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# Effect of Sharing Experiences in an Online Support Group on the Resilience of Family Caregivers of the Disabled Elderly

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## Abstract

**Background:** Caring for a disabled elderly person causes physical and emotional problems and social isolation for family caregivers, thereby reducing their resilience. Online social networks could provide social support and effect on resilience.

**Aim:** This study aimed to investigate the effect of sharing experiences in the online support group on the resilience of family caregivers of the disabled elderly.

**Method:** This randomized clinical trial was conducted on 58 family caregivers of the disabled elderly in Mashhad, Iran. The participants were selected using convenience sampling and assigned to intervention and control groups using the permuted-block randomization technique. The participants in the intervention group shared their experiences of the problems faced by them due to caring for the disabled elderly for six weeks in an online support group with other caregivers. The data were collected using a demographic characteristics form, the World Health Organization Disability Assessment Schedule, and the Connor-Davidson Resilience Scale before and after the intervention. Finally, the data were analyzed in SPSS software (version 24).

**Results:** The participants in the intervention group reported a significantly higher level of resilience at the end of the intervention, compared to the control group ( $P < 0.05$ ).

**Implications for Practice:** The creation of an online support group for caregivers is a low-cost measure and does not require advanced clinical facilities. Furthermore, nurses can implement interventions to improve caregivers' resilience. Moreover, an increase in resilience can improve caregiving abilities while caring for disabled elderly.

**Keywords:** Aged, Disabled persons, Family caregivers, Resilience, Support group

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## Introduction

Disability is one of the consequences of aging that makes the elderly dependent on the caregiver and increases their need for support. Disability also increases the cost of living for the elderly by reducing income and the ability to perform basic life activities (1). In Iran, due to high costs of care in private centers and hiring nurses at home, lack of government rehabilitation centers, and inadequate follow-up after discharge, most families of disabled elderly take the role of main caregivers (2, 3). However, caring for the disabled elderly make these people face problems in their lives, such as anxiety, stress, sleep problems, depression, social isolation, economic issues, as well as physical and emotional problems (4, 5). Moreover, it can restrict the family's ability in providing care and even interrupt the care, and impose the cost and burden of care on the treatment system (6, 7). Nevertheless, not all caregivers suffer equally. In other words, people's resilience in difficult situations is different depending on factors, such as family relationships, social support, and spirituality (8, 9).

Resilience is the ability to recover from a persistent difficulty and restore oneself. Even when humans are exposed to severe stress, resilience leads to success in the face of accidents and events and increases the social, economic, and welfare functioning of individuals (10). Previous studies have shown that resilience has a positive relationship with social interaction, optimism, strength, and functional independence (11). Furthermore, some interventions can somehow provide the chance of social interactions for caregivers; however, it is difficult to bring together family caregivers for the disabled elderly at the right place and time since they cannot leave the elderly alone (12). In addition to solving these problems, the use of online social media can have benefits, such as availability, cost-effectiveness, the possibility of multidimensional communication, as well as the ability to develop and be continuous (13).

According to a study conducted by Inci et al. (2016), the peer support group for caregivers improved participants' resilience (8). Online support media trusted by caregivers can help family caregivers increase social interaction, alleviate the suffering of caring for disabled patients, and increase their resilience (14). In another study in 2007, the participants reported that online support groups in addition to being available at all hours of the day, had other benefits, such as providing appropriate social support for each individual and helping him/her learn ways for adaptation and emotional support by peers.

Moreover, studies have shown that members of online support groups can think about what they want to say as much as they want or talk more easily about issues that they do not want or cannot express face-to-face (15). In another study, caregivers stated that the support of other peer caregivers plays an important role in learning caring skills and supporting them emotionally. Nonetheless, it was difficult for them to find their peers (16). This study aimed to form an online support group to find peers for family caregivers of the disabled elderly. In Australia (17), Germany (18), Canada (19), and the United States (20), there are online support groups for caregivers of the elderly with dementia; however, no similar group was found for caregivers in Iran. In this new support group, the members could share their experience of caring for their family members and receive support from other members. Accordingly, the present study aimed at investigating the effect of sharing experiences in an online support group on the resilience of family caregivers with disabled elderly members.

