



# Psychoeducational Program for the Family Member Caregivers of People with Dementia to Reduce Perceived Burden and Increase Patient's Quality of Life: A Randomized Controlled Trial

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## Abstract

**Background:** Dementia is one of the world's greatest public health issues. Most people with dementia receive home care, and family members are vulnerable to feeling burdened and depressed that reinforces the need for caregiver-driven services to mitigate these negative effects. **Objective:** The purpose of this research was to evaluate the effect of the psychoeducational program on burden and quality of life of family caregivers for people with dementia. **Methods:** This randomized controlled trial (RCT) was conducted on 60 family caregivers. Participants were randomly assigned to receive either the 8-session psychoeducational program (study group) or routine care only (control group). The demographic data of the caregivers and their patients, the burden of caregivers using Zarit Burden Interview (ZBI), and the quality of life of the patients using Quality of Life in Alzheimer Disease (QoL-AD) questionnaire were measured before and after the psychoeducational program and compared between the study group and the control group. **Results:** The results revealed that 80% of the family caregivers were female and 42% were daughters. The mean  $\pm$  SD of the baseline burden was  $61 \pm 13.7$  and  $60.9 \pm 10$  in the study and the control group, respectively. ZBI burden score in the study group demonstrated a significant drop after the psychoeducational program compared to the control group. Logistic regression analysis showed that caregivers who received the psychoeducational program have OR (95% CI) of 14 (3.1–67.8) compared to those who did not receive the psychoeducational program. **Conclusions:** Psychoeducational program is effective in reducing the family caregivers' perceived burden. These findings need to be considered in developing comprehensive dementia care programs to well increase the strategies that help caregivers to deal with their patients.

## Keywords

Alzheimer's disease, old age, burden, quality of life, Egypt

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## Introduction

The World Health Organization (WHO) reported that in 2015 there will be 46.8 million people living with dementia worldwide and this figure will almost double every 20 years, reaching 74.7 million in 2030.<sup>1</sup> In Egypt, a systematic review estimated that the prevalence of dementia among individuals aged  $\geq 50$  years was 2.01%–5.07%.<sup>2</sup> Dementias is one of the leading contributors to the burden of illness and disability as they have significant implications for individuals, their families, the health care system, and the economy.<sup>3,4</sup> Therefore

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future research is about reducing the impact of dementia on aged care facilities and home caregivers.<sup>5</sup>

Many studies showed that the caregivers of people with dementia have trouble dealing with patients' psychological needs and they need to learn more about the condition, ways of coping with the behavioral and psychological symptoms, and psychological support such as stress reduction.<sup>6-9</sup> Thus, many interventions aimed at reducing burden in dementia patient caregivers have been developed such as (a) formal support through community services (eg, day centers, etc.); (b) psychoeducational programs; and (c) counseling.<sup>10</sup> Interventions that were effective in reducing caregiver burden are based on psychoeducational models that cover a number of different areas: information about the disease, practical advice, skills training for the handling of the behavioral problems of the patient, and advice about self-care.<sup>11-13</sup>

Therefore, we aimed to try out psychoeducational intervention in our society to assess its effectiveness in reducing caregiver's burden and improving the quality of life of patients with dementia.

## Methods

### Study Design

This randomized controlled trial (RCT) was conducted using a parallel design with 1:1 allocation ratio.

### Settings, Sampling, and Participants

This study was performed at the Old Age Psychiatry Outpatient Unit in Psychiatry and Addiction Medicine Hospital at Cairo University. Data were collected in the time period between September 2019 and the end of January 2020.

Diagnosis and classification of dementia into mild or moderate stages were made by the attending psychiatrist based on the DSMV criteria.

The researcher then identified eligible patients and their family caregivers. The following were the eligibility criteria:

The caregivers must have the following criteria:

- Unpaid caregivers.
- Be responsible for home-based care of the person with dementia.
- Be 18 years and above.

Exclusion criteria:

- The care recipient (CR) suffers from severe dementia according to DSMV.
- The CR suffers from other severe mental pathologies.
- Caregivers who had received any form of psychosocial education in the previous year, specifically directed at alleviating the burden.

