RESEARCH ARTICLE

Editorial Process: Submission:12/11/2021 Acceptance:03/21/2022

The Effect of Family-Centered Education on the Care Burden of Family Caregivers of the Elderly with Cancer: A Quasi-Experimental Study

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Abstract

Introduction: Given the role of the family in decisions related to the patient's health, their role in educating the patient should be considered in the health care program. Therefore, the present study was conducted to determine the effect of family-centered education on the care burden of family caregivers of the elderly with cancer. **Methods:** In this quasi-experimental study, 30 elderly caregivers with cancer were selected and randomly divided into two groups of 15 intervention and 15 control from 1 March 2020 to 1 July 2021. Data collection tools were demographic characteristics questionnaire and care burden questionnaire. The intervention was performed as individual training to caregivers in two one-hour sessions. 6 weeks after the intervention, care burden was measured in both groups. Data were collected and analyzed using PSSS software version 23. **Results:** According to the independent t-test, before the intervention, there was no significant difference between the mean score of care burden in the intervention and control groups, but after the intervention, the mean score of care burden in the intervention group decreased from 56.93 ±11.08 to 42.93 ± 9.78 and in the control group It changed from 54.27 ± 11.38 to 56.80 ± 11.43 and there was a statistically significant difference in the mean scores of the two groups (P <0.001). **Conclusion:** Based on the findings of the present study, family-centered education intervention can be effective in reducing the care burden of caregivers of the elderly with cancer in a sample of Iranian society. Therefore, it is predicted that providing such educational services in the health care delivery system is absolutely necessary and effective, and the use of this type of training in nursing activities is recommended.

Keywords: Aged- Caregiver Burden- family- neoplasms

Asian Pac J Cancer Prev, **23 (3)**, 1077-1082

Introduction

Aging is a set of changes in a person over time that these process changes occur in physical, mental and social dimensions (Ng and Chow, 2021). According to the definitions of the World Health Organization, to people 60 to 65 years and older based on developmental criteria every society is referred to as the elderly (Kalasic and Vidovic, 2018). The number of people aged 60 and over is expected to more than double by 2050, from 962 million in 2017 to half a billion (Masoudi et al., 2020). Studies show that about two thirds of the world's elderly population live in developing countries and it is said that in the near future, aging will be one of the most important social and welfare challenges in developing countries (Kazemi et al., 2019). Including Iran, which is likely to become one of the oldest developing countries in the coming decades, and its aging rate will be as unique as the rate of declining fertility because in Iran the average life expectancy has reached 67 years and the elderly population in Iran is expected to reach more than 25 million by 2050 (Rajabi et al., 2017, Zahmatkeshan et al., 2012, Mishra et al., 2020). However, the increase in the elderly population includes important challenges in the field of health and economic and social issues of the elderly. Because in old age we face physical changes and an increase in chronic diseases caused by aging. One of the chronic diseases that the risk of developing significantly increases with age is cancer (Laconi et al., 2020). About 3.2% of the affected people are over 65 years old. Cancer is also the leading cause of death between the ages of 65 and 75, and about 60% of cancers are diagnosed in people over the age of 70 (Vakili et al., 2015) But due to underlying diseases, other disorders and social factors, they suffer from burnout that

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may affect their ability to pursue cancer treatment, they are limited in their daily activities of life, so not only They are affected themselves, but family members who provide some kind of care may also be affected (Shi et al., 2020).

These informal (home) caregivers provide their free care to the elderly. Many sources refer to them as gatekeepers of the elderly due to the importance of the family in caring for the elderly. In general, families have an important but hidden part of supporting and caring for the elderly (Xiong et al., 2020). However, it should be noted that caring for a sick, disabled and dependent elderly person at home creates many challenges for the family (Dawson et al., 2020). Caregivers are under a lot of burden as people at risk. The term care burden is used to describe the effects of care that include the physical, emotional, financial, and social problems associated with care (Fekih-Romdhane et al., 2020). These caregivers need to do their day-to-day work and take care of their job commitments and other responsibilities. In such cases, if the caregiver cannot manage the patient's care time and his / her own time, he / she will move towards the care burden (Alqhtani, 2021). In confirmation of this matter, as a result of the study of Sadat Hosseini et al., 2014, it was found that 62% of women caring for the elderly with Alzheimer's disease had high care burden (Bastani et al., 2015).

