

EFFECT OF EDUCATIONAL INTERVENTIONS ON CARE GIVER BURDEN OF PARENTS HAVING CHILD WITH LEUKEMIA

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ABSTRACT

Background:

One of the most common forms of cancer among children under the age of 15 is leukaemia. Leukemia accounts for 32.5% of all paediatric cancer cases globally. Leukemia was discovered in 46.5% of Pakistani children with cancer. The mother and father share responsibility for the direct and indirect care of their leukemic child. The responsibilities involved in providing care for the leukemia-stricken kid fall under the category of direct care, while facilities and financial assistance are considered indirect forms of care.

Objective:

To determine the effect of educational intervention on Care burden among parents having Children with Leukemia

Methodology:

A quasi experimental study designed was used. A sample of n=81 participants was recruited from Sadiq Abbasi Hospital Bahawalpur, through convenient sampling. The care burden questionnaires were used to measure care burden and psychological wellbeing among parents having children with leukemia. Pre assessment was done during May 2022 and then 6 sessions of educational interventions were provided during the period of June 2022 to December 2022. After completing intervention, the post assessment was done in January 2023. Filled questionnaires were entered and analyzed through SPSS version 21.

Results:

A very highly statistically significant difference was found in results of pre intervention and post interventional scores of parents caring for their leukemia children, $z(-8.013)$, p value=0.000, with mean and SD (85.91±2.248 vs. 54.21±12.489). It is shown by the above study results that the interventional program had a statistically significant effect on parents' psychological wellbeing and care giver burden.

Conclusion:

Hundred percent of the parents of children with leukemia in this study were having high care burden before the interventional program. After the interventional program, a very highly significant effect was found where the care giver burden was decreased with clinical and statistical significance

Key words:, Care burden, Leukemia, educational intervention, parents

INTRODUCTION:

The primary cause of death and morbidity in the globe and one of the major health problems of concern is cancer. Cancer is the second biggest cause of mortality and one of the chronic illnesses¹.

Cancer numbers are high in underdeveloped nations like Pakistan. In Pakistan, there were 22,858 instances of pediatric cancer reported between 2010 and 2019². One of the most common forms of cancer among children under the age of 15 is leukemia. Leukemia accounts for 32.5% of all childhood cancer cases worldwide³. Leukemia is found in 46.5% of Pakistani children with cancer⁴.

Every year, 443.4 out of every 100,000 kids worldwide are afflicted by cancer. In the end, the predicted cancer death rate for men and women is 158.3 per 100,000⁵. The death rate among children is quite high. As compared to low- and middle-income countries, the death rate for children with cancer in developed nations is almost 20% lower than that in the latter two groups⁶. The death rate also changes depending on the patients' cancer screening and treatment plan⁷.

Chemotherapy is the basic and primary treatment option for pediatric leukemia patients. Chemotherapy prevents the proliferation of cancerous cells and prevents the spread of cancer. Similarly, chemotherapy is a cytotoxic medication with severe side effects and problems⁸. Among these problems the most common are Oral mucositis, weakness, hair loss and gastrointestinal problems which increase the care burden of caregivers⁹.

Both the mother and father are involved in the direct and indirect care of their child with leukemia¹⁰. Direct care is the tasks with the care of the child with leukemia and indirect care is the financial support and the facilities provided to the patients¹¹. The parents are mostly involved in the care of the children and to deal with all the complications associated with the disease and treatment. Therefore, similar to other chronic diseases, parents of children with leukemia also experience mental and physical problems such as depression, anxiety and disappointment¹².

Care burden among parents of children with leukemia effect the quality of life and psychological wellbeing of parents. Several psychological problems such as stress (21%), mild anxiety and depression (95%) is commonly prevalent among the parents of children with leukemia¹³.

Various studies reported that caregivers especially the parents experience high level of care burden. The care burden results in painful experiences such as weeping, social isolation, avoidance, social relationship reduction, fatigue, unwilling to talk, decline in quality of life and decrease appetite¹⁴. The parent's role changes after the involvement in the care of the children with leukemia. Also, the parents adopt a new role as a member of the caring and treatment team¹⁵.

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Hospital Bhawalpur. Written informed consent was taken from all the participants. All information and data collection was kept confidential. Participants were kept anonymous throughout the study.

