Effect of Dementia Education 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. The purpose of the current study was to assess the impact of an educational program on Dementia patients' caregivers’ burden.

Methodology: This study employed a quasi-experimental one-group pre-test-post-test design. The study was conducted in three elderly nursing 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. Formal & informal caregivers must help Dementia patients to manage these changes, which are the most challenging for caregivers (Sarkar, 2015).

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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. Formal caregivers shape the daily lives of Dementia patients and play a vital role in the care provision (Squires et al., 2015).

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

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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:

The study aimed to assess the impact of an educational program on a burden of Dementia formal caregivers.

Hypothesis:

Dementia formal caregivers burden scores will be decreased after implementation of the educational program.

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 homes in Jordan. These homes were selected randomly.

Sampling

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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 5 subscales: (1) degree of dependence on caregiver. (2) Career development. (3) Emotional health. (4) Social relationship. (5) Physical health.

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.

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Modifications were made according to the panel judges. The tool was tested for reliability using Cronbach's Alpha with score of 0.76.

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.

The time spent to fill the questionnaires ranged between 10-15 minutes (pre and post-test). The program was implemented separately in each elderly home. The study sample was divided into three groups based on the availability of the caregivers, with the mean of 6 caregivers in each group. The duration of each session was about 30 minutes. Teaching methods and media included were group discussions, videos, case scenarios, and power point presentations. The program was implemented on 4 sessions from the first of January 2019 to the end of January 2019.

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' caregivers (n=50).

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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
	Mean + SD	***34.3+2.1***	
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
	Mean +SD	***6.2+ 5.8***	
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

Table (1) shows that, 78% of caregivers were females, 36% aged from 30-40 years with a mean age 34.3+ 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+.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

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Degree of dependence	8.76	.960	7.44	1.091	6.08	1.576	83.726 .000**
Career development	7.44	1.981	5.68	1.942	4.26	2.423	91.730 .000**
Physical health	6.20	1.895	4.00	1.414	2.78	1.298	106.989 .000**
Emotional health	5.36	2.126	3.76	1.923	2.60	1.690	60.865 .000**
Social relationship	5.72	2.000	3.74	1.861	2.88	1.710	65.538 .000**
Total scores	33.4	6.45	24.62	6.05	18.60	5.95	254.483 .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)

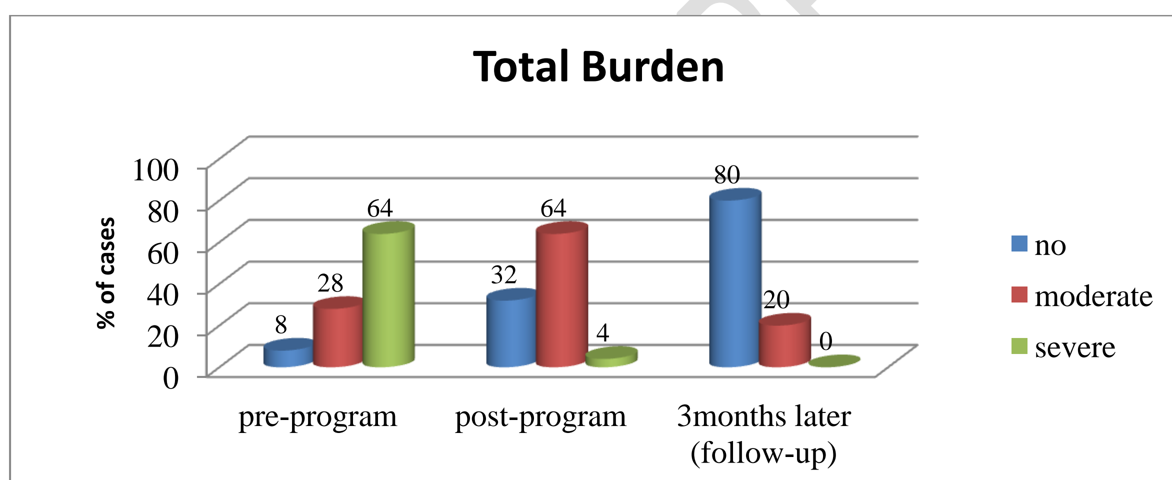

Figure (1): Percentage distribution of Dementia patients' caregivers' level of burden pre-post and 3 months after implementation of education program (n=50).

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	P value

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	scores	
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 ≤.01
*correlation is statistically significant at the level of ≤.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

The results of the current study indicated that two-third of the study sample aged less than 40 years with mean age of 34.34± 2.06years old, more than three- quarters were females and half of them were married, and more than half of caregivers completed high school (See Table 1). These findings are in agreement with Martins et al. (2019), Brazil, who stated that two- third of formal caregivers age is less than 40 years old, more than three quarters of them were females, more than half of them were married and completed high school. These similarities in results may be due to the similarity of type of sample and type of setting. Furthermore, more than two- third of the caregivers in the present study had less than 10 years of experience with a mean of 6.24+ 5.79 years, more than half of them worked from 8-12 hours per day (Table1). These findings are congruent with Ibrahim & El-Lassy (2017), Egypt, and El-kattan, El-Afandy and El-Fatah (2017), Egypt, who revealed that more than half of formal caregivers had less than 10 years of experience.

The present study informed that more than half of caregivers' monthly income was not enough and more than one third of caregivers provided daily care for more than seven

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patient /day (Table1). These findings are supported by a study done by Warshaw & Bragg (2014) at the USA and found that most of the formal caregivers receive minimum salaries and need to improve the work environment and decrease daily work load. Also, Martins et. al.,(2019), Brazil, mentioned that, the majority of the formal caregivers receive minimum salaries.

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. Ain 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.

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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, WDementiae, 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

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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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