The minimum required sample was calculated based on the following assumption from a previous research<sup>14</sup> with power 90% and confidence interval (2-sided) 95%, ratio of sample size (Group1/Group 2) of 1 and mean ( $\pm$ SD) score before intervention of 54 ( $\pm$ 12), and mean ( $\pm$ SD) score after intervention of 34 ( $\pm$ 12) using G-power software,<sup>15</sup> sample size was 26 caregivers and we added 25% to anticipate dropout and loss of follow-up, so it was to 35 caregivers for each group.

### Study Procedures

The psychiatrist who was running the clinic diagnosed patients with mild or moderate dementia based on the DSMV criteria. The researcher who was attending the clinic then identified their family caregivers who met the inclusion criteria and who did not have any exclusion criteria.

After completing the total number of sample size, caregivers were listed into a random numeric listing and were assigned a participation code (from FC1 to FC 70), the first 35 caregivers being the study group (SG) who received the psychoeducational program and the next 35 caregivers being the control group (CG) who received the usual care provided by the hospital.

### The Psychoeducational Program

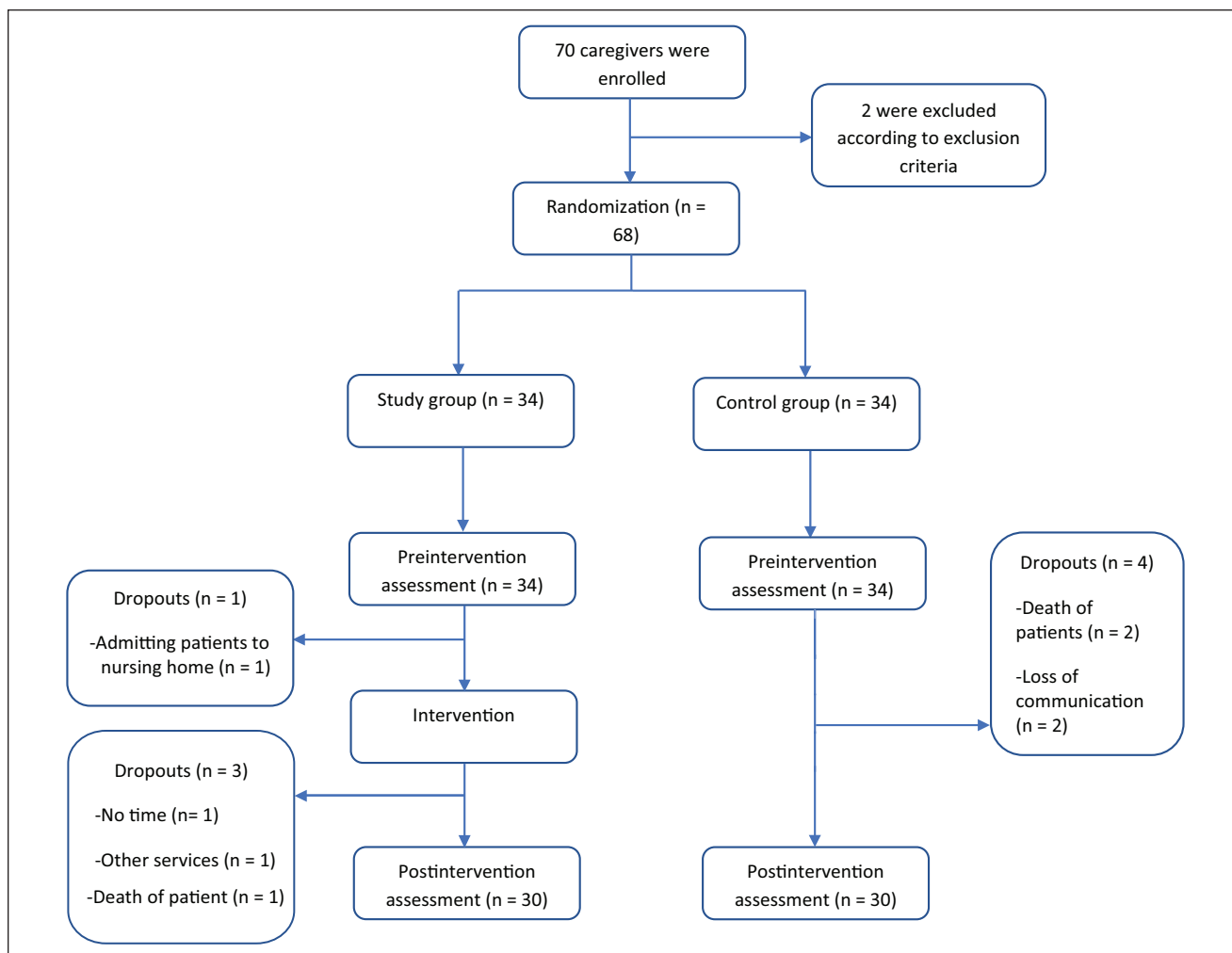
The psychoeducational program was in the form of group sessions (each group consisted of 15-20 participants) that were offered to the study group only. The main objectives of this program were (a) Giving information about different dementia behaviors such as agitation, apathy, repetitive behaviors and questions, wandering, refusal to take medications and hallucinations and tips to deal with them; and (b) Finding a caregiver support and discussing some de-stress techniques. The program consisted of 8 1-hour sessions scheduled once every week for 2 months in a specialized place for group sessions in the Old Age Psychiatry Outpatient Unit in Psychiatry and Addiction Medicine Hospital at Cairo University. Different methods were used to achieve these objectives as role playing, brainstorming, group discussion, and Arabic spoken videos that were originally produced by Alzheimer's and Dementia Care at the University of California in Los Angeles (UCLA).<sup>16</sup> The sessions were administrated by the first author.