Data was collected using three parts of a questionnaire. Part "A" consisted of socio-demographic profile of the participants. Part B Care burden assessment questionnaire where care burden of the parents was assessed using Care Burden Scale (CBS). The scale was developed from a study carried out by Hossein Karimnejad¹⁸. Caregiver burden scale consisted of 22 questions. Each question was answered as Never, Rarely, Sometimes, Frequently and Nearly Always. The caregiver burden was categorized as: Score < 55 or < 50% = little or no care burden; 55-80 or 50% - 72.72% = moderate care giver burden and score > 80 or > 72.72% = severe care giver burden. The reliability (Cronbach's alpha) of the scale was 0.94. All participants were given close ended questionnaires along with further detailed sheet of information. A written consent was implied to every participant along with the questionnaire. Introduction to every participant was done. Participants were questioned individually at the pediatric oncology department of the given hospital where the assessment of the participants was done using data collection tool. After data collection it was entered and analyzed in SPSS version- 21. Quantitative variables were presented in the form of mean \pm standard deviation. Qualitative variables were presented in the form of frequency and percentages. Frequency distribution tables were used to present the psychological wellbeing and care giver burden among the study participants. Paired t test was used to see the effect of educational intervention on the care giver burden on parents.

RESULTS

Table: 1: Age of the parents (N=81)

	Minimum	Maximum	Mean Age (Years)	Standard Deviation
Age of Parent	23	45	34.22	5.758

Above Table 1 revealed that the average age in years of the parents having children with Leukemia was 34.22 years with standard deviation of 5.758 years with a range of 22 years

Tables 2: Demographic Characteristics of Participants (Parents N=81).

Gender	F (%)
Male	26 (32.1%)
Female	55 (67.9%)
Education Status	
Illiterate	24 (29.6%)
Primary	33 (40.7%)
High School	16 (19.8%)
Graduation or Above	8 (9.9%)

Table 2 above showed that 26 (32.1%) of the study participants were fathers (male) while 55 (67.9%) were mothers (female). It was also revealed from the findings that 24 (29.6%) among the study participants were illiterate, 33 (40.7%) were educated till primary, 16 (19.8%) of the parents were having high school education and 8 (9.9%) were graduated and above.

Table: 3 Parents Care Giver Burden (Pre & Post Intervention) (N=81)

Care Giver Burden	Pre Intervention {n (%)}	Post Intervention {n (%)}
Low Care Giver Burden	0 (0.00%)	57 (70.4%)
Moderate Care giver Burden	0 (0.00%)	16 (19.8%)
High Care Giver Burden	81 (100.00%)	8 (9.9%)

Table.3 shows the participants' care giver burden regarding children with Leukemia in the pre interventional phase as well as in the post interventional phase. Results shown in the table above found that before the interventional program, all 81 (100%) of the parents were having high care giver burden. After the interventional program, the care giver burden among the parents of children having leukemia was decreased to a greater extent where it was revealed that low care giver burden was found among majority of the parents 57 (70.4%), moderate care giver burden was found among 16 (19.8%) of parents and very few parents 8 (9.9%) were having high care giver burden after the interventional program.

Table: 4 Comparisons of Care Givers Burden before & After Intervention (N=81)

Variable	Pre-intervention	Post-intervention	Mean difference
	Mean \pm SD	Mean \pm SD	
Care Giver Burden	85.91 \pm 2.248	54.21 \pm 12.489	+31.70

* *p* value was obtained by Wilcoxon Signed Rank test with 0.05 level of significance.

In this table 4, included on care givers burden, in which pre-care giver burden total score mean \pm SD was 85.91 \pm 2.248 and in the post intervention phase, the parents' care giver burden score was decreased to 54.21 \pm 12.489, where the mean difference between pre and post care score is +31.70.

Table: 5 Mean and Standard Deviation of participants' Care Givers Burden before & After Intervention (N=81)

Variables	Pre-intervention Mean \pm SD	Post-intervention Mean \pm SD	z	P value
Care Giver Burden	85.91 \pm 2.248	54.21 \pm 12.489	-8.013	.000

Table 5 above presented the testing of hypothesis for care giver burden where Wilcoxon signed ranked test was used to evaluate the effect of interventional program parents' care giver burden regarding taking care of children with Leukemia. A very highly statistically significant difference was found in results of pre intervention and post interventional scores of parents caring for their leukemia children, $z(-8.013)$, p value=0.000, with mean and SD (85.91 ± 2.248 vs. 54.21 ± 12.489). It is shown by the above study results that the interventional program had a statistically significant effect on parents' psychological wellbeing and care giver burden.