## Methods

This experimental study was conducted with two groups of control and intervention without blinding. The participants were selected using non-random purposive sampling. Initially, the elderly and caregivers who were referred to the neurology clinics and wards of Ghaem and Imam Reza hospitals, Mashhad, Iran, were examined and selected through personal interviews with the caregiver and the elderly in February and March 2020. These hospitals are two major governmental centers for admitting neurologic patients in Mashhad, Iran. Neurologic clinics and wards were selected for better access to disabled elderly patients. The sample size was determined at 21 cases in each group using the formula for "comparison of two independent population's averages" (21) and considering 0.5 effect size based on a study performed by Naderi et al. (22). Regarding the sample attrition, the minimum sample size of 25 cases in each group was determined, and finally, 29 individuals were included in each group. It should be mentioned that during the research procedure three individuals in each group were excluded from the study.

Initially, the study procedures and objectives were explained briefly, and if the main caregiver of the

elderly was willing to participate in the study, his/her phone number was recorded in some pre-established lists. The researcher then talked to the caregivers via phone calls and completed the Disability Assessment Schedule (DAS-II) for the elderly. The inclusion criteria for the elderly were the presence of moderate to severe disability and reception of care at home. In addition, the inclusion criteria for the caregivers were: 1) a family member of the elderly, 2) provision of the care to the elderly for at least three months, 3) lack of receiving money for care, 4) a minimum level of literacy, 5) no major physical or mental health problems, 6) no membership in other related support groups, and 7) the ability to participate in online social groups or use the Internet. On the other hand, the elderly's death, change of the main caregiver, and lack of willingness to participate for two or more weeks were the exclusion criteria.

Out of the eligible persons, 58 (29 individuals per group) cases were selected from those who met the inclusion criteria, and they were then divided into two groups of control and intervention using the permuted-block randomization technique. In this way, two codes were initially given to the groups, and codes A and B were considered as intervention and control groups, respectively. There were two blocks AB and BA and one of the blocks was randomly selected. If the first block (AB) was selected, the first person would be assigned to group A (intervention group) and the second person to group B (control group). This process had continued until all samples were allocated; therefore, both groups were equal in the sample size (Figure 1).

The researchers then talked to each participant of both intervention and control groups during a session held online due to the coronavirus pandemic conditions and explained the objectives of the study, the impact of caring for the elderly on individuals' life and its significance. Furthermore, they discussed the problems and challenges of caring for the disabled elderly and the stresses experienced by caregivers following these problems. The researcher also tried to establish an empathic relationship with the participants and encourage their active participation. At the end of the session, the demographic characteristic form and the Connor-Davidson Resilience Scale (CD-RISC) were filled out electronically by the participants through a link provided to them.

The participants in the intervention group were then asked to attend the second online session. In this session, after explaining the intervention, procedure, and objectives of the online support group, the researcher asked the caregivers to express the most important problems they faced in their personal