The data were collected using the following tools:

1. A predesigned structured interviewing questionnaire

It was used to collect demographic and socioeconomic data for people with dementia and their caregivers.

2. Zarit Burden Interview (ZBI)



**Figure 1.** Flowchart of the study participants.

It is a translated and validated self-administrated 22-item questionnaire used to determine the severity of the burden on caregivers.<sup>17-19</sup>

ZBI was done in the initial interview and after 3 months.

### 3. The Arabic version of Quality of Life in Alzheimer Disease (QOL-AD) questionnaire

It is a translated and validated brief measure of the quality of life among people with dementia.<sup>20,21</sup> QoL-AD questionnaire was done in the initial interview and after 3 months.

A pilot study was conducted on 7 subjects (approximately 10% of the sample size) to pretest the questionnaire and it revealed that some questions must be explained to them by the researcher.

Participants' flowchart is illustrated in Figure 1. Dropouts were excluded from all statistical analyzes.

### Statistical Analysis of Data

The data collected were analyzed statistically using Statistical Package for Social Sciences (SPSS) software, version 18.

All *P*-values less than .05 were considered significant.

Simple descriptive statistics (arithmetic mean and standard deviation) were used for a summary of quantitative data and frequencies were used for qualitative data. Paired sample *t*-tests were conducted to assess the effect of the overall program. Multiple logistic regression model has been conducted to find significant predictors for ZBI score.

### Results

A total of 60 caregivers participated in the study, the mean  $\pm$  SD of their age was  $37.4 \pm 11$  and  $38.3 \pm 14.3$  years

