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Caring for Geriatric Dementia Patients in Egypt: The Effect of an Educational Training Program for Caregivers

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Abstract

Background: Most persons with dementia in Egypt live at home, supported mainly by family caregivers, who often develop psychological problems due to this burden affecting their quality of life. The aim of the study is to assess the effect of a caregiver training program on relieving psychological problems of Egyptian caregivers of elderly patients with dementia.

A prospective interventional study was conducted on one hundred caregivers of elderly demented patients recruited from the outpatient clinic at Abbasia Psychiatric Health Hospital. The sample was divided into two groups, a control group and a treatment group subjected to a 5 steps training program.

Results: The training program was associated with a significant reduction in caregiver burden (P<0.001). Severity of depression decreased from 30% to 20% in the treatment group after education. Similarly, anxiety, assessed by the Spielberger State-Trait Anxiety Inventory (STAI) was observed to decrease from 80% to 70%.

Conclusion: Training of family caregivers of persons with dementia can reduce family caregivers' burden, stress, and improve their quality of life. Therefore, it is highly recommended.

Keywords: Caregivers training; dementia; older persons with dementia; quality of life; psychological wellbeing.

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Background

Dementia is the most common disorder requiring informal caregiving. This need is likely to increase as dementia prevalence increases. Compared to caregiving for persons with other illnesses, dementia caregiving is challenging because of the duration of illness, behavioral disturbances, disease progression, and functional dependence. Over 46 million people live with dementia worldwide, and the number will increase to 131.5 million by 2050 [1]. Without caregivers, persons with dementia (PWD) would have a poor quality of life (QOL) and prognosis and would need institutionalization more quickly [2].

Two-thirds of PWD are living at home, with their family providing most of the needed care. Family caregivers of PWD who suffer depression or anxiety may reach up to 40% among other psychological symptoms [3]. Many studies found it more disturbing to care for a person suffering from dementia than it is for one suffering from a physical disability [4]. Higher caregiver stress may affect caregivers' health leading to depression, cardiovascular diseases, poor life quality, and increase mortality risk. It also affects their efficacy in the dementia caregiving process, managing behavioral problems, and ability to access community resources ultimately leading to an increased possibility of placement in nursing homes [5]. Caregivers educational program has a

positive impact, for example, Sorensen and colleagues [6] showed that it decreased burden on caregivers and improved their ability, knowledge, own sense of well-being, self-satisfaction, and reduced depression, which ultimately improved care receiver symptoms. The effect of the intervention was more apparent on the ability and knowledge rather than it was on the burden of care and depression. Outcomes of caregivers' education included increased knowledge, confidence in caregiving abilities, strategies for coping with their care recipients decreased strain, depression, stress, burden, and ultimately improved caregiver health [7]. Given this significance from the literature, we aimed to assess the effect of a caregiver training program to relieve care giver burden regarding health condition, psychological wellbeing, financial and social issues.

Methods:

Study design: A prospective interventional study.

Sample: 100 caregivers of community dwelling elderly with dementia recruited from the outpatient clinics of Abbasia psychiatric Health Hospital. Caregivers in our study were defined as informal caregivers who included spouses, adult children, daughters- and sons-in-law and friend who lived with the care recipients throughout the study period and for at least one year before it started. Caregivers who had any pre-caregiving psychiatric or neurologic disorder and who were not living with the care recipient were excluded.

All caregivers gave informed consent to participate in the study. The caregivers were divided by simple randomization into two groups. The first group received the educational program along with custom dementia outpatient care. The second group only received custom dementia outpatient care.

Both groups were evaluated at the start of the study and then 9 weeks later. During these 9 weeks, the first group received the educational program composed of five 2-hour sessions with 1 week interval in-between the sessions. The educational program was delivered in small groups (10 caregivers at a time). After the fifth session, a period of one-month was given to allow caregivers to practice the program's strategies.

Then we performed a post-program evaluation. Caregivers' age ranged from 20 to 60 years.

