

# The effect of a supportive educational program based on COPE model on caring burden and quality of life in family caregivers of women with breast cancer

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## ABSTRACT

**Background:** The family caregivers of the people with cancer such as breast cancer experience a decrease in their quality of life and an increase of their caring burden. In most of the cases, the researchers consider the quality of life and physical and psychological problems in patients with cancer and pay less attention to the family caregivers. To reduce the caring burden imposed to the caregivers and improve their quality of life, supportive strategies such as problem solving can be used. These interventions may have benefits for the caregivers although the research results are contradictory. The aim of this research was to determine the effect of a supportive educational program, based on COPE model, which focuses on creativity, optimism, planning, and expert information on individuals, on the caring burden and quality of life in the family caregivers of women with breast cancer.

**Materials and Methods:** The present study is a clinical trial, which was conducted in Seyed-AI-Shohada Hospital of Isfahan University of Medical Sciences and a private center of chemotherapy in 2012. In this study, researchers investigated the effect of a supportive educational program based on COPE model on the caring burden and quality of life in the family caregivers of women with breast cancer. This supportive educational program included two hospital visits and two telephone sessions based on COPE model for 9 days. A total of 64 patients were selected based on the inclusion criteria and randomly assigned into two groups. Data were collected by use of Caregiver Quality of Life Index-Cancer (CQOL-C), World Health Organization Quality of Life — Bref (WHOQOL-Bref), and Zarit caring burden at the beginning of the intervention and a month after the intervention.

**Results:** The results showed that in the experimental group, the mean score of physical, mental, spiritual, environmental domains and overall quality of life in the family caregivers was significantly increased compared to the control group, but there was no change in the social domain of quality of life in the two groups. In the experimental group, the mean score of caring burden among the caregivers was significantly decreased compared to the control group.

**Conclusion:** Results of the present study suggested that a supportive educational program can improve physical, mental, spiritual, environmental domains and overall quality of life. It can also decrease the caring burden in the family caregivers of women with breast cancer. Further studies are needed to evaluate the impact of these interventions on quality of life and caring burden in the family caregivers of women with breast cancer undergoing other cancer treatments.

**Key words:** Breast cancer, burden, COPE, education, family caregiver, Iran, nursing, quality of life, supportive

## INTRODUCTION

Cancer is one of the major health problems in the world.<sup>[1]</sup> In 2008, the World Health Organization (WHO) has estimated cancer as the cause for 12% of mortality from non-communicable diseases in the world and as the fourth cause of mortality in Iran.<sup>[2]</sup> Breast

cancer is the most prevalent type of cancer in Iranian women (24.85%) and in Isfahan (27.67%).<sup>[3]</sup> Based on the reported statistics, prevalence of breast cancer in Iran and the province of Isfahan is high, and necessitates provision of high-quality services to these patients. There has been a change in giving services to the women with breast cancer, like other sections of health system in the world. The most important change has occurred in taking care of the patients at their homes, which leads to more services given to these patients by their family members.<sup>[4,5]</sup> In fact, family members act as key members of the treatment team and are named caregivers.<sup>[6]</sup> Caregiving is an important phenomenon in today's world,<sup>[7]</sup> and family caregivers are at the frontline of giving care to the patients with chronic diseases like cancer.<sup>[8]</sup> There is no statistics about the population of caregivers in Iran. Parallel to the increase of

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care given by the family members, they need more time to spend on the patients.<sup>[9]</sup>