**Table 1.** Comparison of the Caregiver's Sociodemographic Data of the Study Group and the Control Group.

Sociodemographic data	Study group	Control group	P-value
Age (mean $\pm$ SD)	37.4 $\pm$ 11	38.3 $\pm$ 14.3	.906*
Gender			
Male (n (%))	4 (13.3%)	8 (26.7%)	.197**
Female (n (%))	26 (86.7%)	22 (73.3%)	
Marital status			
Married (n (%))	22 (73.3%)	22 (73.3%)	1
Single (n (%))	7 (23.3%)	8 (26.7%)	
Widowed (n (%))	1 (3.3%)	0 (0%)	
Occupation			
Irregular (n (%))	23 (76.7%)	23 (76.7%)	1
Manual working (n (%))	2 (6.7%)	3 (10%)	
Professional (n (%))	5 (16.7%)	4 (13.3%)	
Educational level			
Illiterate (n (%))	9 (30%)	6 (20%)	.060
Basic education (n (%))	6 (20%)	11 (36.7%)	
Secondary education (n (%))	10 (33.3%)	13 (43.3%)	
High education (n (%))	5 (16.7%)	0 (0%)	
Caregiver relation			
Son (n (%))	3 (10%)	4 (13.3%)	1
Daughter (n (%))	13 (43.3%)	12 (40%)	
Wife (n (%))	9 (30%)	8 (26.7%)	
Husband (n (%))	1 (3.3%)	2 (6.7%)	
Granddaughter (n (%))	2 (6.7%)	1 (3.3%)	
Grandson (n (%))	0 (3.3%)	1 (3.3%)	
Sister (n (%))	1 (3.3%)	1 (3.3%)	
Brother (n (%))	1 (3.3%)	1 (3.3%)	

\*Student's t-test.

\*\*Chi square test.

for the study and control groups, respectively, 80% of them were females, 73% were married, 77% were not working, and 25% were illiterate. There were not statistically significant differences between the two groups with respect to their sociodemographic characteristics as shown in Table 1.

Out of the 60 patients who participated in the study, 68% of them were males and the mean  $\pm$  SD of their age was 69.9  $\pm$  4.3 and 67.8  $\pm$  6.7 years for the study and control groups, respectively. There were no statistically significant differences between the two groups with respect to their sociodemographic characteristics as shown in Table 2.

ZBI score for both groups was about 61 (that represents sever burden) and there were no statistically significant differences between the 2 groups with respect to their ZBI score and the QoL-AD score that was completed by the patient (QoL-AD patient) as illustrated in Table 3. Scores of both ZBI and QoL-AD that were completed by the caregiver significantly improved after the 3 months of the initial assessment in the study group compared to the control group as presented in Table 4 and Figure 2.

Table 5 illustrates the analysis of predictors for the effectiveness of the psychoeducational program in which

multiple logistic regression model has been conducted to find significant predictors for ZBI categories (improved or not improved). The variables (predictors) that entered the model were study group and pre QoL-CG and shows that the group of caregivers who received the psychoeducational program showed 14 times more improvement in their ZBI score than who did not receive it.

## Discussion

This study focused on teaching the caregivers how to deal with the behavioral and psychological symptoms of patients with dementia that are considered the most burdensome symptoms and the most common causes of institutionalization,<sup>10</sup> and provides evidence of support for the short-term effectiveness of the psychoeducational program in improving caregiver's perceived burden, and it was consistent with another study that aimed to reduce of Alzheimer caregivers' burden, depressive and anxious symptoms.<sup>22</sup>

Overall, we found that ZBI score in the study group decreased significantly after the psychoeducational program from 61  $\pm$  13.7 to 55  $\pm$  9.2 (with a mean change score of -8.4  $\pm$  8) that is consistent with another study that was

**Table 2.** Comparison of the Patient's Sociodemographic Data Between the Study Group and the Control Group.

Sociodemographic data	Study group	Control group	Total (n (%))	P-value
Age (mean $\pm$ SD)	69.9 $\pm$ 4.3	67.8 $\pm$ 6.7		.296*
Gender				
Male (n (%))	20 (66.7%)	21 (70%)	41 (68.3%)	.781**
Female (n (%))	10 (33.3%)	9 (30%)	19 (31.7%)	
Marital status				
Married (n (%))	17 (56.7%)	20 (66.7%)	37 (61.7%)	.789
Divorced (n (%))	1 (3.3%)	1 (3.3%)	2 (3.3%)	
Widowed (n (%))	12 (40%)	9 (30%)	21 (35%)	
Previous occupation				
Irregular work (n (%))	10 (33.3%)	9 (30%)	19 (31.7%)	.806
Manual working (n (%))	9 (30%)	12 (40%)	21 (35%)	
Professional (n (%))	11 (36.6%)	9 (30%)	20 (33.3%)	

\*Student's t-test.

\*\*Chi square test.

