

The effect of a family need-based program on burden of caregivers of leukemia patients in Isfahan in 2013-2014

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ABSTRACT

Background: The family of cancer patients experience burden of care because of their caring role. Therefore, appropriate and effective interventions are essential in order to decrease burden. The goal of the present research was to determine the effect of a family need-based program on the burden of care in caregivers of leukemia patients.

Materials and Methods: In this clinical research, 70 caregivers of leukemia patients who referred to Sayed Al-Shohada Medical Center in Isfahan, Iran were chosen and divided, through convenient sampling method and using table of random numbers, into two groups, experimental and control. Caregivers of the experimental group attended five training sessions. The data collection tool of this study was the Zarit Burden Scale. It was completed by members of both groups before, immediately after, and 1 month after the intervention. The data obtained were analyzed with SPSS software.

Results: During the study period, burden slowly decreased in the experimental group and increased in the control group. Mean burden of care score before, immediately after, and 1 month after the intervention was 63.6, 30.4, and 23.03, respectively, in the experimental group and 62.5, 67.3, and 68.8, respectively, in the control group.

In addition, the mean burden score in the experimental group significantly decreased in comparison with the control group ($P < 0.001$).

Conclusion: This family need-based program can decrease burden in caregivers of leukemia patients and may potentially improve the quality of life of both patients and caregivers.

Key words: Burden, family caregiver, family need-based program, Iran, leukemia patients

INTRODUCTION

Today, taking care of cancer patients is mostly done at home by families and family caregivers.^[1] These caregivers are the primary source of support for cancer patients.^[2,3] Moreover, they provide psychological, physical, emotional, and financial support for the person with cancer.^[4] Evidence shows that following a cancer diagnosis in a person, anxiety, depression, and stress are experienced by the family caregivers.^[5] In addition, disease and disability impose extreme pressure and burden on families, and this load and pressure of care affects the quality of life and quality of care of the patients.^[6] Patients with leukemia are in particular

need of support and care due to its complications, followed by chemotherapy (pancytopenia, electrolyte imbalance, etc.). Therefore, these patients should be cared for at home by family caregivers, and this places great mental and physical strain on caregivers.^[7]

Burden of care includes physical, emotional, financial, and social problems, and if unnoticed and untreated, can result in damaging the physical and mental health of caregivers.^[4] A study on the family of cancer patients showed that stress can have negative impact on the health and well-being of family caregivers.^[5] Research shows that the highest burden and cost imposed on families for cancer care include social, economic, psychological, and physical costs and burden.^[8] A meta-analysis was performed on various literatures on caregivers, published in the years 1983-2009.^[5] This meta-analysis showed that families of cancer patients, as a result of their caring role, suffer from the burden of care. Thus, they need training and information on the illness of their family member, methods of treatment, adaptation strategies (adaptive behavior and problem-solving skills), access to supportive resources, and self-care.^[5] The study by Al-Jauissy *et al.* on 82 cancer patients' caregivers also showed that most of these caregivers' needs are regarding self-care, work problems, financial problems, health care, interpersonal relationships, activity management, and

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problem solving.^[9] Although the needs of family caregivers are not a new problem, patients and their families are not trained to manage and control mental and physical symptoms.^[10] Although the families of cancer patients care for their patients for extended periods of time, findings show that they have little information on the care of their patients, or they are not sufficiently supported in this important and vital role.^[5] Even though extensive studies have been performed on identifying the needs of family members and the effect of cancer stress on patients and their families, little experimental research has been performed to rectify and address these needs.^[11,12] In this regard, Belgacem *et al.* performed a study on the impact of training program on improvement of quality of life and burden of care of cancer patients and their families. They showed that a training program can improve the quality of life and burden of care of cancer patients and their families.^[13] Nurses are in communication with the patients and their families for a long period of time. Therefore, they have a unique position to identify stress and the psychological burden of caregivers, and the appropriate and effective interventions required to reduce the burden on caregivers.^[4] A limited number of studies and interventions have been conducted on caregivers of cancer patients, especially patients with leukemia, in Iran and other countries, and these studies have had different results. In addition, in most studies, less attention has been paid to comprehensive support, including physical, emotional, mental, and spiritual as a whole.^[13] Therefore, the researcher aimed to conduct a research to study the effectiveness of a family need-based program on the burden of family caregivers of leukemia [acute myeloid leukemia (AML) and acute lymphoblastic leukemia (ALL)] patients.