Research shows the hazardous effects of a caring role include negative emotional,<sup>[10-12]</sup> social,<sup>[7]</sup> physical,<sup>[7,9,10,12,13]</sup> professional, and economic outcomes,<sup>[14]</sup> so that consequently, caregivers' quality of life is impaired.<sup>[15,16]</sup> Previous studies have shown low quality of life among the family caregivers of cancer patients.<sup>[15,17,20]</sup> Preservation of caregivers' quality of life is not only to their benefit but also is associated with their ability to provide the cancer patients with care and for the fulfillment of their needs.<sup>[21]</sup> Caregivers' quality of life is influenced by the caring burden they tolerate.<sup>[19]</sup> On the contrary, their caring burden can be diminished through preservation and improvement of their quality of life.<sup>[22]</sup> Caring burden is a distress that is felt by a caregiver when giving care.<sup>[9]</sup> Family caregivers' caring burden has been reported minor,<sup>[14,23,24]</sup> moderate,<sup>[25]</sup> and high in most of the studies, and its severity has been reported in breast cancer patients.<sup>[14]</sup> Caring burden is a product of caring duties.<sup>[25]</sup> Sign control in patients with breast cancer is among these given duties. Although this kind of care is provided by the family caregivers for a long time, they do not receive adequate preparation, information, and/or support in relation with this issue from health providers.<sup>[5]</sup>

The patients and their families have reported to use trial and error to manage most of these signs, which consequently leads to caregivers' high financial burden and stress.<sup>[27]</sup> Therefore, fulfillment of these needs in family caregivers should be considered. One of the conducted interventions, demanded by the caregivers, is supportive interventions.<sup>[9,22]</sup> Supportive interventions include provision of information and psychological support in the form of counseling sessions held through face-to-face or phone counseling.<sup>[9]</sup> Some of the studies have reported that this program may have positive effects in terms of reduction of caring burden and improvement of the patient-caregiver communication.<sup>[25]</sup> In this regard, caregivers' educational needs should be specified, and then, planning and education through family conference, skills education, use of texts, a video, a CD, a website and problem-solving strategies occur. Educating problem-solving strategies is one of the educational methods. Problem-solving approach can lead to reduction of reliance and increase of stress and burden, and results in positive consequences for the patients.<sup>[9]</sup>

Among these strategies, development of problem-solving skills can be named, which is conducted by use of various models. One of these models is COPE model<sup>[12]</sup> designed by Houts *et al.* (1996), which focuses on promotion of creativity, optimism, planning, and expert information

in individuals.<sup>[28]</sup> The results of its application have been various in different parts of the world. For instance, some studies have reported its positive effects on patients' and caregivers' quality of life,<sup>[29,30]</sup> while some have not.<sup>[31-34]</sup> No study on supportive programs was conducted in Iran, especially through problem-solving method with participation of the caregivers of the patients with breast cancer.

Therefore, this study aimed to define the effect of a supportive educational program based on COPE model on the promotion of quality life and reduction of family caregivers' caring burden of women with breast cancer.

## MATERIALS AND METHODS

This is a two-group two-step before-after clinical trial that was conducted in 3½ months during August–November 2012. The subjects comprised 64 family caregivers of the women with breast cancer, undergoing chemotherapy and referring to Seyed-Al-Shohada University Hospital affiliated to Isfahan University of Medical Sciences and a private oncology center in Isfahan, Iran. The sample size was calculated by power of  $P = 0.08$ , significance level of 5%, and  $d = 0.7$ . The inclusion criteria were: caregivers of age 18-60 years, not being health care personnel, not taking care of another chronic patient concurrently, subjects' self-report of having physical and psychological ability to attend the study, being allocated as the main caregiver based on caregivers' self-report and the involved patients' claim, being interested in attending the study, and the patient the caregiver was taking care of should have been suffering from breast cancer with no history of psychological disorders, referring to the related centers for chemotherapy at the time of study, and have had passed at least one session of chemotherapy. The exclusion criteria were occurrence of any problems prohibiting the caregivers attending the study, patients' death during the study and caregivers' absenteeism in one phone and/or one hospital session.

Data collection tool included a four-section questionnaire. The first section was on breast cancer patients' demographic characteristics including age, education level, employment status, and the length of the disease. In relation with the caregivers, age, sex, education, marital status, occupation, income, participation of any other persons in care and their relationship with the patient were inquired.