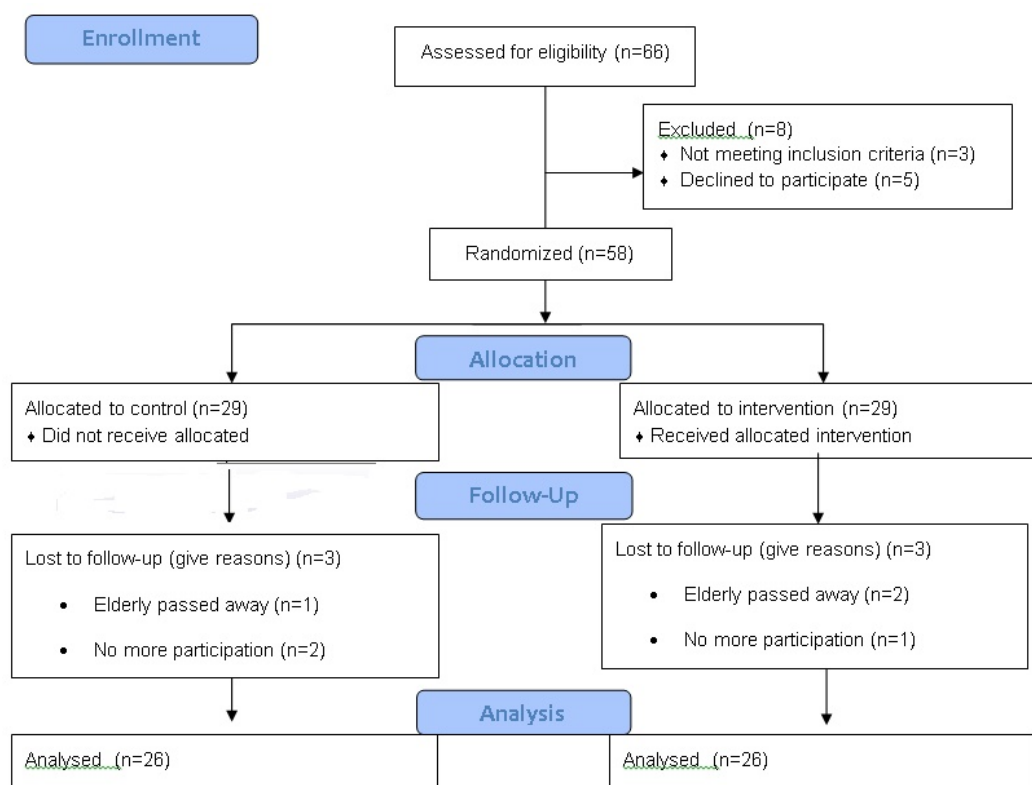


Figure 1. CONSORT diagram of the study

life when taking care of the disabled elderly. Following that, the researcher listed the problems pointed by the participants and asked them to prioritize the problems in order of importance for themselves. In the next stage, the researcher summarized the problems in six categories (Table 1), and the family caregivers approved the listed problems regarding priorities.

Afterward, the members of the intervention group joined an online support group in one of the social media approved by all members of the group. At the beginning of each week, one of the problems was chosen from the top of the list and was discussed by the caregivers. Following that, they shared their experiences, problems, and feelings about that topic with other group members to benefit from each other's guidance and empathy.

The researcher encouraged the group members to actively participate in the discussions and express their experiences while guiding the discussion. In case that a member required more advice and guidance on a problem that could not be provided by other group members, the researcher would provide the necessary instructions or introduced a suitable source for obtaining information about the problem. Although the support group focused on sharing experiences by the participants, the researcher also intervened in cases, such as possible ill-advised guidance, and tried to correct the mistake and provide the correct solution. The researcher also shared materials as incentives to promote further discussion on each topic and get more people involved in the discussion. He also sent private messages to those who did not participate in discussions effectively and asked them their reasons for not involving in sharing experiences and then tried to persuade them for more participation in the group. At the end of the week, if necessary, the discussion was summed up, and the topic for the next week's discussion was introduced. The group discussion lasted for six weeks upon the request of the group members. It is worth mentioning that the caregivers in the control group received no special intervention; however, they were under control regarding the attainment of exclusion criteria.

At the end of the study, the CD-RISC was provided to the members of both intervention and control groups via a link to be completed online. It is worth mentioning that six cases from the control (n=3) and intervention groups (n=3) left the study due to unwillingness to continue cooperation or the death of the elderly. Accordingly, the study continued with 52 participants.

The data were collected using a demographic characteristic form, the World Health Organization Disability Assessment Schedule (WHODAS-II), and CD-RISC. The researcher-made demographic characteristic form covered such characteristics of the elderly as age, type of disease, and the caregiver's relationship with the elderly. The 36-item WHODAS-II measures the level of functioning in six domains of life, including cognition, mobility, self-care, getting along, life activities, and participation in society and over the past thirty days that were rated on a five-point Likert scale of None, Mild, Moderate, Severe, Extreme or Cannot do. This scale was utilized in this study to determine the level of disability of the elderly person. The psychometric properties of this instrument were approved by WHO (23).

The 25-item CD-RISC is rated on a five-point scale. The minimum and maximum scores on the scale are 0 and 100, respectively, and each respondent's score is calculated as the sum of the scores assigned to all items in the scale. According to the scores, individuals are divided into four groups of low (0 to 25), moderate (26 to 50), good (51 to 75), and excellent (76 to 100) in terms of resilience (24). It should be noted that the validity and reliability of this standard tool were confirmed by Connor and Davidson (2003) and also by Mohammadi (2006) in Iran (25). The obtained data were analyzed via

**Table 1. Problems stated by the caregivers and their priority**

Priority for the family caregiver	Problems
1	High burden of responsibility towards the family and the elderly
2	Physical, mental, and emotional problems caused by continuous care
3	Chronic and constant stress in relation to the elderly, as well as personal and family life
4	Lack of understanding, respect, and support from relatives and community
5	Lack of sufficient rest and fun, along with chronic fatigue, and no independency or time to be alone
6	Feeling of inadequacy in performing personal, family, and professional duties



SPSS software (version 24). The normality of the distribution of quantitative variables was checked using the Kolmogorov-Smirnov test. Moreover, to determine the relationship between demographic variables and independent variables, the independent samples t-test (the quantitative data of demographic variables) and the chi-square test (the qualitative data of demographic variables) were used in this study. Furthermore, the paired samples t-test and independent t-test were run for intergroup comparisons. In case the distribution of variables was not normal, the non-parametric Wilcoxon test and Man-Whitney U test were employed. A p-value less than 0.05 was considered statistically significant in this study.