Care recipients were defined as caring of a patient diagnosed as dementia from at least one year and the caregiver lived with the patient all along the study and for at least one year before.

The ethical committee of Ain Shams University approved the study (FWA-000017585) and revised the prepared informed consent.

Five assessments were conducted initially for the selected caregivers:

- 1. Socio demographic assessment collecting information on the caregiver's age, gender, educational status, relationship with the care receiver, working status, income, and hours spent on caregiving
- 2. Twelve items general health questionnaire (12GHQ) [8]: It is the most commonly used screening instrument for psychiatric well-being. We used the validated Arabic translation of the test [9].
- 3. Zarit Burden Interview (ZBI) [10]: The Zarit Caregiver Burden Scale was developed by Zarit and coworkers in 1985 and is a self-administered 22-item questionnaire. The questions refer to the caregiver/patient relationship and evaluate the caregiver's health condition, psychological well-being, finances, and social life. Similarly, the Arabic version was used [11].
- 4. Hamilton depression rating scale (HDRS) [12]: It is the most widely used interview scale to measure the severity of depression.
- 5. Spielberger State-Trait Anxiety Inventory (STAI) [13]: we used the validated Arabic translated version [14]. It measures and differentiates between anxiety as a trait and a state.

Additionally, four assessments were initially performed for all patients:

1. Comprehensive geriatric assessment.

- 2. Mini-mental state examination (MMSE-30) [15] Arabic version [16]
- 3. Cornell scale for depression in dementia (CSDD) [17], designed for older persons with underlying cognitive deficits.
- 4. Activity of daily living (ADL) [18] & Instrumental activity of daily living (IADL) [19] used to assess care recipients' functional status.

The designed program received by the treatment group comprised of five weekly sessions (each session was 2 hours). Participants were arranged into 5 subgroups (each subgroup comprises 10 participants).

Description of sessions:

1st session: Brainstorming. During the session, each participant tells his story with his care recipient and the problems he faced and if he can cope with these problems. The caregiver's problems were recorded to be discussed in the subsequent sessions.

2nd session: Education about communication with the care recipient and dealing with troubling behaviors. It provided some practical methods for dealing with troubling behavioral problems and communication difficulties. We tried to facilitate this by using photos and videos that show caregivers how to monitor problems, identify probable events that trigger disturbances, and develop more effective responses.

3rd session: Multiple areas for improving knowledge, attitude, and practice of caring. The session included education about healthy nutrition, dressing, bathing, problems of incontinence. Some videos were used to facilitate program application.

4th Session: Supportive intervention was provided. This session included some important tips for caregivers as learning as much as they can, seeking other caregivers ...etc.

5th session: Exchanging experiences. This session focused on building rapport among participants and creating a space to discuss problems, successes, and feelings regarding

caregiving, and how the educational program sessions can affect every participant.

After the five sessions, a one-month period was given during which we asked caregivers to practice the program's strategies, then we performed the post-training evaluation for both the control and treatment groups. The evaluation was comprised of the same five assessments conducted before the program.

Statistical presentation and analysis of the present study was conducted, using the mean, standard deviation, student t- test, paired t-test, Chisquare, Linear Correlation Coefficient and Analysis of variance (ANOVA) tests by SPSS V17.

Results:

The sample consisted of more women caregivers than men with caregivers' mean age being (32.76) \pm 7.84 years. Most of caregivers (70.9%) were educated. 70% were not receiving help in the care giving process. About 85% of caregivers were spending over 12 hours per day caring for their patients. 70% of caregivers were spouses and 30% were sons or daughters (Table 1).

35% of caregivers for demented patients were suffering from moderate-to-severe depression, 80% were suffering from anxiety, 60% were under stress and 50% were feeling the burden.