The second section included a questionnaire of cancer patients' caregivers' quality of life. This questionnaire was designed by Weitzner *et al.*<sup>[35]</sup> in 1999 and contains 35 items. It is scored in 5-point Likert scale as 0 (never), 1 (little), 2 (somehow), 3 (much), and 4 (very much). The total score

is converted to a 100-score scale in which higher scores show better quality of life. Validity and reliability of this questionnaire have been measured by Khanjari<sup>[36]</sup> in Iran and Skoie and Langius-Eklof (2012) in the family caregivers of women with breast cancer. Its internal reliability was reported to be 0.72-0.94.

The third section included WHO brief questionnaire of the quality of life that measures physical, psychological, and spiritual, social, and environmental dimensions of the quality of life.

It contains 26 questions, scored 1-5, and measures quality of life in four dimensions of physical (7 questions), psychological and spiritual (6 questions), social (3 questions), and environmental (8 questions) domains. Higher scores show better quality of life for all items except for items 3, 4, and 26. The obtained score is converted to a 100-score scale. Its validity and reliability were confirmed by Nejat *et al.*,<sup>[37]</sup> and its Cronbach's alpha was reported to be 0.7 for its all dimensions except for social dimension. Social dimension includes only three questions which can be a reason for its low obtained Cronbach's alpha (0.59). The fourth section was a caregivers' caring burden questionnaire, which was designed by Ziret *et al.* in 1980, and includes 22 items. The scoring scale is a 5-point Likert scored as 0 (never), 1 (seldom), 2 (sometimes), 3 (very often), and 4 (always). The lowest caring burden score was zero which meant lack of burden and the highest was 88 which meant the highest caring burden<sup>38</sup>. Its validity and reliability were confirmed by Navidian *et al.*<sup>[39]</sup> in 2004 ( $r = 94\%$ ). In the present study, the subjects were selected through convenient sampling after obtaining their informed written consent. Then, they were randomly assigned to the study ( $n = 32$ ) and control ( $n = 32$ ) groups. Randomization was done by random numbers table. With regard to a pilot study and similar studies,<sup>[29,40]</sup> two sessions were held for the caregivers attending the research, in the hospital during the first 9 days of caregiving.

The caregivers were called once between the first and the second sessions and once after the second session in the hospital by the researcher. The first session lasted for 60 min. Researcher explained the steps of problem solving and the four components of COPE model for 30-35 min by use of a flip chart. With regard to the component of creativity, the caregiver was encouraged to have a new approach toward the problem to design new alternatives. For instance, a goal for the caregiver was "I apply creativity to control the nausea of the patient under my care." In the component of optimism, the caregiver was encouraged to have a positive

and realistic attitude in relation with the problem-solving process. Caregivers were educated to communicate with the patients with optimism and realism to show them their perception and hope and to involve the patient in planning as much as possible: For instance, "I believe that the nausea of the patient under my care can be controlled." In the component of planning, logical goals were determined and necessary interventions were defined to access them: For instance, a goal of care was "I can schedule medication of the patient under my care so that he/she can also enjoy the time being with the family."

In the component of expert information, the caregivers learned how to get help from the experts to solve the problem. Then, in the rest of the session, the caregivers were encouraged to state their experiences and ask questions. They were also asked to make a list of the problems they faced, based on the priority of the problem. If needed, the researcher guided the subjects.

The second session lasted for 30 min and was held on the 5<sup>th</sup> day. During this session, COPE model was reviewed. The interventions, discussed in the former session, were reviewed and checked, and the next problem was considered and its related chapter in the log book was reviewed. With regard to similar previous studies<sup>34</sup>, the caregivers were contacted through a 30-min phone call after each session by the researcher to follow-up the conducted care, encourage the caregiver to administer it, and reply to caregivers' questions. The subjects in the control group received conventional care. The questionnaire was completed in both groups on the 1<sup>st</sup> and 30<sup>th</sup> days of the study through questioning. The data were analyzed by descriptive and inferential statistical tests through SPSS version 11.  $P \leq 0.05$  was considered significant.

