

**EFFECT OF DEMENTIA EDUCATIONAL PROGRAM ON FORMAL  
CAREGIVERS BURDEN IN ELDERLY HOMES.**

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## ABSTRACT

**Background:** Dementia disease is usually identified among older patients, but it is not a part of the normal aging process. The number of Dementia's patients in the Arab countries is increasing due to increased longevity and improvement in the health care system. This study aimed to assess the effect of an educational program on Formal Caregivers Burden in Elderly Homes.

**Methodology:** This study employed a quasi-experimental one-group pre-test-post-test design. The study was conducted in three elderly nursing private homes in Amman, Jordan using purposive sampling of 50 formal caregivers.

**Results:** Dementia patient's caregivers' burden was decreased after program implementation, with statistically significant between pre- post, and three months after program implementation ( $p < .001$ ). Findings demonstrated that the formal Dementia caregiver's education program can effectively decrease burden among caregivers.

**Recommendation:** Conducting continuing education program for Dementia patient's caregivers in the nursing homes to promote their practices and decrease their burden.

## INTRODUCTION

Dementia is a syndrome in which there is deterioration in cognitive function beyond what might be expected from the usual consequences of biological ageing (WHO, 2021). Dementia mainly affects older people with 55 million people worldwide are living with it. It is the seventh leading cause of death among older people globally. Dementia has multifactorial impacts not only to people affected by it but also for their carers, families and society at large. Signs and Symptoms of Dementia appeared in three stages: Early stage which may include forgetfulness, losing track of the time and becoming lost in familiar places; Middle stage which include becoming forgetful of recent events and people's names, becoming confused while at home, having increasing difficulty with communication, needing help with personal care, experiencing behaviour changes, including wandering and repeated questioning; and the Late stage is one of near total dependence and inactivity. Memory disturbances are serious and the physical signs and symptoms become more obvious and may include becoming unaware of the time and place, having difficulty recognizing relatives and friends, having an increasing need for assisted self-care, having difficulty walking and experiencing behaviour changes that may escalate and include aggression (WHO, 2021).

Dementia disease is usually identified in older patients, but it is not a part of the normal aging process. Memory problems are the first signs of cognitive impairment related to Dementia; the first symptoms of Dementia vary from patient to patient. For many, deterioration in non-memory aspects of cognition, such as word-finding and impaired reasoning or judgment, may indicate the very early stages of Dementia disease (National Institute on Aging, [NIH], 2018). Hence, the progression of Dementia can be very stressful for patients & caregivers. Caregivers may feel hopelessness when the patient's behavior changes or the patient no longer recognizes close family members (National Institute on Aging, 2018). Caring of Dementia patients has unique challenges; patients in the middle and last stages of the disease develop losses in judgment, orientation, and the ability to

communicate and understand as well as the personality and behavior of patients are affected.

Burden is the reaction resulting from an imbalance of care demands relative to the degree of dependence on caregivers, career development, emotional health, physical health and social relationships. Formal & informal caregivers must help Dementia patients to manage these changes, which are the most challenging for caregivers (Sarkar, 2015). Furthermore, studies have been made in Italy. Limongi, Noale, Bianchetti, Ferrara, Padovani, Scarpini, Trabucchi, & Maggi (2019) examined the tools used in Italy to diagnose mild cognitive impairment (MCI) with the use of questionnaire to describe how MCI is diagnosed in the Italian Centers for cognitive disorders and dementia (CCDD). Results revealed that multitude of instruments are being used to diagnose MCI with major differences in the clinical assessment of geriatricians and neurologists. 98.5% used the Mini Mental State Examination, 83.9%, the Clock Drawing Test and other neuropsychological, imaging and biomarker tests were utilized less frequently. With this, the authors recommend that standardized testing protocols, validated instruments and cut-off points need to be identified and adopted by the CCDDs for assessing MCI. Moreover, in the study conducted by Bonanni, Cagnin, Agosta, et al. (2017), Dementia with Lewy bodies (DLB) is the second most common neurological cause of dementia after Alzheimer's disease (AD). They have studied 572 national dementia centers to prepare an Italian large longitudinal cohort using a semi-structured questionnaire. Results revealed that 5624 patients with DLB are currently followed by the 135 centers in a year. DLB patients are lower than that of Alzheimer's disease and frontotemporal dementia. Majority or 91 % considered the clinical and neuropsychological assessments as the most relevant procedure for a DLB diagnosis. The most available diagnostic tool is MRI with 95 %. Researchers recommend to recruit a large harmonized Italian cohort of DLB patients for future cross-sectional and longitudinal multicentre studies.