MATERIALS AND METHODS

This was a clinical trial (IRCT2013093011895N2) with two groups and three stages, and was conducted in Isfahan, Iran on 70 caregivers of patients with acute leukemia. The research environment included Sayed Al-Shohada Medical Center, affiliated to Isfahan University of Medical Sciences. The inclusion criteria for the subjects were as follows: Being the main caregiver of a patient with acute leukemia, over 18 years of age, lack of mental illnesses, able to speak, read, and write in Farsi, and not participating in any other similar studies. If the subject did not attend more than two training sessions, had an acute and chronic mental and physical disease that prevented them from caring for the patient, or if the patient died, those caregivers were excluded from the study.

In this study, the sample size of the survey, based on feedback from statistics professors, was calculated as 64 people. Due to the possibility of loss of samples during the

study period, the sample size was estimated at 70 samples. Sampling was performed after obtaining the permission of the Ethics Committee of Isfahan University of Medical Sciences. It was performed by the researcher among the caregivers of acute leukemia patients who referred to Sayed Al-Shohada Medical Center, who satisfied the inclusion criteria. A written informed consent was obtained from each participant. Then, the subjects, by convenient sampling method and using table of random numbers, were assigned to two groups, experimental and control.

The data collection tool of this study was a two-part questionnaire. The first part of the questionnaire included characteristics of the patient and their primary caregiver (13 questions). The second part of the questionnaire included the Zarit Burden Inventory (ZBI) which contained 22 items and each item was scored as follows: Never (0), rarely (1), sometimes (2), often (3), and always (4). The total of points gained by the caregivers (with scores ranging from 0 to 88) shows the amount of stress and burden of care experienced by them.^[14] This questionnaire was specifically designed to assess caregivers' burden and has been used in several countries for caregivers of cancer patients.^[15] Its reliability and validity have been confirmed by previous studies.^[16,17] Furthermore, in Iran, this questionnaire was validated by Navidian in 2004, according to the culture of the country.^[18] The participants completed this questionnaire before, immediately after (after the five sessions), and 1 month after the intervention.

The researcher arranged the intervention program based on the needs assessment conducted according to the view of specialists in this area and a survey of patients' families done in this center, and through interviews with the subjects, reviewed studies in this regard, and his 9 years of working experience in this center. Then, the intervention was applied in the experimental group to the eligible patients' families. The supportive training program was performed for the experimental group in five 90-min sessions, in groups of 8-12 members.^[19-21] In addition, methods such as lectures, question and answer, and role playing, and techniques such as brainstorming, group discussion, and small groups were used.

Training program content is summarized as follows:

- First session: Introducing the caregivers to the researcher and setting plans and goals, and question and answer
- Second session: Providing information on leukemia, the complications after medication therapy, and importance of follow-up and care of patients
- Third session: Providing information about self-care, and strengthening the social dimension and social interactions of the caregivers

- Fourth session: Providing information on problem-solving skills and techniques to reduce stress and anxiety in caregivers
- Fifth session: Strengthening their spiritual dimension.

In the final session, a CD containing relaxation, and stress and anger management techniques, and educational booklets on the content of each session in summary were prepared and provided for the study subjects. Furthermore, for spiritual intervention, a religious expert helped. In addition, for 1 month after the intervention, the experimental group members were given advice based on their needs via telephone, and if needed, they were referred to the assistance unit or psychiatrist specialists. The caregivers of the control group did not participate in this program. However, at the end of the intervention, the CDs and booklets were left at their disposal. The collected data were analyzed by SPSS software (version 16; SPSS Inc., Chicago, IL, USA) and descriptive and inferential statistical methods [Mann–Whitney, repeated measures analysis of variance (ANOVA), independent *t*-test, and Chi-square].