Most caregivers feel that they have little power to work and often feel tired and helpless. Frequent headaches, nausea, sleep disturbances and changes in eating habits are also present in these people. Depression, feelings of helplessness and feeling trapped at work are some of the emotional problems of these people (Kimura et al., 2020). In addition, increasing burden on caregivers will have several consequences such as inadequate care and abandonment of the patient (Marsack-Topolewski, 2021). While families also play an important role in the patient's compliance with the proposed medical and dietary recommendations, diagnostic tests, surgical procedures and important decisions in the later stages of life. It is even suggested that people, especially in chronic diseases, to their family members. They are dependent and even their attitude is influenced by the family. As Nasiri et al. Stated in their study, family empowerment increases patients' knowledge, attitude and performance, accelerates their recovery and reduces complications (Nasiri et al., 2020). Therefore, the impact of the family's role in educating the patient should be considered as a An important point to consider in regulating health care. Because family education is one of the basic responsibilities of nurses and is very useful in controlling the disease. Family-centered education is a process in which family members are trained to increase their skills and abilities to help a family member who has the disease (Kayadjanian et al., 2021). Although caregiver support services are unfortunately low in Iran (Farahani et al., 2020), family relationships are deeply rooted and Iranian families often tend to take care of their patients. It turns out that the family can be used to educate the patient (Tong et al., 2020). Therefore, this study was conducted to determine the effect of family-centered education on the care burden of family caregivers of the elderly with cancer in 2021.

Materials and Methods

The present study is a quasi-experimental study (pre-test-post-test design) with a control group that aims to determine the effect of family-centered education on the care burden of family caregivers of the elderly with cancer from 1 March 2020 to 1 July 2021. The statistical population of this study consisted of all the main family caregivers (each patient is a caregiver) of the elderly with cancer referred to Tohid Hospital in Sanandaj for chemotherapy. Criteria for sample selection include age 18 to 55 years, daily care of the patient for at least 5 hours, chemotherapy in less than 2 months, having a grade 1 ratio with the patient, no neurological and mental disorders, the patient's disease Chronic other than cancer and exclusion criteria were absenteeism for more than one day in training sessions, unwillingness to continue research, and the occurrence of any stressful events in the family.

Finally, 30 caregivers who expressed their desire to participate in the study were randomly selected and placed in the intervention (n = 15) and control (n = 15) groups by random allocation (one in between). The sample size was estimated based on the study of Ghane et al., 2017) and according to the following formula (Abdollahimohammad and Firouzkouhi, 2019).

Data collection tools included two questionnaires: 1- Self-made questionnaire of personal characteristics including questions in two parts: in the first part 12 questions related to personal characteristics of caregivers: age, place of residence, gender, level of education, employment status, marital status , Relation to the patient, number of children, duration of caregiver contact with the patient, support from other families for care, health status and monthly income, and in the second part includes 8 questions related to the patient's characteristics: patient's age, occupation, duration of illness, duration Treatment time, type of cancer, history of other diseases, insurance status, and residence status. The 24-item Care Burden Inventory (CBI) was developed by Novak and Gast in 1989 to measure objective and subjective care burden and measures mental care burden with greater emphasis. The questionnaire was translated into Persian by (Abbasi et al.,) And its validity and reliability were confirmed. The questionnaire consists of 5 subscales, which are: time-dependent care burden from question one to five, developmental care burden from six to ten, physical care burden from eleven to fourteen, social care burden up to nineteen and emotional care burden up to question twenty. Five, which responds to caregivers on a 5-point Likert scale are never (0), rarely (1), sometimes (2), often (3), and almost always (4). According to this questionnaire, the lowest score obtained is the care burden 0, and the highest score is 96, and the higher this number, the higher the care burden. Scores of 36 and above indicate high care burden (Novak and Guest, 1989).

