information about chemotherapy ($\chi^2 = 9.1, p = 0.01$).

Conclusion: Information brochure was effective to enhance the knowledge and practice of Caregivers regarding home management of side effects of chemotherapy. A qualitative approach can be used to explore comprehensive findings in future studies.

Keywords: home management, chemotherapy, caregivers, information brochure, knowledge and practice

Introduction

Cancer is a large group of diseases in which uncontrollable growth of abnormal cells go beyond their usual boundaries to invade adjacent parts of the body and/or spread to other organs that can start in almost any organ or tissue of the body (metastasis). Major cause of death from cancer is due to metastasis. Cancer is otherwise known as neoplasm and malignant tumors. Globally the second leading cause of death is due to cancer, accounting for an estimated 9.6 million deaths, or one in six deaths, in 2018 [1].

In children aged 5 - 14 years the second leading cause of death is due to cancer [2]. The World Health Organization estimates the incidence of childhood cancer to be 100 per 1000000 cases [3]. In 2018, 10590 children under 15 years of age were diagnosed with cancer [4]. Currently, the prevalence of childhood cancer in developing countries is higher than 40 per 1000 people [5].

Cancer chemotherapy is of pronounced advantage to patients in the treatment of malignant and non-malignant tumors [6]. Chemotherapy is a drug treatment that uses powerful chemicals to kill fast-growing cells in your body. Many different chemotherapy drugs are available which can be used alone or in combination to treat a wide variety of cancers. Though chemotherapy is an effective way to treat many types of cancer, chemotherapy treatment also carries a risk of side effects. Some chemotherapy side effects are mild and treatable, while others can cause serious

complications [7]. The side effects associated with chemotherapy are so harmful that result into poor adherence, poor quality of life, morbidity or even mortality [8].

Family caregivers provide physical, psychological, spiritual, and emotional support to patients and they play an important role in the management of cancer. Their cooperation and inclusion in the unit of care are considered critical parts to effective cancer management. This is the main reason oncology units include family caregivers in treatment planning, decision making, and implementation [9]. Studies show that caregivers, especially mothers of cancer patients usually carry more burdens which occasionally results in painful experiences such as excessive weeping, gloominess, avoidance of social interaction, impaired social relationships, refusal to talk, lethargy, decreased appetite, and deterioration in the quality of life [10, 11]. Early education and information to the caregivers of children on chemotherapy side effects helps to manage and cope with them and improve the quality of life.

Very limited experimental studies have been conducted to improve knowledge and practices of caregivers of children undergoing chemotherapy about home management of chemotherapy side effects in particular areas. This is the main reason researchers conduct the present study. The objectives of the study were to determine the effectiveness of information brochure on knowledge and practices of

caregivers regarding home management of side effects of chemotherapy in selected hospitals from Uttar Pradesh and to find out various factors associated with it.

Material and Method

Research approach: Quantitative approach

Research design: Pre experimental one group pretest posttest design.

Setting of the study: The study was conducted in Pediatric oncology department of KGMU Lucknow, India

Study Population: Caregivers of Children admitted at department of pediatric oncology KGMU, Lucknow, India

Sample size: 60

Sampling technique: Non-probability convenient sampling technique

Inclusion criteria

- Caregivers who are in the age group of 25-45 years
- Caregivers who are taking care of children comes under 5-12 years of age
- Caregivers of Chemotherapy children who can understand, read and speak Hindi or English

Exclusion criteria

- Caregivers who are taking care of children undergoing chemotherapy for less than one month
- Caregivers of chemotherapy children who have attended similar type of this study
- Caregivers who are health care workers

Tool

The research tool for data collection consists of three sections:

Section 1: - Demographic tool

It consists of age of caregivers, relation with child, educational status, occupation, number of children, duration of receiving chemotherapy and previous information about chemotherapy.