**BACKGROUND:**

Globally, the burden of Dementia disease has increased in recent years. The long duration of Dementia before death affect significantly to the public health impact of the disease because Dementia patients spend most of their time in disability and dependence (Dementia Association, 2019). The burden of caregivers is often affected by the patient's behavioral and cognitive condition, hours involved in care, stress, availability of support resources, and caregiver characteristics (Rezq et al., 2020). Formal caregivers shape the daily lives of Dementia patients and play a vital role in the care provision (Squires et al., 2015). Formal caregiver in this study refer to the person who performs care for dementia patients in the elderly home.

Although the Family caregivers or unpaid care provider provide (80%) of the care for Dementia patients, the number of family caregivers is decreasing. There were seven caregivers for each elderly need assistance in 2010, while the number will drop to four for each one in 2030, which creates a higher demand for formal caregivers (Dementia Association, 2017). However, an increasing number of Dementia patients will increase the need for formal caregivers. Formal caregivers need to be increased from 3.27 million in 2014 to 4.56 million in 2024 (Squires et al., 2015). In the long-term setting, the significant challenges are to retain the care providers; the turnover rate ranges from 40% to well over 100%. Policy and procedures need to be reviewed in long term setting to keep the care-provider since the demand is increased in the community (Gilster et al., 2018).

In Jordan , the percentage of the elderly population will increase over the next coming years to a projected rate of 8.6% by the end of 2030 and 15.8% by the end of 2050 (National Council For Family Affairs, 2018), as well as, due to demographic changes in the family support system related to youth migration and women enter the labor force, there is an increased demand for formal care. However, there are no statistics available to establish the volume of the use of formal caregivers because such arrangements poorly documented. Long

term care needs related to older Dementia in Jordan tend to see as a family role or responsibility rather than governmental or societal responsibility. Moreover, Health care systems in Arab region have ignored the needs of elderly nursing homes. Charities or the private sector only initiate it. For example, In Egypt, there are 34 older adult homes for over one million older adults, and some homes have waiting lists for elderlies to be admitted in these homes (Abyad, 2015). While in Jordan, there are ten elderly nursing homes for over 500 thousand older adults, and these homes not a specialized unit for Dementia disease patients. The majority of the caregivers in these nursing homes are unqualified to provide dementia care, low paid, low status, no requirement for special education or training to be a caregiver, which affect negatively on the quality of care, caregivers' health, burden, and burnout (National Council For Family Affairs, 2018)

#### **Aim of the study:**

This study aimed to assess the effect of an educational program on Formal Caregivers Burden in Elderly Homes.

#### **Hypothesis:**

There will be a difference in Dementia formal caregivers burden test scores after implementation of the educational program compared to before.

### **METHODOLOGY**

#### **Design**

A quasi-experimental one-group pre-test-post-test with three months follow-up design was used.

**Setting:** This study was conducted in three elderly Private homes in Jordan. These homes were chosen because they represent the three largest homes in terms of the number of elderlies and caregivers.

#### **Sampling**

A purposive sample of 50 caregivers from elderly homes who fulfilled the inclusion criteria were included in the study. Inclusion criteria required participants to be working for at least 8 hours per day, five days per week, with at least three months' experience in their job. The data was collected within five months, from January 2019 to May 2019.