## RESULTS

Independent *t*-test, Mann-Whitney, chi-square, and Fisher's tests showed no significant difference between the two groups of study and control, concerning demographic characteristics [Tables 1 and 2]. Independent *t*-test showed no significant difference between the mean scores of quality of life and caregivers' caring burden before intervention in the study and control groups [Table 3]. There was a significant difference in the mean scores of physical ( $P < 0.001$ ), psychological and spiritual ( $P = 0.017$ ), environmental ( $P = 0.047$ ) dimensions, and overall quality of life ( $P < 0.001$ ) among the caregivers in the study and control groups [Table 4]. The *t*-test showed no significant difference in subjects' mean scores of quality of life in social dimension in the study and control groups after intervention ( $P = 0.845$ ) [Table 4]. Independent *t*-test showed a significant difference between the mean scores

**Table 1: Demographic characteristics of patients**

Demographic characteristics	Control group mean (standard deviation)	Experimental group mean (standard deviation)	P-value	Statistical test
Age (years)	49.7 (10.5)	49.8 (9.9)	0.971	t=0.03
<i>Educational</i>				
Sixth grade and lower	25 (78.1%)	21 (65.6%)	0.255	z=1.13
Diploma	6 (18.8%)	9 (28.1%)		
BSc	1 (3.1%)	0		
MSc and higher degree	0	2 (6.2%)		
<i>Employment status</i>				
Employed	0	2 (6.2%)	0.246	
Unemployed	32 (100%)	30 (93.8%)		
Time since diagnosis (months)	4.8 (2.3%)	4.7 (1.7%)	0.901	t=0.13

**Table 2: Demographic characteristics of caregivers**

Demographic characteristics	Control group mean (standard deviation)	Experimental group mean (standard deviation)	P-value	Statistical test
Age(year)	38.97 (10.2)	36.94(11.3)	0.452	t=0.76
<i>Sex</i>				
Female	23 (71.9%)	18 (56.2%)		$\chi^2=1.697$
Male	9 (28.1%)	14 (43.8%)	0.193	
<i>Educational</i>				
Sixth grade and lower	13 (40.6%)	8 (25%)	0.313	Z=1.009
Diploma	11 (34.4%)	15 (46.9%)		
BSc	3 (9.4%)	3 (9.4%)		
MSc and higher degree	5 (15.6%)	6 (18.8%)		
<i>Marital status</i>				
Married	28 (87.5%)	26 (81.2%)	0.289	$\chi^2=2.480$
Single	3 (9.4%)	6 (18.8%)		
Divorced	1 (3.1%)	0		
Widowed	0	0		
<i>Occupational status</i>				
Unemployed	6 (18.8%)	4 (12.5%)	0.127	$\chi^2=7.177$
Housewife	15 (43.8%)	8 (25%)		
Employed	11 (34.4%)	15 (46.9%)		
Student	0	3 (9.4%)		
Retired	1 (3.1%)	2 (6.2%)		
Family income (per month)	162 (58)	171 (57)	0.540	t=0.61
<i>Relationship with patients</i>				
Parents	1 (3.1%)	1 (3.1%)	0.656	$\chi^2=2.435$
Sister	8 (25%)	5 (15.6%)		
Brother	0	1 (3.1%)		
Daughter/son	14 (43.8%)	17 (53.1%)		
Husband	9 (28.1%)	8 (25%)		
<i>Care assistance</i>				
Yes	24 (75%)	23 (71.9%)	0.777	$\chi^2=0.080$
No	8 (25%)	9 (28.1%)		
Hours of care (in 24 h)	9 (6.8)	8.4 (6.7)	0.672	t=0.42



**Table 3: Comparison of mean scores of four dimensions and total scores of quality of life and caring burden in the two groups of study and control before intervention**