Section 2: - Self-structured knowledge questionnaire

It consists of 30 items for assessing knowledge of caregivers regarding home management of side effects of chemotherapy. Every item was of multiple-choice types with one correct answer carrying 1-mark remaining options 0 marks. The total maximum score was 30 and the minimum score 0. The scores were graded as 0-10 inadequate knowledge, 11-20 moderate knowledge and 21-30 adequate knowledge.

Section 3: - Self-structured Practice checklist

A Practice checklist consists of 20 yes or no questions used for assessing the Practice of caregivers regarding home management of side effects of chemotherapy. The total maximum score is 20 and the minimum score is 0. The score was graded as 0-6 poor practice, 7-13 average practice and 14-20 good practice.

Content validity of the tool was determined by experts in the field of Medicine and Nursing. The reliability of the knowledge and practice questionnaires was tested by using the spearman brown split half method and the score was found to be 0.76 and 0.72 for knowledge and practice respectively. The tool was prepared in English and Hindi to facilitate better comprehension. Interventional module, information brochure was prepared based on the review of literature which consists of areas such as introduction, side

Effects and common complications of chemotherapy and its home management.

Data collection procedure

The study was approved by the Institutional Ethical Committee. Informed consent was obtained and the confidentiality and anonymity of the participants were maintained. Pre -test was conducted to know the knowledge and practice regarding home management of side effects of chemotherapy among caregivers and an information brochure was provided and the post-test was done after the gap of 10 days.

Statistical analysis

The collected data were tabulated and analyzed with the help of descriptive and inferential statistics. SPSS 25 (Statistical Package for the Social Sciences, India) was used for Statistical analysis and 0.05 was considered as the level of significance.

Results

The major findings of the study were as follows:

Table 1: Frequency and percentage distribution of demographic variables of subjects (n=60)

Demographic data	Frequency (F)	Percentage (%)
1. Age of caregivers		
25-30	9	15
31-35	17	28.3
36-40	22	36.7
41-45	12	20
2. Relation with child		
Mother	36	60
Father	24	40
3. Educational Status		
No formal education	14	23.3
Primary	21	35
Secondary	8	13.3
Higher secondary	10	16.7
Graduate & above	7	11.7
4. Occupation		
Unemployed	9	15
Daily wages	23	38.3
Self-employee	13	21.7
Private job	9	15
Government job	6	10
5. Number of Children		
1	13	21.7
2	31	51.7
>2	16	26.7
6. Duration of receiving chemotherapy		
1 month – 1 year	38	63.3
> 1 year	22	36.7
7. Previous Information about chemotherapy		
Yes	22	36.7
No	38	63.3

Table 1 displays that frequency and percentage distribution of demographic variables, the majority of the subjects 36.7% were in the age group of 36- 40 years, 60% were mothers in terms of relation with child, 35% had primary education, 38.3% were daily wagers, 51.7% had two children, 63.3% were receiving chemotherapy less than one year and 63.3% did not have any previous information about chemotherapy.

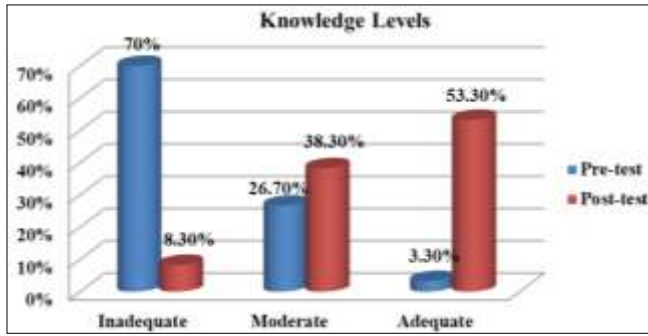


Fig 1: Percentage distribution of overall gradation of pretest and posttest knowledge level

Figure 1 depicts that percentage distribution of knowledge levels regarding home management of side effects of chemotherapy among caregivers, in the pretest majority 70% had inadequate knowledge, remaining 26.7% moderate knowledge and 3.3% adequate knowledge but in the post-test, the majority 53.3% had adequate knowledge followed by 38.3% moderate knowledge and 8.3% had inadequate knowledge.