### **Tools of Data Collection:**

Data of this study was collected through two tools:

**First tool: Dementia Caregivers Demographic Characteristics questionnaire.** It includes eight questions related to gender, age, marital status, education level, experience, income, working hours, & daily patient load.

**Second tool: Dementia Caregiver Burden Scale.** It was developed by the researcher based on the Caregiver Burden Inventory (Novak and Guest, 1989). It includes 24-item measuring caregiver burden with 5 subscales: (a) degree of dependence on caregiver, which includes 5 items : (1) my care receiver needs my help most of the time,(2) my care receiver is completely dependent on me, (3) I have to constantly monitor my care receiver , (3) I have to help my care receiver with many basic functions (such as bathing and eating), (5) I don't have a minute's rest because I have many care receivers and daily tasks. (b) Career development, which includes 5 items: (1) I wish to find a job other than my current one, (2) I expected to be out of this place at this point in my life, (3) I can't keep this job for long, (4) I feel angry at my care receiver and their health, (5) I feel like I'm missing out on normal life. (c) Emotional health, which include 5 items, (1) I feel embarrassed because of my care receiver inappropriate behaviour in front of others, (2) I feel ashamed of them and their behaviour, (3) I feel bad about my care receivers and their health, (4) I feel uncomfortable when I tell my friends about my work, (5) I feel angry about my constant contact with patients. (d) Social relationship, which include 5 items: (1) I cannot communicate with my family members due to the nature of my work, (2) Others do not appreciate my work and nature, (3) I am facing

problems in my marriage and with my family members due to the nature of my work, (4) I can't do my errands at home and with others, (5) I can't socialize with others. Finally (e) Physical health, which include 4 items: (1) I don't get enough sleep because of my work, (2) my health is physically affected by work, (3) taking care of many care receivers physically exhausts me, (4) I'm physically tired now.

### **Scoring system:**

Each question has three points Likert scale with response choices ranging between Never (0), Sometimes (1), Always (2). Caregivers who got <50% were considered as having no burden at all, while those who got from 50 to <70% were considered as having moderate burden, and those who got >70% were considered as having severe burden. The scale was used before, immediately, and three months after the implementation of the program.

### **Validity & Reliability**

Five experts from the community health nursing department, were asked to check the tools for content validity, including clarity, wording, format, and overall appearance of the tools. Modifications were made according to the panel judges. The tool was tested for reliability using Cronbach's Alpha with score of 0.76.

### **Ethical considerations**

Approval to conduct the study was obtained from the general administration in each nursing homes after explanation the purpose of the study, data collection tools, and the educational program. The purpose of the study was explained to the participants by the researcher, stating the possibility to withdraw at any time. The researcher emphasized that participation in the study was entirely voluntary; written informed consent was obtained from each participant, by the researcher after explanation of the study objectives and procedures. Anonymity and confidentiality were assured through coding the data, participants were assured that all data

will not be reused in another research without taking the permission of the participants

## Procedures

### **Data collection:**

Data were collected before the educational program implementation, all caregivers completed informed consent, demographic characteristics, then the pretest conducted for assessment of caregiver's burden. Post-test had been conducted immediately and three months after the educational program implementation for all caregivers.

## Procedures

Upon receiving the formal approval to conduct the study, official permission was obtained from nursing homes to approve the fieldwork and collect data. The researcher explained the purpose and steps of the study to participants before the beginning of the study. Written consent was obtained from the caregivers who were included in the study. Dementia educational program for caregivers was developed through the following phases:

1. Assessment phase: assessment of caregivers' burden by using Dementia Caregiver Burden Scale. In this phase, the researcher met the caregivers' in the morning in a closed room in each elderly home. Caregivers were asked to fill out the tool in the same room during the day and the researcher remained with the caregivers while they were filling out the tools to ensure that all questions were answered and to be sure that there was no missing data, and to ensure an individualized response. -The time spent to fill the ranged between 15-20 minutes, then the researcher collected the questionnaires from each caregiver separately to check any unanswered or missed questions. The assessment phase took three weeks and the researcher visited each elderly home once/week.
2. Planning phase: based on the assessment results and comprehensive review of relevant literature, the researcher designed an educational program to decrease the level of burden among caregivers by increasing their knowledge, and improving their practices.

