



The Effect of Cyberspace-Based Education on Care Burden in Caregivers Who Care about Elderly with Dementia

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Abstract

Background: Dementia prevalence is identified as one of the consequences of aging. Care for patients with dementia has significant consequences for caregivers like poorer physical health, emotional stresses, depression and high mortality risk. This study was accomplished in order to determine the cyber-based education effect on care burden in caregivers of elderly with dementia.

Methods: This study is a quasi-experimental study performed on 86 caregivers of elderly with dementia who were referred to the Taleghani Hospital. This study samples were selected in both intervention and control groups as available sampling. Data collection tool was Zarit's care burden Questionnaire that was completed by using telephone interview (before and by passing two months from the end of intervention). Cyberspace-based educational intervention was conducted for one month, in the form of videos, clips, photo and text. The collected data were analyzed using SPSS software version 16 by applying Chi-square, independent t-test and paired t-test.

Results: This study population included 86 participants (43 people in the intervention group and 43 people in the control group). The questionnaire reliability in this study was 0.92 (Cronbach's alpha=0.92) and the physical and psychology dimensional reliability were measured as 0.75 and 0.9, respectively. Results indicated significant changes in the reduction of total care burden after education in the intervention group ($P<0.001$). Moreover, the amount of physical burden ($P<0.001$) and psychological burden ($P<0.001$) have reduced after intervention.

Conclusions: With respect to finding, cyber-based learning is suggested for caregivers of elderly with dementia in order to reduce the care burden.

Keywords: Care burden, Caregivers, Dementia, Elderly, Education based on cyber.

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syndrome in which memory, thinking, behavior, and ability to perform daily activities are eliminated and the person experiences speech disorders and psychological changes, although, this syndrome occurs more often in elderly, but it is not part of normal aging. Approximately 47 million people suffer from dementia in all over the world and about of 10 million new cases are added in each year.⁴ The number of people with dementia was estimated to be 24 million in 2001, which reached to 35 million in 2010.⁵

Accordingly, a new case of dementia is diagnosed in every 4 seconds. Consequently, the World Health Organization (WHO) estimates the number of people with dementia will increase to 75.6 million and 135.5 million between 2030 and 2050, respectively.⁶

Amongst the elderly in all over the world, dementia is identified as one of the important causes of disability and dependency.⁷ The largest number of people with dementia in the world are living in China, with the number of about 9.19 million people.⁸ Between the years of 2000 and 2016, death as a result of dementia increased more than doubled and was reported as the fifth cause of death in 2016. Regarding, it was also identified as the third cause of death in high-income countries.⁹ In Iran, one person gets dementia in every 11.5 minutes.¹⁰

With respect to dementia complications and consequences, including behavioral changes, along with disruptions in daily living activities, memory impairment and other cognitive functions (judgment, thinking, etc.), these patients required help and be controlled by caregivers on their daily activities.³

Regarding, these patients need more care for continuing their lives.¹¹ Investigations have indicated that more than 80% of this care is performed by families.¹²

Caring those patients with dementia has significant consequences for caregivers, including poorer physical health, emotional stresses, depression and a high mortality risk.¹³

In addition to social and economic difficulties, dementia has a lot of direct medical and care costs, that puts stress and pressure on families and caregivers.¹⁴ As a result, the total global social cost of dementia in United States was estimated to be 604 billion dollar in 2010, which is equal to 1% of GDP in all over the world.⁴

Generally, dementia creates more care burden for caregivers.¹⁵ Care burden is defined as a physical, psychological and social reaction resulting from an imbalance between care necessities and other tasks of caregivers. This

Introduction

Recently, people have a long life in all over the world and they can expect to live longer than 60 years old for the first time in history. Therefore, the world's population is getting older and it is estimated that the population of elderly will rise from 12% to 22% around the world, between the years of 2015 to 2050, this population is going to be doubled.¹ nowadays, 31 million of Iran's populations are in middle-aged, that will enter the elderly age up to future 20 years.² One of the getting old consequences is the chronic diseases prevalence associated with age, including dementia.³ Dementia is a progressive

imbalance is associated with social, personal, physical, emotional and financial resources of caregivers.¹⁶

In fact, the caregivers burden has a hidden nature and totally individual and this concept perception is personal and subjective.¹⁷ Nowadays, there is no treatment for dementia, however, an effective way to reduce the behavioral and psychological dementia symptoms is support and improve the lives of caregivers and family members of those patients with dementia.⁴

These patients condition, more care requirement, longer timing of care and more supervision, all of them will lead to a heavier caregiver burden and therefore, a high level of care costs.¹⁸

Long-term care has a complex system also with many complications. Therefore, due to this and also with respect to the increasing number of elderly and people with this disease, it appears that providing training for caregivers can decrease their caregivers burden^{19,20} and this is the only intervention that delays or reduces the transition from home to care facilities.²¹