The educational program for caregivers of demented patients was effective in reducing burden as assessed by the Zarit Burden Interview (Table 4). A reduction in the burden severity for the treatment group from 50% to 30% was observed after the education program. The difference between the control and treatment group was significant (p value<0.001). Similarly, for severity of depression, as assessed Hamilton depression rating scale, a reduction from 30% to 20% was observed in the treatment group after education, with a significant difference between treatment and control groups (Table 3). Similar results for anxiety as assessed by in Spielberger State-Trait Anxiety Inventory (STAI) were observed, decreasing from 80% to 70% in the treatment group after education, with a significant

difference between treatment and control groups (Tables 5 a & b).

As regard stress as assessed by 12 item general health questionnaire (Table 2): there is a decrease in severity of stress from 60% to 46% in caregivers who received the educational program (group 1) and this decrease was statistically significant with a significant difference between treatment and control groups 1&2.

With regards to the impact of the educational program on care recipients (patients), there was no statistically significant difference observed between the patients of the two groups of caregivers with regards to MMSE, CSDD, ADL and IADL, and no difference pre and post training. The study showed also that there is a negative correlation between patient cognitive state and the burden of caregivers (p-value 0.001)

Discussion

This study aimed at assessing the effect of a caregiver training program to relief caregiver and improve their psychological wellbeing. It was found that the educational program significantly reduced the burden, depression, anxiety, and stress of caregivers of dementia patients as assessed by different tools (ZBI, HDRS, STAI, and 12GHQ). These findings are consistent with a study by Northouse, et al., [20] who concluded that information can improve caregivers' knowledge and relieve caregivers' distress arising from uncertainties about their ill family members' disease, treatment status and the care they may need. This study is also in line with a study by Sorensen and colleagues [6] which indicated that intervention by education of caregivers is successful in increasing general subjective well-being, caregiving ability and knowledge.

In line with Cooper et al. [3] in which; anxiety significantly affected about a quarter of caregivers and that of Cochrane et al. [21] where caregivers had higher rates of anxiety disorders than non-caregivers [21], the current study found that caregivers who did not receive the educational program exhibit more anxiety than caregivers who received the program using STAI. These results are also consistent with the results of Grov

et al. [22] which found that the level of anxiety was significantly higher in caregivers without education than caregivers who were educated on how to deal with their patients. In our study, we found a significant reduction in caregiver's burden (using ZBI) after the educational program, and this result was like that of Camila et al. [23] in which the educational and support programs significantly reduced the burden.

Many educational programs proved successful in empowering caregiver abilities, decreasing caregiver stress throughout multiple settings. This was clearly observed in our study, in which caregivers of PWD who do not receive an educational or training program consistently reported higher levels of stress (by 12GHQ) than caregivers who received the educational program. This is also broadly consistent with Brodaty and Luscombe [24] where the intensive intervention program described for caregivers of PWD reduced caregivers' psychological stress and morbidity and delayed the placement of the patients in institutions without excessive consumption of health services by either patient or caregiver.

The most significant psychiatric consequence of caregiving for PWD is the high incidence of depression. In our study, we investigated depression in caregivers using HDRS and it caregiver training showed that decreased depression severity by about 30%. This is a significant finding that adds to the literature around prevalence of depression like Waite et al. [25], which reported depression to be present in 32% to 43% of dementia patients' caregivers. Results are also in line with, Pinquart and Sorenson [26], which found caregivers of PWD to be more stressed, depressed, and had lower levels of subjective well-being, physical health, and selfefficacy than non-caregivers.

There was a significant negative correlation between patients' cognitive state and burden of care, which is in line with the literature, where more impaired the care-recipients were in cognition as evaluated by MMSE, the greater the caregivers' expressing of burden [27].

As regard socio-demographic data, we found that most caregivers were married women. Elemary and colleagues (2011) [28] found similar results in which 64% of caregivers were married. On the other hand, Dilworth-Anderson et al., (1999) [29] found that most of the caregivers were unmarried, a change in demographic which shows characteristics over time. We also found that about 70% were spouse and 30% were sons or daughters, which differs from another study done by Perkins et al. (2013) [30] in which they found that within each caregiving strain group, those who provided care to a parent represented the largest proportion of caregiver-care recipient relationships, followed by a spouse, another child, and a sibling. Not to mention, Andrén and Elmståhl (2007) [31] who found the adult children tend to carry a greater burden than other family members.

