



# **EFFECT OF EDUCATIONAL PROGRAM TO IMPROVE PSYCHOLOGICAL WELL-BEING IN A SAMPLE OF EGYPTIAN CAREGIVERS FOR ELDERLY PATIENTS WITH DEMENTIA**

*Thesis*

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تأثير البرنامج التعليمي للارتقاء بالسلامة النفسية في  
عينة من مقدمي الرعاية المصريين للمرضى الذين  
يعانون من اليمينشيا

رسالة

توطئة للحصول علي درجة الدكتوراة في طب وصحة المسنين وعلوم الاعمار  
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٢٠١٨

## رؤية الكلية

تصبو كلية الطب جامعة عين شمس إلى الريادة الإقليمية والشراسة العالمية فى التعليم الطبى والبحث العلمى للإرتقاء بصحة المجتمع

## رسالة الكلية

تقوم كلية الطب جامعة عين شمس بإعداد طبيب مدرب ذو مهارة تنافسية على المستوى المحلى والإقليمى، وقادر على التدريس و التعلم والتدرب مدى الحياة وملتزم بمعايير الخدمة الطبية والأخلاق المهنية، وتدعم الكلية التطوير المستمر للبرامج والمقررات والبحث العلمى مع الحرص على التوسع فى الأبحاث العلمية التطبيقية وبرامج الرعاية الصحية لخدمة إحتياجات المجتمع وتنمية البيئة".

بِسْمِ اللَّهِ الرَّحْمَنِ الرَّحِيمِ

قالوا

سبحانك لا علم لنا  
إلا ما علمتنا إنك أنت  
العليم العظيم

صدق الله العظيم

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## ***Dedication***

***Dedicated to those who inspired me  
throughout my whole life  
to my family & to my Husband  
Ahmad for his endless  
patience and support***

## **CONTENTS**

<b>Subjects</b>	<b>Page</b>
• List of Abbreviations .....	I
• List of tables .....	III
• List of Figures .....	IV
• Introduction .....	1
• Aim of the Work.....	7
• Review of literature: .....	
Chapter 1: Dementia.....	8
Chapter 2: Caregivers of demented patients .....	25
Chapter 3: Chapter (3): The educational program for caregivers.....	56
• Patients And Methods.....	61
• Results.....	98
• Discussion .....	114
• Summary .....	126
• Conclusion .....	129
• Recommendations .....	130
• References .....	134
• Appendix .....	174
• Arabic Summary .....	-

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## LIST OF ABBREVIATIONS

<b>AARP</b>	: American association of retired persons
<b>AD</b>	: Alzheimer's Disease
<b>ADI</b>	: Alzheimer disease international
<b>ADL</b>	: Activities of Daily Living
<b>A<math>\beta</math> plaques</b>	: Beta amyloid plaques
<b>CB</b>	: Caregiver Burden
<b>ChEIs</b>	: Choline esterase inhibitors
<b>CR</b>	: Care recipient
<b>CSDD</b>	: Cornell Scale for depression in dementia
<b>DLB</b>	: Dementia with Lewy Bodies
<b>DSM-IV</b>	: Diagnostic and Statistical Manual of Mental Disorders-IV
<b>DSM-V</b>	: Diagnostic and Statistical Manual of Mental Disorders-V
<b>EDHS</b>	: Egypt demographic and health survey
<b>FTD</b>	: Frontotemporal Dementia
<b>GBD</b>	: Global burden of disease
<b>GDS</b>	: Geriatrics Depression scale
<b>GHQ-12</b>	: 12 item General Health Questionnaire
<b>HDRS</b>	: Hamilton Depression Rating Scale
<b>HRQoL</b>	: Health related quality of life
<b>IADL</b>	: Instrumental Activities of Daily living
<b>ICD 10</b>	: International Classification of Diseases-10
<b>IWG</b>	: the International Working Group
<b>LTCF</b>	: Long-term care facility
<b>MCI</b>	: Mild Cognitive Impairment
<b>MMSE</b>	: Mini Mental Status Examination
<b>NAC</b>	: National alliance for caregiving
<b>NCD</b>	: Neuro-Cognitive Disorders
<b>NIA-AA WG</b>	: National Institute on Aging and the Alzheimer's Association Working Group
<b>PWD</b>	: Person with dementia
<b>PWD</b>	: Person with dementia
<b>S</b>	: Standard