In those low and middle income countries, the families role for care elderly with dementia is considerable, and the best way to support patients with dementia is to help and recognize the family members essential role.²²

Care burden could increase the amount of referral of caregivers to health clinics. Investigations have indicated that female caregivers are more likely to be exposed to care burden.²³ The caregivers' burden as a source of stress greatly threatens the caregivers life quality, therefore reducing the care burden should be prioritized.²⁴

The results of the study accomplished by Timothy Kwok et al. in 2013 in Hong Kong, demonstrated that after performing 12 training sessions, the intervention group had lower caring levels and more self-confidence in comparison with the control group.²⁵

Tremont et al. also in their study in Iceland in 2017, concluded that the rate of hospital services using after telephone training was decreased in the intervention group's caregivers.²⁶

A study conducted by Fatemeh Ghaedi Heidari et al., in 2014, demonstrated that, the amount of stress and anxiety of caregivers was significantly reduced after the educational intervention.²⁷ The results of the study accomplished by Razieh Sadat Hosseini et al., in 2011, indicated that, educational counseling program can improve the general health of those women who were looking after patients with dementia.²⁸

Although, various studies have demonstrated that training can reduce the care burden, but many caregivers are unwilling to participate in training sessions, due to the reason that for caring a person with dementia, they are completely isolated.²⁹

Nowadays, with the advent of extensive communication networks like the Internet, a development has been created in educational methods, and has made it possible for people to be covered by the educational network at different points, and from far and near distances.³⁰

A large part of cyberspace-based communications was accomplished through numerous networks, which were started in this field.³¹ This study was performed for the purpose of determining the cyber- based education effect on care burden in caregivers of elderly with dementia.

Materials and Methods

This study is a quasi-experimental research that was accomplished before and after in both experimental and control groups. The population studied, are caregivers (family caregivers and nurse) of the elderly with dementia who were referred to the memory clinic of Taleghani hospital in Tehran in 2018.

The investigated samples were selected as convenience sampling. For this purpose, 740 cases were investigated. The criteria for participating in the study were: 1- the caregivers (family caregivers or nurse) have lived with elderly for one year or more. 2- The caregiver do not have a memory and cognitive impairment. 3- The caregivers have the ability to read and write and having the ability of using messenger network. If the patient dies at the time of the educational curriculum, or the caregiver for any reason do not have the ability to care for the elderly person, Samples are excluded from this study.

The sample size was calculated with respect to the study of Dehghani et al. in 2015.²⁰ According to the following formula, the sample size was obtained 39, which sample size was selected as 43 subjects by counting 10% more than sample size to compensate for possible sample reduction.

$$n = \frac{(Z_{\alpha} + Z_{\beta})^2 \times S(\Delta)}{ES^2}$$

In order to control the data, one group was applied as the control group. Therefore, a total of 86 sample size people were calculated (43 people in the intervention group and 43 people in the control group). Also, it took about 3 months and 12 days from the first telephone call and obtaining the consciously satisfaction of caregivers, until the completion of the questionnaire first phase.

During this period, one of the elderlies who was suffered from dementia went to a coma, three of the elderlies suffered from dementia were died, one of the elderlies went abroad to continue the treatment and one of the caregivers refused from continuing co-operation. Totally, six people were excluded from this study.

In order to measure the amount of care burden, a summarized form of Zarit's care burden Questionnaire was used. This questionnaire has been validated and reliability by Rajabi Mashhadi et al. in 2014 in Iran. Moreover, a summarized form of the Zarit care burden questionnaire consists of 12 questions of 5-option was applied in three sub-scales of caregiver burden,¹⁻¹² psychological burden^{2,3,4,5,7,8,9} and physical burden.^{1,6,10,11,12}

Cronbach's alpha coefficient is equal to 0.75, 0.78 and 0.72 for each sub-scale, respectively, and the total Cronbach's alpha of the questionnaire is also 0.78. The range of questions was considered in terms of the Likert spectrum and the scores were ranged from 0 to 48. Each question has 0 up to 4 scores. Scores 0, 1, 2, 3, 4 in each sub-scale is in the sense of never, rarely, sometimes, often and always, that the participants choose one of the phrases, respectively.³²

After completing the first stage of questionnaires, intervention's group were joined in the telegram channel with the title of "Caregivers of the Elderly with Dementia". The

educational messages were loaded every day at 11 am from Saturday to Thursday (6 educational messages per week) on the earlier mentioned channel.

In this way, 24 educational messages were given to caregivers during 4 weeks. Every week in Friday for an hour, caregivers were joined with the researcher in a telegram group entitled "Caregivers of the Elderly with Dementia." This work purpose was to establish a mutual association amongst the researcher and caregivers along with caregivers with themselves.