**Table 3.** Comparison Between the Study Group and the Control Group Regarding Caregiver's Burden and Patient's Quality of Life Before Intervention.

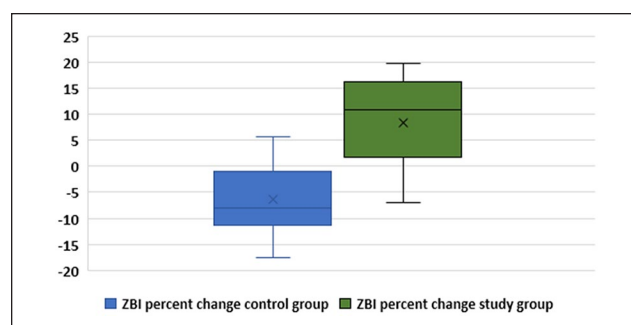
Measures	Study group	Control group	P-value
ZBI score			
Mean $\pm$ SD	61 $\pm$ 13.7	60.9 $\pm$ 10	.912
QoL-AD patient			
Mean $\pm$ SD	20.9 $\pm$ 5.2	18.3 $\pm$ 5.7	.257
QoL-AD caregiver			
Mean $\pm$ SD	15.6 $\pm$ 1.1	13.4 $\pm$ 2.4	<.001

**Table 4.** Comparison Between the Study Group and the Control Group Regarding Caregiver's Burden and Patient's Quality of Life After 3 months of the Initial Assessment.

Measures	Study group	Control group	P-value
ZBI score			
Mean $\pm$ SD	55 $\pm$ 9.2	64.3 $\pm$ 7.8	<.001
QoL-AD patient			
Mean $\pm$ SD	20.9 $\pm$ 5.2	18.3 $\pm$ 5.7	.257
QoL-AD caregiver			
Mean $\pm$ SD	16.5 $\pm$ 1.5	13.4 $\pm$ 2.4	<.001

conducted in Spain in which ZBI score decreased significantly from 62  $\pm$  14.9 to 54  $\pm$  15.9 (with a mean change score of  $-8.1 \pm 17.3$ ).<sup>10</sup> This improvement in caregiver burden was also supported by a review that focused on the psychological ingredients in many effective caregiver interventions in RCTs in the past 5-6 years.<sup>5</sup>

On the other hand, the scores of the ZBI of the control group after the psychoeducational program increased significantly from 60.9  $\pm$  10 to 64.3  $\pm$  7.8 (with a mean change score of 6.42  $\pm$  6.77); this increase in burden was higher than the increase in the burden of the control group in

**Figure 2.** Percent change in the ZBI score between the study group and the control group regarding the ZBI score after 3 months of the initial assessment.**Table 5.** Predictors of ZBI Score.

Predictor	P-value	Adjusted OR	95% CI for adjusted OR
Study group	.001	14.5	3.1–67.8
Pre-QOL-CG	.838	1	0.7–1.4
Constant	.761	0.4	

another study<sup>10</sup> in which it increased slightly from 58.4  $\pm$  15.9 to 60.5  $\pm$  16.6 (with a mean change score of 2.1  $\pm$  16.5). This difference may reflect the need of our community's caregivers for those kinds of caregiver interventions.

The sociodemographic characteristics of the study sample correlate well with those found in other studies in this field in Egypt; that fact may allow us to suppose that our results may be applicable in general to the dementia caregiver population in Egypt.

In this study the mean age of PWD is 69.9  $\pm$  4.3 in the SG and 67.7  $\pm$  6.7 in the CG which is almost similar to



another study<sup>6</sup> in which mean age was  $70.70 \pm 6.23$  that can be explained that the increasing age is the greatest risk factor for developing Alzheimer's dementia, but it was lower than the mean age in another study that was conducted on 57 caregivers in Taiwan, Japan which was 77 years and this can be explained by the higher life expectancy in the developed countries.<sup>23</sup>

Among the studied population, female caregivers outnumbered male ones (80%) that was almost similar to the female percentage in another study that took place in 2 randomly selected villages of Shebin El-Kom Menoufiya, Egypt.<sup>6</sup> The explanation of this is that in the Egyptian culture females (mother, wife, or daughter) are responsible for providing full-time care to family members who are suffering from either psychiatric or physical disorder.<sup>24</sup> So, different culturally sensitive support programs should be developed by social and health policies to be offered for families who have family members with dementia.