DISUSSION

Findings of this current study revealed that the average age of the parents who were having children with Leukemia and were providing care as primary caregiver was 34.22 years with standard deviation of 5.758 years. A previous research study found similar results where the mean age of the study participants was 34.89 ± 5.99 ; 46.5% of the parents, which very congruent to the current study findings²⁰. Similarly in another past study the majority of the parents (59.0%) were 31-40 years old who were recruited in the study²¹.

Also the current study showed that 26 (32.1%) of the study participants were fathers (male) while 55 (67.9%) were mothers (female). Findings are consistent with a past study where the study revealed that the majority of the parents (98.3%) were mothers²⁰. In another past study congruent findings were found where 92.10% of the caregivers were mothers recruited in the study²². Another past study also support the findings of this current study where 70 mothers (89.7%) and 8 fathers (10.3%) were equally divided into the intervention and control groups²¹.

It was also revealed from the findings that 24 (29.6%) among the study participants were illiterate, 33 (40.7%) were educated till primary, 16 (19.8%) of the parents were having high school education and 8 (9.9%) were graduated and above. Different findings were achieved in past studies where 34.9% of the participants had primary education, 18.6% had secondary school, 27.9% of the participants had high school and 15.7% of the study participants were having university education²⁰. Similarly in another past study a very high number more than 70% of the parents included in the study were having high school and above education qualification²¹.

This current study also found that before the interventional program, all 81 (100%) of the parents were having high care giver burden. After the interventional program, the care giver burden among the parents of children having leukemia was decreased to a greater extent where it was revealed that low care giver burden was found among majority of the parents 57 (70.4%), and very few parents 8 (9.9%) were having high care giver burden after the interventional program.

The results of a previous study reported that the mean of care burden score was 56.43 ± 9.32 and ranged from 0 to 88. 10.7%, 79.7%, and 9.6% of parents had low, moderate and high care burden, respectively²².

In this study on psychological wellbeing and care givers burden, in which pre-psychological wellbeing total mean \pm SD score was found as 54.11 ± 2.092 and in the post interventional phase, the psychological wellbeing mean \pm SD score was found to be increased to 95.52 ± 8.870 . On the other hand, pre-care giver burden total score mean \pm SD was 85.91 ± 2.248

and in the post intervention phase, the parents' care giver burden score was decreased to 54.21 ± 12.489 .

A past study found that pre-test score of psychological wellbeing was 67.22 ± 5.99 which was enhanced to 74.50 ± 7.18 with statistical significance of P value (0.0029)²³. The findings of another past study revealed the effectiveness of intervention in overcome the care burden and improving the physiological well-being among parents of children with leukemia. The mean physiological well-being score was increased after intervention from 31.1 to 33.3¹⁹. Similarly, another past study found that educational interventions are effective in overcome the care burden of parents of children with cancer. The mean care burden of the parents after interventions reduced from 33.38 to 24.67²¹.

In this study, a very high significance was shown in results of pre intervention and post interventional scores of parents caring for their leukemia children, $z(-8.013)$, p value=0.000, with mean and SD (85.91 ± 2.248 vs. 54.21 ± 12.489).

In a past study similar finding was found where the mean pre-intervention Care giver Burden score in the intervention and control groups was 19.97 ± 5.25 and 18.97 ± 10.03 , respectively. The mean post-intervention CB score was also 17.17 ± 4.78 and 19.18 ± 9.93 , respectively. Intervention significantly reduced CB score in the intervention group ($p < 0.001$)¹⁸.

CONCLUSION

Hundred percent of the parents of children with leukemia in this study were having high care burden before the interventional program. After the interventional program, a very highly significant effect was found where the care giver burden was decreased with clinical and statistical significance.

RECOMMENDATIONS

To enhance the parents' care burden, the parents having children with Leukemia among them, such interventional studies are needed to be conducted on a larger scale. Support groups might be further established to raise care providers' understanding of and concern with CP, which could help them identify the most appropriate and timely interventions for their charges

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