RESULTS

From a total of 70 participators, 3 experimental group and 3 control group participants were excluded from the study due to lack of participation in the sessions, not completing the questionnaire, or the death of their patients. Moreover, 64 subjects participated in the study until the end, 32 subjects in the intervention group and 32 subjects in the control group. The results of Chi-square, Student's independent *t*-test, and Mann–Whitney test revealed that there was no statistically significant difference between the control and experimental groups in terms of age, gender, marital status, caregivers' and patients' educational level, the duration of illness and care, and the family's relation with the patient ($P > 0.05$) [Table 1]. The mean scores of burden of care in the three time periods of before, immediately after, and 1 month after the execution of the test program were 63.6 (± 3.5), 30.4 (± 8.7), and 23.03 (± 6.01), respectively. Comparison of these means using repeated measures ANOVA showed that there was a significant difference between the means of these groups ($F = 916.12$) [Table 2]. The least significant difference (LSD) *post-hoc* test showed a significant difference between the mean burden of care scores of these groups before and immediately after the study, before and 1 month after the study, and immediately after and 1 month after the study ($P < 0.001$).

The mean burden of care scores of the control group in the three time periods before, immediately after, and 1 month after intervention were 62.5 (± 4.1), 67.3 (± 4.2), and 68.8 (± 3.6), respectively. Comparing these means using repeated measures ANOVA showed that there

Table 1: Patients' and caregivers' demographic characteristics in the study and control groups

	Caregivers (n=32)		Patients (n=32)	
	Study	Control	Study	Control
Age (years)	(39.1 \pm 9.6)	(40.3 \pm 12.1)	(41.5 \pm 14.1)	(43.4 \pm 17.07)
Length of care (months)	(6.1 \pm 3.8)	(7.03 \pm 3.9)	-	-
Length of disease (months)	-	-	(6.1 \pm 3.8)	(7.03 \pm 3.9)
Gender	%	%	%	%
Female	71.9	51.4	48.8	34.4
Male	28.1	40.6	56.2	65.6
Employment status	%	%	%	%
Working	28.1	43.8	43.8	18.8
Jobless	9.3	6.2	6.2	12.4
Homemaker	56.4	50	34.4	50
Retired	6.2	0	15.6	18.8
Marital status	%	%	%	%
Single	6.2	15.6	15.6	18.8
Married	87.5	78.1	62.9	42.9
Divorced	3.1	3.1	3.1	6.2
Widowed	3.1	3.1	3.1	6.2
Education level	%	%	%	%
Illiterate	0	0	12.5	21.9
Primary school	40.6	43.8	18.7	12.5
High school	28.2	31.2	31.2	46.9
University	31.2	25	37.5	18.7
Relationship with the patient	%	%		
Father	6.2	6.2	-	-
Mother	9.4	21.9	-	-
Spouse	50	25	-	-
Children	18.8	34.4	-	-
Immediate family	15.6	12.5	-	-

Table 2: Comparison of mean and SD of care burden before, immediately after, and 1 month after the intervention in the study and control groups

Group	Study		Control		Statistical test	
	Mean	SD	Mean	SD	Independent t-test	P
Before	63.6	3.5	62.5	4.1	1.21	0.23
Immediately after	30.4	8.7	67.3	4.2	23.54	<0.001
One month after	23.03	6.01	68.8	3.6	36.97	<0.001
Repeated measure ANOVA	F	916.12	66.96			
	P	<0.001	<0.001			

ANOVA: Analysis of variance, SD: Standard deviation

was a significant difference between the means of these groups [Table 2]. The LSD *post-hoc* test showed a significant difference between the mean scores of burden of care

before and immediately after the study, and before and 1 month after the study ($P < 0.001$). Nonetheless, there was no significant difference between the mean burden of care scores immediately after and 1 month after the study. Comparison between burden of care of experimental and control groups during the three time periods using Student's independent *t*-test showed that before the intervention, the difference between the two groups was not significant ($P > 0.05$). However, this difference was significant immediately after and 1 month after the program [Table 2].