It should be mentioned that the study protocol was approved by the Ethics Committee of Mashhad University of Medical Sciences, Mashhad, Iran. Moreover, all the family caregivers were informed about the study objectives by the researchers, and they were assured that their information would remain confidential. Written informed consent was obtained from all participants.

## Results

This study included 58 family caregivers of disabled elderly who were referred to the neurology clinics and wards of Ghaem and Imam Reza hospitals in Mashhad, Iran. Tables 2 and 3 tabulate the demographic characteristics of the caregivers and the elderly. The results of statistical analysis

**Table 2. Background and intervening qualitative variables in intervention and control groups**

Demographic Variables		Group		Significance Level P-value
		Intervention N=26	Control N=26	
		Number(Percent)		
Caregiver's gender	Female	18(69.2)	15(57.7)	0.38*= P
	Male	8(30.8)	11(42.3)	
Caregiver's marital status	Married	20(76.9)	19(73.1)	P=0.74*
	Single	6(23.1)	7(26.9)	
Caregiver's education level	Diploma and under diploma	11(42.3)	13(50.0)	P=0.71**
	Higher than diploma	15(57.7)	13(50.0)	
Caregiver's occupational status	Unemployed	12(46.2)	9(34.6)	P=0.96**
	Employed	14(53.8)	17(65.4)	
Caregiver's incoming rate	Above the minimum level	1 (3.8)	1(3.8)	P>0.99**
	Acceptable	20 (76.9)	20 (76.9)	
	Below the minimum level	5 (19.2)	5 (19.2)	
Caregiver's relationship with elderly	Son	5 (19.3)	8 (30.8)	P=0.63*
	Daughter	13 (50.0)	11 (42.3)	
	Other	8 (30.7)	7 (26.9)	
Living with elderly	Yes	8 (30.8)	9 (34.6)	P>0.99**
	No	18 (69.2)	17 (65.4)	
Elderly's gender	Female	18 (69.2)	14 (53.8)	P=0.25*
	Male	8 (30.8)	12 (46.2)	
Elderly's Marital status	Married	12 (46.2)	11 (42.3)	P>0.99**
	Single	14 (53.8)	15 (57.7)	
Elderly's Income Level	Above the minimum level	2 (7.7)	3 (11.5)	P=0.83**
	Acceptable	18 (69.2)	16 (61.6)	
	Below the minimum level	6 (23.1)	7 (26.9)	
Elderly insurance	Yes	21 (80.8)	22 (84.6)	P>0.99**
	No	5 (19.2)	4 (15.4)	

**Table 2 Continued.**

Elderly's type of residency	Rental Personal	4 (15.4) 22 (84.6)	7 (26.9) 19 (73.1)	P=0.30*
Demographic characteristics		Mean±Standard Deviation		
Caregiver's age		39.8±11.3	39.9±9.8	P=0.97***
Months of caring		61.5±85.3	53.4±50.4	P=0.70****
Hours per week for direct caring		21.4±17.7	21.8±14.4	P=0.72****
Hours per week for indirect caring		11.5±27.3	11.9±23.0	P=0.37****
Elderly's age		78.4±9.4	76.9±7.5	P=0.53****
Duration of elderly's disease (month)		89.6±88.0	68.5±64.8	P=0.50****

\* Chi-square test      \*\* Fisher's Exact test      \*\*\*\* Mann-Whitney U Test

showed no significant difference between the intervention and control groups in any of the variables at the beginning of the study. In addition, the results of the independent sample t-test also revealed no significant difference between the intervention and control groups in the resilience scores at the pre-intervention stage (P=0.70). Similarly, the Mann-Whitney U test showed no significant difference between the intervention and control groups in terms of resilience after the intervention (P=0.06). However, a comparison of the resilience scores before and after the intervention using the Mann-Whitney U test suggested that the change in resilience mean score for the participants in the intervention group was significantly higher, compared to the control group (P=0.008) (Table 3). The results of the Wilcoxon test for intragroup comparisons showed the mean resilience score increased significantly after the intervention, compared to the pre-intervention stage for the participants in the intervention group (P=0.009). However, the results of the paired sample t-test showed that the change in the resilience score after the intervention was not significantly different, compared to that before the intervention for the participants in the control group (P=0.73) (Table 3). In addition, all contextual and intervening variables showed no interaction effect with resilience.