3. Implementation phase: in this phase, the program was implemented separately in each elderly home; The knowledge parts of the educational program were based on educating the caregivers about dementia including definition, risk factors, symptoms, stages, and methods of treatment and care. Regarding the practice part, participants were asked by the researcher about practices related to bathing, feeding, toileting, dressing, grooming, and communication. Feedback was given by the researcher. Videos were shown during this part with case scenarios demonstrations about correct practices. participants were educated also about the management of burden and stress related to caregiving through group discussions, power point presentations, and feedback. The duration of each session was about 30 minutes, the study sample in each setting was divided into three groups related to the availability of the caregivers on their time work hours, with the mean of 6 caregivers in each group. The program was implemented for each group in the same manner by the researcher. At the end of each session, the feedback was given to participants and learning moments were discussed with caregivers. The summary was given after each session. Educational aids were utilized as videos, power point presentations.
4. Evaluation phase: evaluating the effect of the educational program on burden of dementia patient's caregivers was done in this phase. The program effect was measured two times, immediately and three months after implementation of the program to evaluate the level of burden after the program.

### **Data Analysis**

Statistical Package for the Social Sciences (SPSS) program, version 20. Numerical data were expressed as means and standard deviations. Quantitative data were expressed as frequencies and percentages. Comparison between pre-test, post-test, and 3 months follow up test was done by using t-test and ANOVA.

## RESULTS

**Table (1): Frequency distribution of demographic characteristics of Dementia patients'**

Demographic characteristics		Frequency	%
Gender	Male	11	22
	Female	39	78
Age	20 - <30 years	18	36
	30 -<40 years	18	36
	40 -<50 years	7	14
	≥ 50 years	7	14
	<b>Mean ± SD</b>	<b>34.3±2.1</b>	
Marital Status	Single	23	46
	Married	25	50
	Divorced	1	2
	Widow	1	2
Educational level	High school	26	52
	Non- nursing Diploma	10	20
	Nursing diploma	6	12
	Bachelor degree (non-nursing)	8	16
Experience (Years)	1- <5 years	21	42
	5 -<10 years	18	36
	≥10 years	11	22
	<b>Mean ±SD</b>	<b>6.2±5.8</b>	
Working hours	8-12 hours	29	58
	>12 hours	21	42
Patient number (Assigned /day)	1	18	36
	2 - 4	5	10
	5 - 7	8	16
	>7	19	38
Income	Enough	19	38
	Enough & save	2	4
	Not enough	29	58

caregivers (n=50).

Table (1) shows that, 78% of caregivers were females, 36% aged from 30-40 years with a mean age  $34.3 \pm 2.1$  years. Also, this table reveals that 50% of the caregivers were married, 52% of the them completed high school education, 42% of caregivers had 1-5 years' experience with a mean year of experience  $6.2 \pm 5.8$  years. In addition, 58% of caregivers were working from 8-12 hours per day, and 38% of the caregivers were providing care for more than seven patients per day. Regarding the income, 58% of the caregivers reported that their income not enough, while 38% of them reported that their income was enough.