Illiteracy percentage in this study population was 25%, which is almost similar to another study in which the percentage is 28%,<sup>25</sup> and those percentages are consistent with a study by Egypt's Central Agency for Public Mobilization and Statistics (CAPMAS) published in 2017 which stated illiteracy at 20.1% in Egypt, or 14.3 million individuals, with women forming 9.1 million of the total number;<sup>26</sup> this also can be due to the site of the study as it was conducted in Cairo University Hospitals Outpatient Clinic which is a totally free-of-charge health care facility attracting patients from lower socioeconomic and educational levels.

This high illiteracy level and the improvement in the caregiver's perceived burden following the psychoeducational sessions suggest that the used program of face-to-face psychoeducation method with an additional video tool was very appropriate for the carers' educational level while more technically advanced methods as online tools and smart phone applications may be useful to a highly educated study population as what was done in another study that was done on 47 participants in the USA who were educated, and they reported feeling more confident in caregiving skills and communication with their family members.<sup>27</sup>

In this study as in many other studies, there is a consistently high level of family caregiver's perceived burden. Here, the mean ZBI score before the psychoeducational program of the study group was  $61 \pm 13.7$  and that of the control group was  $60.9 \pm 10$  which is considered a severe burden; in another study, the mean ZBI was  $50.77 \pm 13.90$ <sup>25</sup>; in another study, the majority of caregivers (63.9%) experienced severe burden with a mean score of  $35 \pm 14.1$ <sup>25</sup>; in another study that was conducted in Taiwan on 53 dementia caregivers, the mean score was  $41.79 \pm 12.24$ <sup>28</sup>; and in another study that was conducted in Spain, the mean ZBI score at baseline for study group was  $58.64 \pm 15.8$  and for the control group was  $61.42 \pm 15.83$ .<sup>10</sup> So, these differences in the average of the caregiver's perceived burden may be

explained by presence of different factors that affect caregiver's burden such as dementia symptoms especially neuropsychiatric symptoms, caregiver's age, health status, depression, presence of other responsibilities, etc.

The scores of QoL-AD questionnaires that was administered to the family caregivers of the study group showed significant improvement from  $15.6 \pm 1.1$  to  $16.5 \pm 1.5$  and that significant improvement did not occur in another study that was conducted in Brazil<sup>29</sup>; this difference can be explained by the fact that the psychoeducational program equipped carers with knowledge of the nature of dementia and provided them with effective methods to meet the demands placed on them.

### Study Limitation

There are some limitations to this study, which should be addressed in future research. First, the short duration of the program makes the long-lasting effects are unpredictable. Second, the small sample, since intervention studies with more significant samples may better evaluate the relation between the participation in psychoeducational groups and the decrease of burden level. Therefore, future research with a larger sample and over a longer period of follow-up may allow investigation of the possible relationships between the perceived benefits, the change and learning process of caregiving, and the intervention techniques applied. Third, all participants in this study belonged to a specific segment in the community, those who receive free governmental healthcare services so further investigation of this mode of family-centered intervention, with families from different socio-cultural backgrounds is recommended.

### Conclusion

These findings highlight the high prevalence of perceived burden among dementia caregivers that should be considered while developing a comprehensive dementia care program. The study provides evidence for the effectiveness of psychoeducational program in improving caregiver's perceived burden and suggests Including this program as an integral component of neuropsychiatric services provided to PWD and their informal caregivers, particularly those with evident perceived burden to decrease their burden, improve their healthy lifestyle, powering the coping skills and thus improve their QOL. This coupled with offering training opportunities to mental health professionals, psychologists, and nurses to ensure continuity of the program and maintain service quality.

### Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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## Ethical Consideration

The protocol of this study has been approved by the Faculty of Medicine, University of Cairo IRB (number D-37\_2019), and informed written consent was obtained from caregivers at the beginning of the study after full explanation of the nature of the study, benefits, and possible harm.

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