Fig 2: Percentage distribution of overall gradation of pretest and posttest Practice level

Figure 2 depicts that percentage distribution of practice score regarding home management of side effects of chemotherapy among caregivers, in the pretest majority 48.3% had poor practice, remaining 45% average practice and 6.7% good practice but in the post-test, the majority 46.7% had good practice followed by 41.7% average and 11.7% had poor practice.

Table 2: Comparison of Knowledge score regarding home management of side effects of chemotherapy among Caregivers between Pretest and Posttest

Test	N	Mean	sd	t	df	p
Pretest	60	8.8	3.8	16.1	59	0.0001**
Posttest	60	17.9	5.3			

**Significant (p<0.01)

The table 2 shows that comparison of pre-test and post-test knowledge score regarding home management of side effects of chemotherapy among caregivers by using paired t-test, the mean score of post-test 17.9±5.3 was greater than the pre-test mean score 8.8±3.8, the obtained t- value 16.1, p = 0.0001. It is inferred that there is a significant difference in pretest and posttest knowledge score. So information brochure was effective to improve the level of knowledge regarding home management of side effects of chemotherapy among caregivers.

Table 3: Comparison of Practice score regarding home management of side effects of chemotherapy among Caregivers between Pretest and Posttest

Test	N	Mean	sd	t	df	p
Pretest	60	7.7	3.4	12.6	59	0.0001**
Posttest	60	12.5	3.5			

**Significant (p<0.01)

The table 3 demonstrates that comparison of pre-test and post-test practice score regarding home management of side effects of chemotherapy among caregivers by using paired t-test, the mean score of posttest 12.5±3.5 was greater than the pre-test mean score 7.7±3.4, the obtained t- value 12.6, p = 0.0001. It is inferred that there is a significant difference in pretest and posttest practice score. So, information brochure was effective to improve the level of practice regarding home management of side effects of chemotherapy among caregivers.

Table 4: Association between pretest knowledge level with their demographic variables

Demographic Profile	Levels of Knowledge			x ²	df	p
	Inadequate	Moderate	Adequate			
1. Age of caregivers				1.7	6	0.94
25-30	7	2	0			
31-35	12	4	1			
36-40	14	7	1			
41-45	9	3	0			
2. Relation with child				3.1	2	0.21
Mother	26	10	0			
Father	16	6	2	21.5	8	0.006**
3. Educational Status						
No formal education	13	1	0			
Primary	15	6	0			
Secondary	6	2	0			
Higher secondary	6	4	0			
Graduate & above	2	3	2	11.5	8	0.17
4. Occupation						
Unemployed	5	4	0			
Daily wages	19	4	0			
Self-employee	10	3	0			
Private job	6	2	1	2.4	4	0.66
Government job	2	3	1			
5. Number of Children						
1	9	3	1	1.5	2	0.47
2	23	7	1			
>2	10	6	0			
6. Duration of receiving chemotherapy				3.7	2	0.16
1 month – 1 year	27	9	2			
> 1 year	15	7	0	7.0	2	0.16
7. Previous Information about chemotherapy						
Yes	14	6	2	7.0	2	0.16
No	28	10	0			

**Significant (p<0.01)

Table 4 indicates that Chi-square value in pretest knowledge score with the selected demographic variable like education (x² = 21.5, p=0.006) was significant and other variables like age of caregivers (1.7), relation with child (3.1), occupation (11.5), number of children (2.4), duration of receiving chemotherapy (1.5) and previous information about chemotherapy (3.7) were not significant (p>0.05). Thus it can be concluded that there is an association between caregiver’s levels of knowledge regarding home management of side effects of chemotherapy with their

educational status.