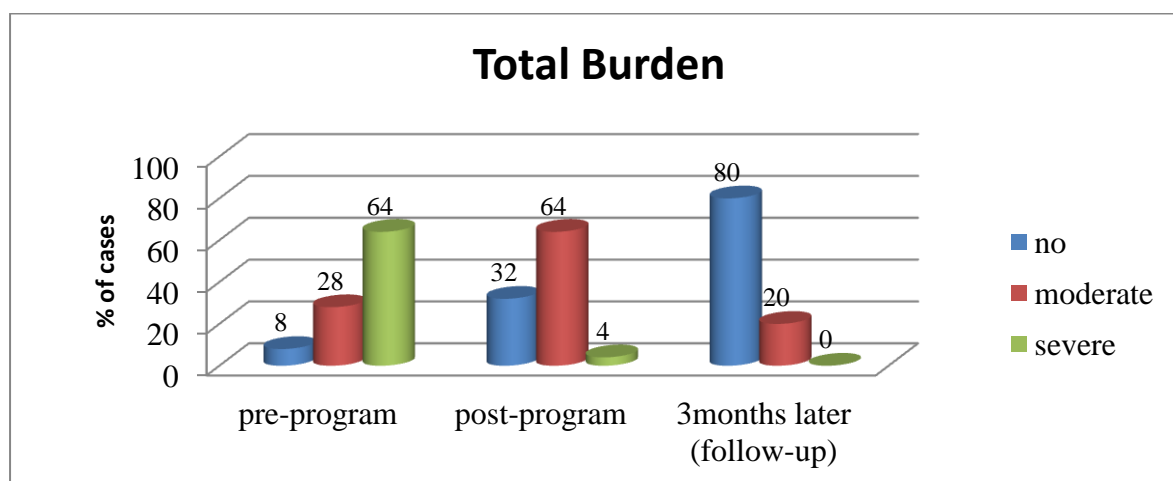
**Table (2): Total mean scores of Dementia patients' caregivers burden scores pre-post implementation of the education program and three months later (n=50).**

Burden items	Pre program		Post program		Follow up (3months later)		F test
	Mean	SD	Mean	SD	Mean	SD	P value
Degree of dependence	8.76	.960	7.44	1.091	6.08	1.576	83.726
Career development	7.44	1.981	5.68	1.942	4.26	2.423	.000**
Physical health	6.20	1.895	4.00	1.414	2.78	1.298	.000**
Emotional health	5.36	2.126	3.76	1.923	2.60	1.690	.000**
Social relationship	5.72	2.000	3.74	1.861	2.88	1.710	.000**
Total scores	33.4	6.45	24.62	6.05	18.60	5.95	.000**

F test = repeated measures ANOVA

\*\* statistically highly significant value<.001

Table (2) shows that, mean of burden items was decreased in post and follow up tests. There was improvement in caregivers burden scores, and this improvement was statistically highly significant after educational program implemented (p<.001)



**Figure (1):** Percentage distribution of Dementia patients' caregivers' level of burden pre-post and 3 months after implementation of education program (n=50).

Figure (1) shows that 64% of caregivers had severe burden before the implementation of program, while 32% and 80% respectively of caregivers had no burden immediately and three months after program implementation.

**Table (3): Correlation between Dementia patient’s caregivers’ demographic characteristics and total burden scores (n=50).**

Demographic characteristics	Total burden scores	P value
Gender	t=2.77	p=.008*
Age	f= .97	p=.42
Marital status	f=1.51	p=.23
Educational level	f=5.07	p=.004**
Years of experience	f=2.58	p=.011*
Working hours	t=8.43	p=.006**
Patient number (Assigned/day)	f=3.82	p=.006**
Income	f=.468	p=.68

\*\*correlation is statistically highly significant at the level of  $\leq .01$

\*correlation is statistically significant at the level of  $\leq .05$

Table (3) shows that a highly statistical correlation was found between caregivers’ total burden scores and caregivers’ educational level, working hours and patient number assigned /day. Also, a statistically significant correlation was found between caregivers’ total burden scores and their gender and years of experience.