Groups variables	Experimental		Control		Statistical test	
	Mean	SD	Mean	SD	t-test	P-value
Physical	64.06	13.33	63.39	16.50	0.859	0.178
Psychological	55.68	16.56	54.29	17.53	0.746	0.325
Social	59.06	17.38	57.29	19.25	0.701	0.386
Environmental	53.62	17.59	52.53	15.11	0.791	0.266
Overall	52.03	11.57	51.29	14.38	0.822	0.22
Burden	29.25	8.40	31.37	11.18	0.394	0.859

**Table 4: Comparison of mean scores of four dimensions and total scores of quality of life and burden in the two groups of study and control after intervention**

Groups variables	Experimental		Control		Statistical test	
	Mean	SD	Mean	SD	t-test	P-value
Physical	73.66	16.09	59.37	17.41	0.001	3.407
Psychological	59.84	17	50	15.18	0.017	2.44
Social	56.71	19.95	55.72	20.46	0.845	0.194
Environmental	59.39	15.26	51.85	14.41	0.047	2.030
Overall	67.45	13	51.76	13.52	<0.001	4.73
Burden	16.46	8.08	35.09	11.82	<0.001	7.357

of caring burden in the study and control groups after intervention ( $P < 0.001$ ) [Table 4].

## DISCUSSION

This is a clinical trial aimed to define the effect of problem-solving education based on COPE model on caring burden and quality of life of the family caregivers of women with breast cancer. This study is among the first studies conducted in the context of investigation and promotion of caregivers' care quality in Iran. As both groups were almost identical concerning patients' and caregivers' demographic characteristics, caregivers' scores promotion after intervention revealed the positive effect of intervention on promotion of quality of life in physical, psychological and spiritual, and environmental dimensions, and on caregivers' caring burden reduction. These studies, if repeated, can be a good evidence for the use of models, and give an appropriate structure to the care. The results showed that most of family caregivers were middle-aged women with high school education or lower and with low economic status. Such a group may face numerous problems in fulfillment of their personal educational and supportive needs.

Unfortunately, with regard to the existing conditions in governmental and even private hospitals in Iran,

these needs have rarely received logical responses. This program could provide the caregivers with the required information as well as an appropriate approach to confront the problems in the form of problem solving in an easy and understandable way. On the other hand, most of the caregivers were the children of the patients, their spouse or sister, who were mostly (70%) helped by someone else or other individuals in care. Meanwhile, on the average, the caregivers spend 8 h on caring in a day. These results show the high amount of time the family caregivers spend on breast cancer patients at early stages of the disease. One of our results was improvement of quality of life in the physical dimension.

Achievement of caregivers' health preservation and its promotion in our educational supportive program is not only important in relation with the care itself but also is a must for the caregivers in playing their caring role. This effect may be as a result of the log book given to the caregivers, in which the caregivers were encouraged to manifest healthy behavior, which may have led to their increased attention to their health and having healthy behavior as much as possible.

We recommended the caregivers to care their own health, if they wanted to take care of their beloved well and to follow recommended behavior to achieve this goal. For instance, we asked them to get help from other family members or friends in case of 24 h care to have enough time to rest. This finding is consistent with the study of Nourthouse *et al.*,<sup>[41]</sup> but is not in line with the findings of Nourthouse *et al.*,<sup>[34]</sup> Northouse *et al.*,<sup>[42]</sup> and Demiris *et al.*<sup>[30]</sup> The difference between our findings and those of other studies can be as a result of the type of the used tool, subjects, and intervention.

Northouse *et al.* (2005) used a combination of physical dimension in Functional Assessment of Cancer Therapy-General population (FACT-G) questionnaire and Short Form-36 (SF-36) questionnaire to measure the physical dimension of quality of life. They claim that this combination may not be strict. We used the World Organization Quality of Life Bref (WHOQOL-Bref) questionnaire, which is a universal tool with confirmed validity and reliability and can measure this dimension better.