Ethical considerations were observed in this study, so that after providing clear explanations about the objectives of the study and the method of conducting it, as well as assuring the research units about the confidentiality of information and their freedom to leave the study at any stage of written consent was obtained from them.

The intervention consisted of two sessions of training in proper communication skills, anger management and nervous tension, and dialogue and problem solving sessions for caregivers during two weeks, which was conducted by a master nurse. Demographic information and care burden questionnaires were completed by both groups before the intervention. The intervention in this research was in the form of individual training, direct dialogue, question and answer, and presentation of a booklet that were prepared and specified under the supervision of expert professors. At the end of the intervention, 15 other primary caregivers were selected as the control group and the questionnaires were completed by them (it should be noted that no intervention was performed for the control group). 6 weeks later, the main caregivers were contacted and referred to the research site and both questionnaires were completed by both groups (15). Data were analyzed by SPSS software version 23 after collection.

Results

In this study, 30 caregivers of the elderly with cancer participated in the study. Findings showed that the mean age of caregivers in the intervention and control groups was about 42.2 and 38.2, the mean duration of caregiver contact with the patient in the intervention and control groups were 11.60 and 9.27 hours, respectively, and the number of children in the intervention and control groups was 1.73 and it was 1.07 people. Independent t-test did not show a statistically significant difference in mean age (P = 0.451), duration of caregiver contact with the patient (P = 0.089) and number of children (P = 0.204) between

Table 1. Demographic Characteristics of the Participants in the Intervention and Control Groups

Variable	N (%)		Z score	P value
	Intervention (n=15)	Control (n=15)		
Gender				
Male	2 (13.3)	6 (40)		
Female	13 (86.7)	9 (60)	-	0.215
Marital status				
Single	5 (33.3)	8 (53.3)	-	0.462
Married	10 (66.7)	7 (46.7)		
Education				
Illiterate	2 (13.3)	2 (13.3)	2.57	0.699
Primary	5 (33.3)	4 (26.7)		
Diploma	2 (13.3)	5 (33.3)		
Higher diploma	1 (6.7)	5 (33.3)		
University	5 (33.3)	4 (26.7)		
Job				
Employee	2 (13.3)	2 (13.3)	9.44	0.105
Freelance	0 (0)	5 (33.3)		
Housewife	6 (40)	4 (26.7)		
Unemployed	2 (13.3)	3 (20)		
Student	1 (6.7)	1 (6.7)		
Retired	3(20)	0 (0)		
Worker	1 (6.7)	0 (0)		
Relationship with the patient				
Child	6 (40)	12 (80)	5.01	
Spouse	7 (46.7)	2 (13.3)		0.084
Sister or brother	2 (13.3)	1 (6.7)		

Table 2. Mean and Standard Deviation of before and after Care Burden in the Two Groups of Intervention and Control

Care burden	Mean+ SD		CI 95% Difference	T score	P value
	Intervention	Control			
Before	56.93 (18.08)	54.27 (11.37)	-8.63, 13.97	-0.483	0.633
After	42.93 (9.78)	56.80 (11.43)	21.82, 5.91	3.57	0.001
Variable	Mean (CI 95%)		CI 95% Difference	F score	P value
	Intervention	Control			
Care burden	42.22 (45.96-38.48)	57.51 (61.25,53.77)	20.59, 9.99	34,99 = (27,1)	P<0.001

the two groups. Also, there was no statistically significant difference between the two groups in terms of gender, marital status, and place of residence, level of education, occupation, and patient ratio ($p>0.05$).

Discussion

The results showed that elderly caregivers were under low to moderate degrees of care stress. In confirmation of this result, Abuzadeh Gatabi et al., (2016) at the end of their study reported the care burden of caregivers of elderly family members following the care process as moderate (Kh, 2016). Kazemi et al., (2019) reported mild to moderate stroke under their study. However in the study of Bastani et al., (2015), it was found that 62% of caregivers of the elderly with Alzheimer's disease had high care burden. It should be considered by health care providers. But in any case, all these results suggest a degree of care in the elderly caregivers, the researcher considers the dependence of the elderly in daily activities to be effective in forming this care burden. In confirmation of this possibility, Kazemi and Sabzevari at the end of their study identified the factor of increasing this care burden as increasing the dependence of these elderly people (Sabzwari et al., 2016, Kazemi et al., 2019).