DISCUSSION

The results of the present study confirmed the hypothesis that the implementation of a supportive-training program intervention based on needs assessment, mental health care, and routine spiritual and mental care on family caregivers will have a considerable influence on their psychological burden.^[22] Results of family caregivers of patients with acute leukemia showed that the burden of care of caregivers in the experimental group gradually reduced during the three time periods, i.e. before, immediately after, and 1 month after the intervention. Moreover, the burden of care scores in these three time periods were significantly different. These findings were also consistent with the studies of Ghaedi *et al.* and Navidian *et al.* In both studies, the burden of care showed a significant decrease after the training program of the caregivers in the experimental group, compared to before.^[21,23] The results of the present study were also consistent with the study by Millan *et al.*, evaluating the effect of the intervention on problem-solving and coping skills, burden, and quality of life of caregivers in America. Millan *et al.* concluded that the quality of life and burden of care in the experimental group 2 weeks after and 1 month after the intervention had improved.^[22] Among other studies which were consistent with the present study results, the study of Chin *et al.* can be mentioned. The results of this study showed that after the intervention, anxiety and satisfaction in the experimental group, compared to the control group, were significantly different.^[24] Nevertheless, the study by Greedle *et al.* on the effectiveness of a collaborative care program on the burden of care of the caregivers of cancer patients showed that the program had no impact on reducing caregivers' burden of care.^[25] The differences in methodology, especially the implementation of education programs, such as the training content, may explain this difference. Carrasco *et al.* conducted a study in Spain to evaluate the benefits of a psychoeducational program for Alzheimer patients' family caregivers in terms of their burden of care. They observed no significant difference between the burden of care before and immediately after the implementation of the program (4 months after baseline) in the intervention group.^[20] The researcher believes that

lack of similarities between the findings of this study and other similar studies can be related to the duration of the intervention and the disease type, and that most Iranian caregivers are women who report a decrease in burden by receiving psychological support. Another reason is that in Iran, the financial burden is reduced for caregivers due to receiving insurance services. Another factor to be noted is that in the Iranian culture, spiritual support has significant effects on tolerating crisis, and other studies have not included this in their programs.

Results showed that in the control group, the burden of care of caregivers gradually increased during the three time periods, i.e. before, immediately after, and 1 month after the intervention. However, the difference between the burden of care immediately after and 1 month after the implementation of the program was not significant. These findings were consistent with the three studies of Davidson *et al.*, Carrasco *et al.*, and Belgacem *et al.*^[12,13,20] These results were also consistent with the study by Chin *et al.*, in which the anxiety of caregivers in the control group significantly increased after the intervention compared to before.^[24] The researcher believes that the cause of this increase was illness type, lack of information about the disease, and stress followed by anxiety of having a serious illness due to passing of time without any support and training interventions for caregivers. Northouse *et al.*, in their study on the families of cancer patients, also showed that caregivers' stress can have a negative impact on their health and well-being and that these patients' families will suffer from burden of care due to their caregiving role.^[5]

The findings also show that in all the time periods, except before implementing the program, there was a significant difference between the burden of care of experimental and control groups. Mean score of burden of care immediately after the intervention and 1 month after the intervention in the experimental group was significantly lower than in the control group. Belgacem *et al.* confirmed the results obtained in the present study on the effectiveness of a training program on the quality of life and burden of care of cancer patients and their families. They found that this program enhanced the quality of life of patients and caregivers, and decreased the burden of care for caregivers in the experimental group compared to the control group. Furthermore, burden of care in the experimental group was significantly lower than in the control group.^[13] This finding was consistent with several other studies.^[21-24]

The researcher believes that the reason for the relative success of the program could be its content, which was designed based on reviewing problems identified in similar studies and needs assessment of patients' caregivers at

this center. Moreover, in the present study, group training method we used which is more effective in comparison to individual learning method.^[26,27]

The limitations of this study could be the individual differences of the families in respect to religious beliefs, spiritual and cultural values, and attitudes toward life that might have affected the amount of burden on families. It was also possible that, during the intervention, the families in the control and experimental groups have interacted with each other. On the other hand, they might have had access to information through sources such as mass media that can influence the caregivers' knowledge and burden. This matter was beyond the researchers' control.

CONCLUSION

Overall, the findings show that implementing this supportive-training program based on family needs had increased the awareness and adaptability of family caregivers in the care of patients with leukemia and reduced the burden of care. Nevertheless, due to the limitations of this study, such as small sample size, limited time for the intervention, and thus, lack of long-term effectiveness follow-up, which was considered to be due to the intervention time limitation and the possibility of great sample loss, these results cannot be generalized to the entire society. Therefore, further research is needed in this regard in order to confirm the positive effect of this family needs-based program on the burden of care giving.

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