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## *List of Abbreviations*

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<b>SPAS</b>	: Spell Perger Anxiety Scale
<b>VaD</b>	: Vascular Dementia
<b>ZBI</b>	: Zarit Burden Interview

## LIST OF TABLES

<b>Tab. No.</b>	<b>Subject</b>	<b>Page</b>
<b>Table (1)</b>	Descriptive analysis of demographic data for caregivers	99
<b>Table (2)</b>	Comparison between the two groups as regards demographic data for patients	101
<b>Table (3)</b>	Comparison analysis between group 1 of caregivers'(who received the educational program) as regard pre and post- test	102
<b>Table (4)</b>	Comparison between the two groups as regard 12 item general health questionnaire, and comparison within each group (1&2) pre and post training program	103
<b>Table (5)</b>	Comparison between the two groups as regard Hamilton depression rating scale, and comparison within each group (1&2) pre and post training program	104
<b>Table (6)</b>	Comparison between the 2 groups as regard Zarit Burden Interview(ZBI)	106
<b>Table (7a)</b>	Comparison between the 2 groups as regard Spill Berger Anxiety State Scale:	107
<b>Table (7b)</b>	Comparison between the 2 groups as regard Spill Berger Anxiety trait	108
<b>Table (8)</b>	Comparison between patients of the 2 groups of caregivers as regard Cornell Scale for depression in dementia (CSDD):	109
<b>Table (9)</b>	Comparison between the patients of the two groups of caregivers as regard Mini Mental State Examination (MMSE)	110
<b>Table (10)</b>	Correlation between patients Mini Mental State Examination (MMSE) and Zarit Burden Interview (ZBI) for caregivers	111
<b>Table (11)</b>	Correlation between patients MMSE and 12 item general health questionnaire for caregivers	112
<b>Table (12)</b>	Correlation between patients Mini Mental State Examination ( MMSE) and Spillperger Anxiety Scale	112
<b>Table (13)</b>	Correlation between patients Mini Mental State Examination( MMSE) and Hamilton Depression Rating Scale(HDRS)	113

## LIST OF FIGURES

<i>Fig. No.</i>	<i>Subject</i>	<i>Page</i>
<b>Fig. (1)</b>	The pre and post test	102
<b>Fig. (2)</b>	Comparison between the two groups of caregivers as regard 12 item general health questionnaire	103
<b>Fig. (3)</b>	Comparison between the two groups as regard Hamilton depression rating scale	105
<b>Fig. (4)</b>	Comparison between the two groups as regard Zarit Burden Interview	106
<b>Fig. (5a)</b>	Comparison between the 2 groups as regard Spill Berger Anxiety State Scale	107
<b>Fig. (5b)</b>	Comparison between the 2 groups as regard Spill Berger Anxiety Trait Scale	108

## Abstract

**Background:** Most people with dementia live at home supported mainly by family carers. These carers frequently develop psychological problems, which affect their quality of life.

**Objectives:** We aimed to assess effectiveness of caregiver training program on relieving psychological problems (stress) of Egyptian caregivers of elderly patients with dementia, and the impact on patients also.

**Methods:**

**Study design:** A prospective cohort study.

**Participants:** One Hundred of caregivers of elderly demented patients, were recruited from the outpatient clinics of Abbasia psychiatric Health Hospital, and were divided into two groups:

1st group: who received the educational program and were assessed pre and post the training program. Caregivers stress, depression, anxiety and burden were measured using validated scales (12 item General Health Questionnaire, Hamilton Depression Rating Scale, Spell-Berger Anxiety Scale and Zarit Burden Interview).