On the other hand, the subjects in the other studies<sup>[30,34,42]</sup> were caregivers of the patients with various acute and recurrent types of cancer, while in the present study, the subjects were caregivers of women with primary breast cancer with lesser need of care. Naturally, acute cases of cancer like lung cancer and more recurrent cases can be the cause for the difference between our results and theirs.

Although in both studies problem-solving process has been educated, the used models are different so that one model may have been easier and more understandable. Our other finding is improvement in psychological and spiritual dimension of quality of life in caregivers in the study group. In our study, at the end of the sessions, the subjects were encouraged to express their feelings. They expressed their positive and negative experiences related to their caring role. As the sessions were held by just attendance of the caregivers, they could express their feelings more conveniently, and this could have acted as an emotional support for the caregivers leading to the promotion of psychological dimension, which is an inseparable component of complete health. This obtained finding is in concordance with that of Northouse *et al.* In the study of Meyers *et al.* (2011), caregivers' mean scores of psychological dimension in quality of life showed a reduction in the study and control groups after intervention, with a significantly less reduction in the study group. The subjects in their study comprised caregivers of the patients in a critical condition, which could have affected their psychological aspect as a result of the severity of the manifested signs in their subjects compared to the subjects in the present study. On the contrary, Northouse *et al.* (2005) obtained different results. We observed promotion of caregivers' quality of life in environmental dimension in the study group, which is an important finding. However, the effect of intervention on some measurement items of this dimension in the questionnaire of WHO, such as the level of access to daily information, can be reasoned. Among the other possible causes, promotion of economic status, residential area, and other issues in the study group can be indicated, of which some have been measured at the beginning of our study but not at the end, and some others were not measured at all. It is suggested to consider these issues in future studies. On the other hand, with regard to the interventions, promotion in this dimension may have occurred with no change in the aforementioned items and following individuals' positive attitude change toward life. Another important finding of the present study was lack of improvement in caregivers' score in social dimension of quality of life, which is consistent with the finding of Demiris *et al.* (2010), while in the study of Meyers *et al.* (2011), caregivers' scores of social dimension in quality of life diminished in the study and control groups after intervention, with a milder significant reduction in the study group. In the study of Northouse *et al.* (2012), the score of social dimension in the two intervention groups remained steady in the 3<sup>rd</sup> and the 6<sup>th</sup> months of study, while it had a significant reduction in the control group in the 3<sup>rd</sup> month. Despite lack of improvement, no reduction occurred in this dimension, which can be a positive sign

although it was steady in the control group. With regard to the other studies, it seems that a more sensible scale should be used in this dimension.

Despite the observed changes in various dimensions of quality of life after the intervention, educational and supportive program based on COPE model has been able to result in promotion of patients' quality of life.

These results are also in line with the part of findings revealing that total score of quality of life, measured by cancer patients' caregivers' quality of life was promoted. Caregivers' caring burden was significantly decreased in the study group after intervention compared to the control group. Mac Millan *et al.* (2006) reported a significant promotion in symptoms' burden and the burden due to the duties in the study group. Reduction in caring burden can support the promotion in quality of life which we have attained. Sherwood *et al.*<sup>[32]</sup> and Demiris *et al.* (2010) reported promotion in one component (caring self-confidence) by use of another tool measuring caring burden. Sherwood *et al.* (2012) found no change in the other four dimensions, while Demiris *et al.* showed its reduction. Overall, as the used tool in the present study is different from that of other studies, an absolute conclusion cannot be arrived at. Further studies should be conducted with regard to the importance of caring burden reduction and its association with quality of life. The findings of the present study should be considered in the frame of its limitations including small sample size, which was inevitable with regard to conducting such a research among these clients and their families in the form of master's dissertation.

## CONCLUSION

It can be concluded that provision of support and education for family caregivers of women with breast cancer can lead to reduction of their caring burden and promotion of their quality of life. It is suggested to conduct studies with a larger sample size, focusing on educating the caregivers concerning problem-solving process in patients with higher grade of breast cancer.

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