Table 5: Association between pretest practice level with their demographic variables

Demographic Profile	Levels of Practice			χ^2	df	p
	Poor	Average	Good			
1. Age of caregivers				5.3	6	0.5
25-30	4	4	1			
31-35	6	9	2			
36-40	11	11	0			
41-45	8	3	1			
2. Relation with child				0.8	2	0.69
Mother	19	15	2			
Father	10	12	2			
3. Educational Status				20.8	8	0.008**
No formal education	9	5	0			
Primary	12	9	0			
Secondary	3	5	0			
Higher secondary	4	5	1			
Graduate & above	1	3	3			
4. Occupation				15.1	8	0.05*
Unemployed	5	4	0			
Daily wages	13	10	0			
Self-employee	7	6	0			
Private job	2	5	2			
Government job	2	2	2			
5. Number of Children				2.9	4	0.57
1	6	7	0			
2	17	12	2			
>2	6	8	2			
6. Duration of receiving chemotherapy				0.9	2	0.64
1 month – 1 year	20	16	2			
> 1 year	9	11	2			
7. Previous Information about chemotherapy				9.1	2	0.01**
Yes	7	11	4			
No	22	16	0			

*Significant (p<0.05) **Significant (p<0.01)

Table 5 shows that Chi-square value in pretest practice score with the selected demographic variable like education ($\chi^2 = 20.8$, $p=0.008$), occupation ($\chi^2 = 15.1$, $p=0.05$) and previous information about chemotherapy ($\chi^2 = 9.1$, $p=0.01$) was significant and other variables like age of caregivers (5.3), relation with child (0.8), number of children (2.9) and duration of receiving chemotherapy (0.9) were not significant ($p>0.05$). Thus, it can be concluded that there is an association between caregiver’s levels of practice regarding home management of side effects of chemotherapy with their educational status, occupation and previous information about chemotherapy.

Discussion

The present study results noticed that the information brochure was effective to improve the knowledge and practices of caregivers of children about home management of side effects of chemotherapy. These results were supported by Kaur R *et al.* [12] which showed that interventional modules like structured teaching programmes were effective ($t=17.37$, $p=0.001$) on home management of side effects of chemotherapy among parents. Another study by Kale A [13] noticed that a planned teaching programme was effective ($p<0.05$) to improve the knowledge among caregivers of children receiving chemotherapy. These results were also consistent by Taha MT *et al.* [14] which concluded that nursing instructions were effective in improving mother’s knowledge and practice regarding care

of their children with leukemia undergoing chemotherapy. Present study revealed that caregivers' knowledge score was associated with their demographic variable like educational status and practice score with demographic variables like education, occupation and previous information about chemotherapy. In contrast, Daniel JM *et al.* [15] concluded that there was no association between knowledge regarding side effects of chemotherapy among caregivers of cancer patients with selected demographic variables.

Implication and Recommendations

Nurse educators could use these information brochures to enrich the knowledge and practices of caregivers regarding home management of side effects of chemotherapy and reduce the psychological issues associated with it. This study profits governmental and nongovernmental organizations to conduct awareness programs, seminars, workshops etc. for preparing staff nurses, ASHA workers, anganwadi teachers and significant others in order to contribute to the welfare of our society. A similar study can be replicated on a large scale for more reliability and wider generalization. Exploratory research design can be used to explore the feelings of the Caregivers using a qualitative approach.

Conclusion

Interventional module information brochure was effective to improve the knowledge and practices regarding home management of side effects of chemotherapy among caregivers of children admitted to oncology units. This study also observed that there was an association between caregivers' knowledge score with their demographic variable educational status and practice score was associated with demographic variables like education, occupation and previous information about chemotherapy. The study is limited to caregivers of children admitted to the department of pediatric oncology units at KGMU, Lucknow, India. There is a solid need to implement any kind of educational and teaching programs to improve the home care management of caregivers of children receiving chemotherapy and decrease their anxiety associated with it.

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Conflicts of interest

There are no conflicts of interest

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