2<sup>nd</sup> group: who did not receive the program but were only assessed as the first group.

The training program consists of five individual sessions over five weeks for each subgroup (and reassessment after one month from the training), aiming at education of caregivers of dementia patients how to deal with troubling behaviors and how to communicate with the patient.

Results: Training program for caregivers of patients with dementia significantly reduces caregiver burden, depression, anxiety and stress (for caregivers) but no obvious effect on-patients.

**Conclusion:** The training program for caregivers of demented patients can, improve family-carers' burden, stress and quality of life, and should therefore be widely applied.

Keywords: Caregivers; training; intervention; dementia; elderly; quality of life; psychological wellbeing.

## INTRODUCTION

Dementia is a clinical syndrome characterized by progressive deterioration in cognitive function which is severe enough to interfere with daily functioning. This impairment in cognition is commonly associated with deterioration in emotional control, social behavior, or motivation (*Prince et al., 2013*).

In the elderly, as regards to dementia multiple pathologies contribute, including changes commonly seen in Alzheimer disease, dementia with Lowy bodies, also vascular changes. Comorbid factors, such as depression, delirium and polypharmacy can contribute to cognitive decline (*Lo Giudice & Watson ., 2014*).

There were an estimated 35million people with Alzheimer's disease and other dementias worldwide in 2010. This number will increase with an ageing world population and will reach 66 million by the year 2030 and 115 million by 2050. The main increase will take place in low income and middle income countries, where more than 70% of the people with dementia will live by 2050 (*Wortmann ., 2012*).

According to the Global Burden of Disease (GBD) estimates from the 2003 World Health Report, dementia contributed to 11.2% of the (Years of life in disability) in people aged 60 years and older. This is more than stroke (9.5%), musculoskeletal disorders (8.9%), cardiovascular

disease (5.0%), and all forms of cancer (2.4%) (**Park, Fredman, Hochberg & Faulkner., 2009**).

Dementia is the most common disorder which requires informal care giving, a need likely to increase as the prevalence of dementia increases. Compared to caring for persons with other illnesses, dementia care-giving is particularly challenging due to the duration of illness, the prevalence of behavioral disturbances, the rapid progression of the disease and the degree of functional dependence (**Givens, Mezzacappa, Heeren, Yaffe & Fredman., 2014**).

The person with dementia commonly experiences behavioral and psychological symptoms of dementia that may cause much distress, including to families and caregivers (**LoGiudice & Watson., 2014**).

People with dementia generally require high levels of care, most of which is provided by informal or family caregivers. Without caregivers, people with dementia would have a poorer quality of life, poor prognosis of the disease and would need institutional care more quickly (**Givens et al., 2014**).

Two-thirds of people with dementia live at home, with their family providing most of their care. About 40% of family carers of people with dementia have clinical depression or anxiety; others have substantial psychological symptoms ( **Cooper, Balamurali & Livingston., 2007**).

Caring for a person with dementia requires several challenges. Caregivers must provide increasing supervision and personal care as the person with dementia becomes more functionally dependent. Caregivers must learn to manage behavioral disturbances, personality changes, and the loss of the ability to communicate effectively with their loved one. As dementia progresses, caregivers experience increasing strain and burnout, depression, anxiety, disruptions in employment, and depleted finances (**Lee, Kawachi & Grodstein., 2004**).

Family caregivers of people with dementia, often called the invisible second patients, are critical to the quality of life of the care recipients. The effects of being a family caregiver are generally negative, with high rates of burden and psychological morbidity as well as social isolation, physical ill-health, and financial hardships (**Brodaty & Donkin., 2009**).

Caregivers face many obstacles as they balance caregiving with other demands, including child rearing, career, and relationships. They are at increased risk for burden, stress, depression, anxiety and a variety of other health complications. The effects on caregivers are diverse and complex, and there are many other factors that may exacerbate or ameliorate how caregivers react and feel as a result of their role. Numerous studies report that caring for a person with dementia is more stressful than caring for a