By passing two months from completing this intervention, the Zarit care burden questionnaire was concluded for both intervention and control groups by telephone interview during 5 days. Also, one elderly of the intervention group and one elderly of the control group were died during this time interval. As a result, the sample size reduced to 39 in both study groups.

Educational content: Educational content was collected in order to reduce the burden on family caregivers, with respect to educational Concepts from the Alzheimer's Association of Iran for reducing the nervous system of caregivers, a staff guide file for working with mental patients families (Welfare Organization), educational content used in related articles in order to reduce caregivers in 8 chapters and were approved with respect to the opinion of the supervisors and counselors. Moreover, for content validity, educational content was provided to 6 men and women with the educational level of under diploma, diploma, postgraduate degree, MB, MS and PHD degrees with different fields of study, and their ambiguities were also eliminated.

The topics discussed for the first chapter included familiarizing with the purpose of the educational session, familiarity with the family role in developing the family members' health condition, the burden and caregivers burden definition, the second chapter on dementia, type of dementia, risk factors, signs and symptoms of Alzheimer's and vascular dementia, third chapter on how to communicate with a person with dementia and how to care, daily caring, how to deal with disease signs and symptoms, immunization of the patient's living environment and events prevention, fourth chapter, on the importance of drug treatment and its role in prevention of the disease progression and the relief of symptoms, the patient's requirement for mobility and exercise, fifth chapter, on acceptance and adaptation of disease, the ways of self-caring (caregiver) to reduce stress and stress management, sixth chapter, on communication skills education, seventh chapter, on cognitive-behavioral education and the eighth chapter on

health of caregiver will be trained by the researcher. Also it is noteworthy to state that educational content was designed and educated by the requirements of caregivers and clinical symptoms of the elderly with dementia, and also with respect to the components of the Zarit care burden questionnaire.

Furthermore, 24 educational messages were extracted from the educational curriculum chapters. In order to prevent fatigue and carelessness, educational messages were developed in the form of clip and photo. Only 9 messages were sent in the form of a text that had a small amount of content and would not cause any complications.

Data collection method: Data were collected using questionnaire and were entered into SPSS software version 16 and were also analyzed by applying Chi-square tests, paired t-test and independent T-test.

Results

In the primary study of data management, data were investigated from two aspects of missing and out list. One of the caregivers of the test group was excluded from this study due to the elderly death during the intervention period and two people from the control group sample were excluded after the test because of being out list (lack of caregiver's burden). Therefore, the sample size in the test group was 39 and it was reduced to 37 in the control group.

The stability of the questionnaire and the stability of two physical and psychological dimensions of the Zarit questionnaire were measured by the use of Cronbach's alpha test. In this study, the total stability of the questionnaire was equal to 0.92 (Cronbach's alpha=0.92) and the physical and psychological dimensions stability were also measured to be as 0.75 and 0.90, respectively.

After that, the normality of data were measured using Skewness and Kurtosis values that were between -2 and +2 limits, which represent the data normality.³³

The results of Chi-square test demonstrated that there were not a significant difference between the control and intervention groups in terms of gender ($P>0.05$), level of education ($P<0.05$), marital status ($P>0.05$) and employment status ($P>0.05$).

Table 1 indicates the demographic characteristics of the investigated samples.

Table 1. The demographic feature of the control and intervention groups by the Chi-square test

Variable	Intervention		Control		χ^2	P.V
	N	%	N	%		
sex						
-Female	29	74.4	28	75.7	0.02	0.90
-Male	10	25.6	9	24.3		
Educational degree						
-Diploma and lower	14	35.9	14	37.85	0.004	0.95
-College education	25	64.1	23	62.15		
Marital status						
-Single	13	33.33	13	35.15	0.005	0.94
-Married	26	66.66	24	64.85		
Employment status						
-Unemployed	23	58.97	21	56.75	0.04	0.84
-Employed	16	41.03	16	43.25		
Total	39	100	37	100		

Women were the most studied cases in two groups of control and intervention and those people with university education were more than people with diploma and lower education. Accordingly, married people were more in both groups compared to single people and the number of unemployed people was also higher.

Demographic features in both groups of control and intervention indicated that the mean age of patients and caregivers in the intervention group were 82.87 and 51.95 years old with a standard deviation of 10.90 and 6.35 and the mean age of patients and caregivers were 78.97 and 51.36 years old with a standard deviation of 7.39 and 15.12 in control group, respectively.

The results of independent t-test demonstrated that there was no significant differences in total care burden rate between the intervention and control groups in the pre-test ($P>0.05$). Also, in terms of physical burden ($P>0.05$) and psychological burden ($P>0.05$) as indicated in table 2.