## DISCUSSION

This study assessed the effect of an educational program on Formal Caregivers Burden in Elderly Homes employing a quasi-experimental one-group pre-test-post-test design in nursing private homes in Amman, Jordan among 50 formal caregivers. Overall, the study revealed that majority of the respondents are female, almost half of them are 18 years old, married, High school graduate, with 1 to <5 years of experience, working from 8 to 12 hours, caring for more than 7 patients, and not enough income (Table 1).

The current study revealed that nearly two- thirds of the caregivers had severe burden before program implementation, while nearly two- thirds had moderate burden immediately after program implementation, and more than three quarters had no burden three months after

program implementation (Figure 1), with a statistically significant difference of caregiver's total burden score before, immediately and three months after program implementation (Table2). These findings were supporting research hypothesis. This decreasing in burden level among caregivers after program indicated that intervention such as education & training maybe support them in their role and decrease their burden related to caregiving.

Previous results are congruent with a study done by Takizawa, Takahashi, Takai, Ikeda, and Miyaoka (2017) in Malaysia, he found that , individual coping skills improved in providing nursing care and reduced burden scores after training program. Another systematic review and meta-analysis of randomized controlled trials conducted by Jensen, Agbata, Canavan, and McCarthy (2015) revealed that educational programs have a positive effect on caregiver burden. In addition, Terayama et al. (2018) in Tokyo, Japan stated that after three months, burden was significantly decreased in the education group. Another study was done by Weigel (2018) in the USA indicating that implementation of the dementia caregiver training program resulted in decreased caregiver burden. These similarities in results suggested that receiving supportive intervention like education and training are needed to reduce the burden could have emanated from caregiving role.

Moreover, the present study results indicated a statistically significant correlation was found between caregivers' years of experience and burden of caregivers (See Table 3). The study findings are in agreement with a study conducted by Beinart, Weinman, Dementiae, and BrDementiay (2012) UK who mentioned that high levels of burden were associated with caregiver years of caregiving. And with another study conducted by Wan, Chan, Yap, and Khalaf (2019) in Malaysia who stated that years of experience were correlated with the high caregivers burden. This agreement in the study results maybe suggested that caregivers burden increased over the years of caregiving due to increase damage to the patient physical and mental health through the process of disease progression.

On the other hand, the results revealed that there is a statistically correlation between caregivers' gender and education level and the burden of Dementia patients' caregivers (See Table 3). This relationship may be due to diversity in caregivers' educational background, and more than three quarters were females. This finding agreed with a study done by Wan et al., (2019) in Malaysia which indicated that Caregivers' burden was correlated to caregivers' gender and educational background.

Regarding the working hours, the results revealed that a highly positive correlation between working hour and caregivers' burden (See Table 3). This results indicated that providing care for longer hours for Dementia patients may increase the caregiver burden. This finding is congruent with the study conducted by Terayama et al.,(2018), Japan which revealed that spending a large amount of time caring for the patients is a major cause a big burden for the caregivers.

Results of the current study indicated a highly statistically significant correlation between caregiver's burden and patients number assigned/day (See Table 3). This finding may be suggested that there is a shortage number of caregivers in nursing homes, maybe due to low income, poor work environment and works overload, which required more efforts at the governmental level to prepare more caregivers, improve work environment and decrease work overload. This finding was supported by the study done by Yakubu & Schutte( 2018), South Africa, who mentioned that work over load were correlated positively with physical heath and burden.

## **CONCLUSION:**

Based on the study results, it is therefore concluded that the level of burden among caregivers was decreased after the program, compared to prior the education program was given. The results show that the educational program for Dementia's patient caregivers had a positive effect on their burden.

## RECOMMENDATIONS:

Based on the study results, the following recommendations are suggested:

- Conduct continuing education program for Dementia patient's caregivers in the nursing homes to promote their knowledge and practices and decrease their burden.
- Conduct future studies on large sample of caregivers of Dementia patients in different settings in the community to assess their need and improve their care with patients.

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