According to the researcher, this dependence is due to the decline in physical and mental strength of the elderly, which makes them unable to take care of themselves. In confirmation of this, Masoudi et al., (2020) at the end of their study, mentioned the high level of unmet needs of the elderly with cancer under their study in physical areas and daily functioning. Another important possible factor underlying the burden of care in According to the researcher, elderly caregivers are involved in high costs of care and treatment. In confirmation of this possibility, the results of a study entitled The effect of financial costs on burnout of elderly adult caregivers showed that financial costs related to home care were an important factor in the burden of care for male and female caregivers (Lai, 2012).

According to the results, most of the elderly caregivers in the study were women with a female ratio. Which is consistent with the results of the previous studies (Bastani et al., 2015; Kh, 2016; Bagherbeik Tabrizi et al., 2015), most of the caregivers were women. According to the researcher, cultural factors have been effective in achieving this result. In confirmation of this possibility, Abuzadeh Gatabi writes, perhaps this is due to the existence of this culture in Iranian society that the care of children, the sick, the disabled and the elderly is more the responsibility of women and girls in the family as part of housework. And is considered a home (Kh, 2016). According to the results, family-centered education has been effective in reducing the care burden of elderly caregivers with cancer. According to the researcher, this type of education may have been effective in reducing the care burden on their elderly patients by helping them solve their care problems. In various studies, various reasons have been proposed in this regard. As Nasiri et al., (2020) argued, family empowerment increases knowledge, attitude and performance improvement. The result of the study of Ismailian et al. also identified this type of training as promoting self-care (Esmaeilian et al., 2019) and Amini et al., (2020) as a result of their study, introduced patient care education to caregivers as a factor of their care knowledge, which from the researcher's point of view, these possibilities can also be raised.

In confirmation of the effectiveness of family-based education in the elderly, Tabari et al., (2019) as a result of their study, family-centered educational program has a positive effect on drug management of the elderly and can be used to improve the quality of education to patients, especially the elderly and Meridani et al., (2015) At the end of their study reported the positive effect of family-centered education on improving the care and control of diabetic elderly. Numerous studies have evaluated and confirmed the impact of this type of training on the elderly, including improving the laboratory parameters of patients with myocardial infarction (Dehkordi et al., 2021; Asgari et al., 2018; Keshavaraz et al., 2021) and improving adherence to the treatment regimen of patients undergoing hemodialysis (Chan et al., 2012; Naderifar et al., 2017; Naderifar et al., 2018), all of which confirm The usefulness of using family-centered education can be suggested by implementing it in hospitals to improve their implementation in order to improve the process of patient care.

In conclusion, based on the findings of the present study, family-centered education intervention can be effective in reducing the care burden of caregivers of the elderly with cancer in a sample of Iranian society. Therefore, it is predicted that providing such educational services in the health care delivery system is absolutely necessary and effective, and the use of this type of training in nursing activities is recommended.

Author Contribution Statement

AW and MR conceived the study. AB and MB collected and cleaned the data, and obtained ethics approval and consent. AB analyzed the data. AW,MH, ZH wrote the first draft of the paper. AB edited the manuscript. All authors prepared and revised the manuscript, including relevant scientific content. All authors approved the final version of the manuscript.

Acknowledgments

This article is the result of the dissertation of internal medicine-surgery master from the nursing school of Zabol University of Medical Sciences with the ethics code IR.ZBMU.REC.1400.024. The authors have no financial relationship with the organizations that sponsored this research.

Funding Statement

The present study was supported by the Zabol University of Medical Sciences.

Ethics Approval and Consent to Participate

This study was conducted in accordance with the Declaration of Helsinki and was approved by the Ethics Committee of all participating institutes in agreement for medical research involving human subjects. All patients signed informed consent before any study related procedures

Availability of Data and Materials

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request

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