Finally, unlike Covinsky et al. (2003) [28], which is one of few studies that tackled this point and finds that caregivers who spent more hours during the caregiving process developed more depression, we found no significant relationship in our results between caregiving duration and caregiver stress, depression, or anxiety.

Conclusion

The training program for caregivers of demented patients can significantly improve family carers' quality of life, reducing burden and stress. Based on these results, we therefore recommend applying it widely.

Consent for publication

Declarations

Ethics approval and consent to participate

We obtained ethical approval from the ethics committee of the faculty of medicine, Ain Shams University, under number FWA-000017585. After a complete description of the study to the subjects, we got verbal informed consent from them, because part of the study participants were the care recipients who as previously mentioned in the methods section, were patients diagnosed with dementia. Also, through this study we aimed

Not applicable

Availability of data and materials

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

Competing interests

The authors declare no conflict of interest.

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Authors' contributions

SH, RE, SR, AA and EA: concept and design. EA: data collection. SH, RE, SR, AA and EA: data interpretation. EA, SH, RE and SR: writing manuscript. SH, RE, SR, and AA: substantively revised the manuscript. All authors read and approved the final manuscript.

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to provide the caregivers with the training service, doing no harm or invasive interventions, which were all approved by the ethical committee.

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Tables

Table1: Descriptive analysis of demographic data for caregivers:

Socio demographic data		Groups	T-Test or Chi- Square					
		Group I		Group II		T or X ²	P- value	
Age	Range	19 -	56	20 -	J 1	1.080	0.283	
Age	Mean ±SD	$32.760 \pm$	11.289	$30.660 \pm$	7.847	1.000	0.203	
Gender	Male	27	54.00	21	42.00	1.442	0.230	
Genuel	Female	23	46.00	29	58.00	1.442	0.230	
Education	Educated	42	84.00	32	64.00	5.198	0.023*	
	Illiterate	8	16.00	18	36.00	3.198	0.025	
If receiving	Positive	17	34.00	14	28.00	0.421	0.517	
help	Negative	33	66.00	36	72.00	0.421	0.317	
Hours for caring	< 12 Hours	5	10.00	9	18.00	1.329	0.249	
	> 12 Hours	45	90.00	41	82.00	1.329	0.249	
	Spouse	34	68.00	43	86.00			
Relation to the patient	Son- daughter	9	18.00	3	6.00	4.870	0.088	
	Brother	7	14.00	4	8.00			
Living	With the pt. alone	20	40.00	20	40.00	0.000	1 000	
Living	With the pt. & others	30	60.00	30	60.00	0.000	1.000	
Duration	> 5 Years	39	78.00	33	66.00	1.786	0.181	
	1-5 Years	11	22.00	17	34.00	1./80	0.181	
Marital	Married	24	48.00	26	52.00			
	Widow	5	10.00	4	8.00	0.218	0.975	
	Divorced	2	4.00	2	4.00	0.218	0.973	
	Single	19	38.00	18	36.00			

Table (2): Comparison between the two groups as regards 12 items general health questionnaire, and comparison within each group (1&2) pre and post-training.

12 item general health Q		Grou	ps	Chi Sauoro						
		Grou	Group I		up II	Tota	ıl	Chi-Square		
		N	%	N	%	N	%	\mathbf{X}^2	P-value	
Pre training	Normal	2	4.00	0	0.00	2	2.00			
	Stress	14	28.00	14	28.00	28	28.00	2.057	0.358	
	Severe Stress	34	68.00	36	72.00	70	70.00			
	Normal	15	30.00	0	0.00	15	15.00			
Post training	Stress	25	50.00	14	28.00	39	39.00	32.798	<0.001*	
	Severe Stress	10	10 20.00		72.00	46	46.00			
P-value		<0.00	<0.001*		0					

^{**}P<0.01 highly significant

Group 1: who received the training program.