**Table 3. Mean and standard deviation of resilience's score of caregivers before and after the intervention according to group**

Resilience	Group		Test Outcome
	Intervention	Control	
Before intervention	64.0±17.7	65.8±15.3	P=0.70 50=df *t=-0.376
After intervention	72.5±11.4	65.7±15.4	**Z=-1.870 P=0.06
Later changes, compared to before	8.4±14.5	- 0.08±1.1	**Z=-2.670 P=0.008
Test outcome	***Z=-2.600 P=0.009	****t=0.348 P=0.73	

\* Independent t-test      \*\* Mann-Whitney U test      \*\*\* Wilcoxon test      \*\*\*\* Paired t-test

## Discussion

The results of this study suggested that sharing experiences in the online support group could improve the resilience level of family caregivers of the disabled elderly. Similarly, Seyed Fatemi et al. showed that psychological training provided through online social media improved the resilience of family caregivers of clients with mental disorders. Inci et al. (2016) found that participating in a support program that included training and sharing experiences in a support group could also improve the resilience of family caregivers of stroke patients and reduce the burden of caring for them (8). In another study, Malekkhahi et al. examined the effect of a peer support group on the mental health of patients undergoing hemodialysis and indicated that there was a significant difference in the mental health score of the patients in the intervention group before and after the intervention.

Although the above study was performed on patients, it confirmed the positive effects of participation

in the peer support group (26). In a clinical trial, Naderi et al. (2018) examined the effect of supportive interventions on resilience and quality of life of family caregivers of patients with advanced heart failure. The results showed that supportive interventions caused higher resilience in the participants in the intervention group (22), as was observed in the present study.

Given the profound effects of caring for the elderly, especially the disabled elderly, on the personal life of the caregiver, the creation of online support groups can have a significant impact on caregivers' resilience that increases their tolerance for these problems. According to the reports of family caregivers participating in this study, caring for a disabled elderly person is a time-consuming process and the caregiver has less time for social interactions and communication with friends, relatives, and colleagues, which in turn reduces the level of resilience in these individuals. It seems that bringing family caregivers of the disabled elderly together in an online support group and helping them to improve their social interactions by sharing experiences and feelings increased their resilience. Furthermore, factors, such as warm support, communication with others, meaningful participation and pioneering, in social ties can affect the level of resilience in individuals.

The participants in this study shared valuable experiences directly with others through the online group, without worrying about negative face-to-face feedback, which in turn evoked a sense of meaningful participation and connection with others in the caregivers. In addition, the participants' empathy for each other was perceived as emotional support that strengthened the social bonds among the caregivers and increased their resilience. Furthermore, the results of this study showed that since the peer support group of the elderly caregivers created an opportunity to share experiences, it helped members to express these experiences and reduce the stress of hard experiences. Moreover, they constantly realized that other people provide care for the elderly with moderate to severe disabilities, and they faced similar problems. In fact, being aware of the experiences of others helps a person learn to deal with difficult and exhausting experiences in a support group, and it is easier for him/her to adapt and deal with that situation if s/he encounters similar situations.

On the other hand, the support group created an environment in which caregivers could share their inner feelings and feel understood by people with similar backgrounds, thereby ultimately improving people's resilience. This study was conducted during COVID-19 pandemic conditions; accordingly, there were no face-to-face sessions and probably this could make caregivers unreliable to the researcher team. Despite this limitation, the researchers tried to establish an empathic and trust-based relationship with caregivers to decrease the effects of this distance. Another limitation of the study was no assessment of the stability of the intervention's effect along the time due to the time limitation of the study. If the study investigated the resilience of caregivers after some time, it could be more effective for investigating the stability of the intervention's effect along the time.

### **Implications for Practice**

The present study showed that sharing experiences in the online support group improved the resilience level of family caregivers of the elderly with disabilities. The creation of support groups for family caregivers can help them become more aware and prepare to take care of their elderly. Considering that nursing intervention by creating a support group for caregivers is a low-cost measure and does not require advanced clinical facilities, nurses can implement interventions to improve caregivers' resilience by creating such groups for caregivers, and then prepare them to care for the elderly in stressful situations, thereby reducing the challenges caused by caring. The findings of the present study can also be used to improve nursing education. Furthermore, nursing educators can use the results of this study in designing and teaching nursing practices related to family caregivers.

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### Conflicts of Interest

The authors declare that there is no conflict of interest regarding the publication of this study.

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