بسم الله الرحمن الرحيم

MONA MAGHRABY

شبكة المعلومات الجامعية

التوثيق الالكتروني والميكروفيلم

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شبكة المعلومات الجامعية

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جامعة عين شمس

التوثيق الإلكتروني والميكروفيلم

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MONA MAGHRABY

Caregivers' Perspectives towards Goals of Care in Dementia Patients

Thesis

Submitted for Partial Fulfillment of Master Degree in ***Geriatrics and Gerontology***

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List of Contents

Title	Page No.

List of Tables ..... **i**

List of Figures ..... **iv**

List of Abbreviations ..... **v**

Introduction **1**

Aim of the Work **3**

- Dementia and Its Burden on Patients 4
- Burden of Dementia on Caregivers 24
- Caregivers' Perspectives Towards Goals of Care of Dementia Patients 36

Subjects and Methods **47**

Results **58**

Discussion **96**

Summary **119**

Conclusion **125**

Recommendations **126**

References **127**

Appendices **162**

Arabic Summary **١**

List of Tables

Table No.	Title	Page No.

Table (1): Socio-demographic data of dementia patients: 58

Table (2): Patients' Smoking status, Medical conditions, and dementia related problems: 59

Table (3): Cognitive and Functional assessment of patients: 60

Table (4): Dementia history of patients:..... 61

Table (5): Socio-demographic data of caregivers: 62

Table (6): Burden of care-giving & Caregivers' knowledge regarding disease progression and required care: 63

Table (7): Caregiver's knowledge score:..... 65

Table (8): Caregiver's attitude towards disease progression and related goals of care: 66

Table (9): Caregiver's attitude score: 67

Table (10): Caregivers' perspectives towards goals of care: ... 68

Table (11): Relation between caregiver's education and caregiver's knowledge regarding disease progression and required care: 70

Table (12): Relation between caregiver's education and burden of caregiving for dementia patients:..... 71

Table (13): Relation between caregiver's education and caregiver's attitude towards disease progression and care goals:..... 72

Table (14): Relation between caregiver's education and caregiver's goals of care: 74

Table (15): Relation between caregiver's education and their perspectives towards care at end of life issues: 76

List of Tables (Cont...)

Table No.	Title	Page No.
Table (16):	Relation between caregiver's relation with patient and caregiver's knowledge regarding disease progression and required care:	77
Table (17):	Relation between caregiver's relation with patient and burden of caregiving for dementia patients:	78
Table (18):	Relation between caregiver's relation with patient and caregiver's attitude towards disease progression and goals of care:	79
Table (19):	Relation between caregiver's relation and caregiver's goals of care:	82
Table (20):	Relation between caregiver's relation with patient and their perspectives towards care at end of life stages:	83
Table (21):	Relation between caregiving time and caregiver's knowledge regarding disease progression and required care:	84
Table (22):	Relation between caregiving time and burden of caregiving for dementia patients:	85
Table (23):	Relation between caregiving time and caregiver's attitude towards disease progression and goals of care:	86
Table (24):	Relation between caregiving time and caregiver's goals of care:	88
Table (25):	Relation between caregiving time and caregivers' perspectives towards care at end of life issues:	89
Table (26):	Relation between duration of dementia diagnosis and caregiver's knowledge regarding disease progression and required care:	90

List of Tables (Cont...)

Table No.	Title	Page No.
Table (27):	Relation between duration of diagnosis and burden of caregiving for dementia patients:	91
Table (28):	Relation between duration of diagnosis and caregiver's attitude towards disease progression and goals of care:	92
Table (29):	Relation between duration of diagnosis and caregiver's goals of care:	94
Table (30):	Relation between duration since diagnosis of dementia and end of life issues:	95

List of Figures

Fig. No.	Title	Page No.

Figure (1): Time line of the thesis.....57

List of Abbreviations

Abb.	Full term
ACP	*Advance care planning*
AD	*Alzheimer's dementia*
ADL	*Activities of daily living*
AGS	*American Geriatrics Society*
AIDS	*Acquired immunodeficiency syndrome*
BPSD	*Behavioral and Psychological Symptoms of Dementia*
COPD	*Chronic Obstructive Pulmonary Disease*
CPR	*Cardiopulmonary resuscitation*
DLB	*Dementia with Lewy bodies*
DNR	*Do not resuscitate*
DSM	*Diagnostic and statistical manual of mental disorders-5*
EAPC	*European Association for Palliative Care*
EDS	*Excessive daytime sleepiness*
EoL	*End-of-life*
FPS	*Faces Pain Scale*
FTLD	*Fronto Temporal Lobar Dementia*
GDS	*Global Deterioration Scale*
I-ADL	*Instrumental activities daily living ADL*
ICD	*International Classification of Diseases*
ICU	*Intensive care unit*
M	*Mean*
MCI	*Mild cognitive impairment*
MMSE	*Mini-Mental State Examination*
NG	*Nasogastric*
NPS	*Neuropsychiatric symptoms*
P-ADL	*Personal activities daily living*

List of Abbreviations (Cont...)

Abb.	Full term

PEG ..... *Percutaneous endoscopic gastrostomy*
PLMS ..... *Periodic limb movement of sleep*
RBD ..... *REM behavioral disorder*
REM..... *Rapid Eye Movement*
RLS..... *Restless leg syndrome*
SD..... *Standard deviation*
SDB ..... *Sleep disordered breathing*
SPSS..... *Statistical Package of Social Science*
VAS..... *Visual Analog Scale*

INTRODUCTION

The prevalence of dementia in Egypt ranged from 2.01% to 5.07%. With the growing prevalence of dementia worldwide, two-third of the people with dementia are projected to be from the developing countries by 2050 ***(Elshahidi et al., 2017).***

In United States (US), 5.8 million Americans aged 65 and older are living with Alzheimer's dementia. Eighty percent aged 75 or older. It's the sixth leading cause of death in the US and the fifth leading cause of death among Americans age ≥65 years ***(Alzheimer's Association, 2019).***

Compared with caregivers of people with non-dementing illnesses, caregivers of people with dementia may be less able to cope with increased stressors as they have twice the rates of substantial financial, emotional and physical difficulties associated with caregiving ***(Freedman & Spillman, 2014).***

In 2018, dementia patients' caregivers reported nearly twice the average out-of-pocket costs (e.g., medical, personal care and household expenses for the person with dementia; personal expenses and respite services for the caregiver) of non-dementia patients' caregivers ($11,233 versus $6075) ***(Rainville et al., 2016).***

Patients' severity of dementia, behavioral disturbances, extent of personality change, cultural values, the relationship with the person with dementia, duration of caregiving as well as the presence of psychiatric symptoms were the main patient‐related factors contributing to caregiver burden ***(Van der Lee et al., 2014).***

Dementia caregivers are at an increased risk of various health problems including cardiovascular problems, lower immunity, poorer immune response to vaccine, slower wound healing, higher levels of chronic conditions, decreased engagement in preventative health behaviors such as exercise, and greater likelihood of smoking, drinking alcohol, and poor sleep patterns ***(Schulz & Martire, 2004).***

Caregivers who are heavily burdened may opt for institutionalization of the relative as a role exit which in fact is associated with increased feelings of burden and depression in some caregivers following placement ***(Schulz et al., 2004).***

As we head into the "dementia tsunami," the burden on the health and social care system will be escalated unless family caregivers are properly supported ***(Cheng, 2017).***