Table 2. Data comparison of intervention and control groups in pre-test

Variable	Intervention		Control		t	P.V
	M	SD	M	SD		
Caregiver burden	32.43	7.74	32.13	5.12	0.18	0.85
Physical burden	13.02	2.82	12.91	2.15	0.09	0.92
Psychological burden	19.41	5.28	19.21	3.58	0.21	0.83

By passing two months from educational intervention, paired t test indicated a significant reduction in the amount of total care burden, physical and psychological burden in the intervention group ($P<0.001$) (table 3,4,5).

Discussion

This study was accomplished in order to determine the cyberspace education effect on the rate of care burden of elderly caregivers with dementia.

The results demonstrated that the care burden of caregivers were at a high level, which it was presented in Chaaya et al. study.²² Also, a study by Griffit et al. that was conducted on 195 formal care staff, indicates that the level of care burden and depression among staff was high before intervention.²⁴ Accordingly, Hagh Goo et al. in their study conducted in 2015, established that the level of care burden was Moderate to severe amongst family caregivers.¹⁷

This study presents that after the educational intervention, the level of total care burden, physical and psychological burden in intervention group have significant changes and were also reduced. Therefore, it can be concluded that cyberspace education can reduce the care burden of caregivers of elderly patients with dementia. This was in agreement with the results of Tremont et al.³⁴ Tremont et al. conducted their study entitled "A telephone intervention for caregivers of patients with dementia, context, design, basic characteristics" in order to investigate the effect of intervention on reducing depression symptoms and caregivers burden in caregivers. This study was performed on 250 caregivers of people with dementia in Iceland in 2013 and an educational package was also given to all participants. Findings demonstrated that educational intervention can reduce the caregiver's burden (29). Moreover, a study conducted by ElhamNawab et al., in 2016, indicated that, by passing 6 weeks from cognitive-behavioral educational intervention, the care burden significantly decreased in the experimental group. This study was performed on 70 family caregivers of elderly patients with Alzheimer's disease and the Zarit questionnaire was used in order to measure the amount of care burden.³⁵ Also, Dehghani et al., in 2015, investigated 30 home-caregivers of elderly with dementia. The results indicated that communication skills education improved the life quality and the caregivers' burden of the experimental group.³⁶

Table 3. The comparison of the amount of total care burden in two groups of control and intervention, two months after the intervention

Group	Pre test		Post test		t	Mean difference	P.V
	M	SD	M	SD			
Intervention	32.43	7.74	16.56	6.23	23.12	15.87	$P<0.001$
Control	32.13	5.12	33.59	4.42	-5.64	-1.45	$P<0.001$

Table 4. The comparison of the amount of physical burden in two groups of control and intervention, two months after the educational intervention

Group	Pre test		Post test		t	Mean difference	P.V
	M	SD	M	SD			
Intervention	13.02	2.82	5.64	2.13	22.38	7.38	$P<0.001$
Control	12.91	2.15	13.64	1.98	-5.29	-.72	$P<0.001$

Table 5. The comparison of the amount of psychology burden in two groups of control and intervention, two months after the intervention

Group	Pre test		Post test		t	Mean difference	P.V
	M	SD	M	SD			
Intervention	19.41	5.28	10.92	4.34	19.53	8.48	$P<0.001$
Control	19.21	3.58	19.94	3.14	-4.14	-0.72	$P<0.001$

In this study, the educational intervention was accomplished with respect to cyberspace, that result shows cyber-based education can reduce the care burden of caregivers of elderly patients with dementia. In this regard, Robert et al, concluded that using online care services could reduce the care burden.³⁷ Also, Blom et al. in their study demonstrated that Internet-based education intervention could significantly reduce anxiety and depression amongst caregivers.³⁸

Web-based studies for caregivers of elderly with dementia presented that the caregivers are easy and useful by applying this method.³⁹

In regard with observing the significant changes in caregiver's burden of the elderly with dementia after the educational intervention, it can be concluded that, using educational programs for caregivers can be effective in improving their health.

Therefore, due to increasing of elderly population, and consequently increasing the dementia incidence, it is essential for the medical education groups to pay attention to this field. Providing the discussion group and the exchange of information for the communication of caregivers can be mentioned as one of this study strengths.

One of this study limitations was the lack of the researcher control on samples about trained behaviors to the caregivers against the behavior of the elderly with dementia elderly indicates violence, the elderly claim of missing objects and etc. accordingly, the observation of the behavior of each research units was impossible.

Ethical Considerations: This study is based on the master's thesis with the IR code of IR.SBMU.PHNS.REC.1397.46, adopted by Shahid Beheshti University of Medical Sciences in Tehran. It is noteworthy to state that before the questioning, caregivers were asked for oral satisfaction and also announced them which participation in the study was completely voluntary.

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Conflict of Interest

The authors declare that they have no conflict of interest.

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