Group 2: who did not receive the training program.

Table (3): Comparison between the two groups as regard Hamilton depression, rating scale, and comparison within each group (1&2) pre and post-training.

Hamilton depression rating scale (HDRS)		Grou	ıps	Chi-Square					
		Grou	Group I		Group II		1	CIII-Square	
		N	%	N	%	N	%	\mathbf{X}^2	P-value
Normal		1	2.00	2	4.00	3	3.00		
	Mild Depression	4	8.00	7	14.00	11	11.00		
Pre training	Moderate Depression	14	28.00	14	28.00	28	28.00	7.099	0.131
	Severe Depression	16	32.00	22	44.00	38	38.00		
	Very Severe Depression	15	30.00	5	10.00	20	20.00		
	Normal	10	20.00	0	0.00	10	10.00		
	Mild Depression	30	60.00	5	10.00	35	35.00		
Post training	Moderate Depression	10	20.00	19	38.00	29	29.00	56.650	<0.001*
	Severe Depression	0	0.00	20	40.00	20	20.00		
	Very Severe Depression	0	0.00	6	12.00	6	6.00		
P-value		<0.0	01*	0.513	3		•		

Table (4): Comparison between the 2 groups as regard Zarit Burden Interview (ZBI) and comparison within each group (1&2) pre and post-training.

Zarit Burden Interview(ZBI)		Grou	ıps	Ch: Canana						
		Grou	Group I		Group II]	Chi-Square		
		N	%	N	%	N	%	\mathbf{X}^2	P-value	
Due tuelulue	Mild Burden	8	16.00	9	18.00	17	17.00			
Pre training	Moderate Burden	29	58.00	26	52.00	55	55.00	0.365	0.833	
	Severe Burden	13	26.00	15	30.00	28	28.00			
	No Burden	7	14.00	0	0.00	7	7.00			
Do at tuo in in a	Mild Burden	33	66.00	9	18.00	42	42.00	41 221	۰0 001*	
Post training	Moderate Burden	9	18.00	26	52.00	35	35.00	41.221	<0.001*	
	Severe Burden	1	2.00	15	30.00	16	16.00			
P-value		<0.00)1*	1.000)					

Table (5a) Comparison between the 2 groups as regard Spielberger State-Trait Anxiety Inventory (STAI-S scale) and comprison within each group (1&2) pre and post-training.

Spielberger State-Trait Anxiety Inventory (STAI-S scale)		Groups	T-Test						
		Group I			Group I	Ι		t	P-value
Pre training	Range	40	-	80	40	-	77	0.146	0.885
	Mean ±SD	56.080	±	10.532	55.780	±	10.078	0.146	
Doct two in in a	Range	21	-	72	40	-	84	C 965	<0.001*
Post training	Mean ±SD	40.760	±	11.628	55.920	±	10.421	-6.865	
Paired Differences	Mean ±SD	15.320	±	6.997	-0.140	±	0.990		
Paired Samples Test	P-value	<0.001*			0.322				

Table (5b) Comparison between the 2 groups as regard Spielberger State-Trait Anxiety Inventory ((STAI-T scale) and comparison within each group (1&2) pre and post-training.

Spielberger State-Trait Anxiety Inventory ((STAI-T scale)		Groups	T-Test						
		Group I			Group I	I		t	P-value
Pre training	Range	40	-	76	44	-	80	-1.119	0.266
	Mean ±SD	57.680	±	8.445	59.680	±	9.404	-1.119	
Doct tuoining	Range	22	-	63	44	-	80	-9.964	<0.001*
Post training	Mean ±SD	41.620	±	8.708	59.680	±	9.404	-9.904	
Paired Differences	Mean ±SD	16.060	+1	7.011	0.000	±	0.000		
Paired Samples Test	P-value	<0.001*	•		1.000	•			