

## Relationship between Care Burden and Psychological Resilience among Family Caregivers of Patients with Dementia

Salma Bakry Attia Ali, Ghada Mohamed Mourad<sup>1</sup>, Hoda Sayed Mohamed<sup>3</sup>

Demonstrator of Psychiatric/Mental Health Nursing<sup>1</sup>, Professor of Psychiatric/Mental Health Nursing<sup>2</sup>, and Doctor of Psychiatric/Mental Health Nursing<sup>3</sup>, Faculty of Nursing Ain Shams University.

### Abstract

**Background:** Dementia is a serious disease that involves progressive losses of cognition, memory, and social function. The burden of dementia is not limited to patients, it also affects the caregiver's psychological resilience among family caregivers effect on the level of burden they experienced. **Aim:** Assess relationship between Care burden and Psychological resilience among Family Caregivers of Patients with Dementia. **Design:** descriptive explorative research design was utilized in this study. **Subjects and Methods:** This study was conducted on 100 family caregivers of patients with dementia at memory clinic at the institute Al Yassin Specialized Medical Hospital affiliated to the Al-Baqiyat Al-Salihah Foundation, for Dr. Abla Al-Kahlawi. **Data collection Tools:** data were collected through: three tools; Interview questionnaire, Burden interview scale, Caregiver Resilience Scale. **Results:** the majority of the studied family caregivers had Moderate levels of Psychological Resilience. While eight of percentage of them had high levels of Psychological Resilience and only three of percentage of the studied family caregivers of patients with dementia had mild levels of Psychological Resilience. Also, more than two fifths of the studied family caregivers had severe level of total burden, and more than one third of the studied family caregivers had moderate level of total burden. While, less than one quarter of them had mild level of total burden. **Conclusion:** This study concluded that, more than four fifths of the studied family caregivers had Moderate levels of Psychological Resilience. While eight of percentage of them had high levels of Psychological Resilience and only three of percentage of the studied family caregivers of patients with dementia had mild levels of Psychological Resilience. Also, more than two fifths of the studied family caregivers had severe level of total burden. and more than one third of the studied family caregivers had moderate level of total burden. While, less than one quarter of them had mild level of total burden. Also, there were highly significant negative correlation between caregiver psychological resilience and their burden levels among family caregivers of patient with dementia. **Recommendations:** Establishment of counseling program for family caregivers of patients with dementia to improve psychosocial wellbeing, psychological resilience and reduce feeling of care burden.

**Key words:** Dementia, family caregivers ,care burden, Psychological Resilience.

### Introduction

**Dementia** is a serious disease that involves progressive losses of cognition, memory, and social function (Alfakhri et al., 2018). The number of aging people with dementia is increasing rapidly

worldwide, and the World Health Organization (WHO) has estimated that the current worldwide number of 35.6 million dementia patients will increase 2 times by 2030 and more than 3 times by 2050 (Dove & Astell, 2017).

Caring at home for a family member living with dementia is known to incur considerable demands. The daily challenges include supervision, managing the impact of the changes experienced by the person with dementia and coping with the changes that occur in relationships. (Roberts, E., & et al, 2018).

**The family caregivers** involved in caregiving experience high levels of burden, poor physical health and social isolation. Furthermore, evidence suggests that levels of burden increase over time, as the changes

arising from dementia progress and become wide ranging in their effect and impact upon the person living with dementia. **(Kim, B., Noh, G.O. & Kim, K.(2021).**

Studies suggest that the care burden is linked to the fact that family Caregivers of patients with dementia provide more care work in hours per week and assist with more numbers of activities of daily living (ADL). Many family caregivers can no longer understand how their relative experiences day-to-day life. This situation may lead to an inability to empathize with one another and thus, feelings of interpersonal distance and grief **(Tretteteig, S., Vatne, S. & Rokstad, A.M.M.(2017).**

**Care burden** refers to physical, mental, social, or financial reactions by the caregiver during care giving shown as a result of an imbalance between patient's needs and health services. Compared with caregivers of persons with others diseases, mental health related indicators like distress and stress, burden or subjective wellbeing are particularly worse for dementia caregivers. (Rezaei. H , Hassan S and Reza Ghanei R,2020).

With the considerable level of burden involved in providing care, the concept of resilience and the availability of social support thus become crucial as they could function as protective factors to guard caregivers from the care burden. **(Hui Lin Ong,2018).**

**psychological resilience** among Family caregivers of patients with dementia refers to ability of family caregivers of patients with dementia to adapt stress and recover from adversity without displaying physical or mental disorders, or even learning to deal with unfavorable conditions more efficiently (. As psychological resilience is increasingly understood as a modifiable characteristic that may respond to a supportive environment. )**Yuli Lia, (2018).**

Also, psychological Resilience can also be seen as a positive psychological process that can be helps to reduce the negative effects of traumatic situations by promoting adaptation. The protective factors associated with resilience

are related to individual characteristics, temperament, intelligence, cognitive abilities, the quality of interpersonal relationships during childhood, environmental factors, planning, self-determination, self-reflection, self-confidence, and self-control.( Palacio. G et al,2020).

Dementia care giving is associated with several dimensions of burden. Objective burden results from the dependency of the person with dementia and behavioral problems in particular. Subjective burden is associated with the appraisal of physical and emotional impact of caregiving and also caregivers' resources **(Seide, D, René .J, 2021).**

### **Significance of the study**

Dementia is defined as a syndrome in which memory, thought, behavior, and the ability to perform daily life activities are impaired Globally, one in 10 people (10 percent) age 65 and older has Alzheimer's dementia **(Alzheimer's Association. Alzheimer's Dement 2018).** The dementia prevalence in Egypt ranged from 2.01% to 5.07% **(Mohamed. H. Elshahidil, Muhammad. A. Elhadidi , Ahmed A Sharaqi, Ahmed Mostafa & Mohamed A Elzhery., 2017).**

Caring for a person with dementia can be stressful and can result in negative physical and psychological consequences for carers, a phenomenon known as carer burden. Previous studies have reported that resilience play an important role in reducing physical and psychological burden in caregivers. **(Joling KJ et al., 2016).**

Thus, it is important to assess psychological resilience and it's relation to care burden among family caregivers of patients with dementia as a way to increasing the psychological resilience to reduce the care burden among family caregivers, improve quality of life for caregivers and improve quality of care for their patient's, However, it is indicated that there is insufficient information about the relationship between psychological resilience and caregiver burden in the literature. For this reason, this study will be investigating the relationship between care burden and

psychological resilience among family caregivers of patient with dementia.

### **Aim of study**

To Assess relationship between Care burden and Psychological resilience among Family Caregivers of Patients with Dementia.

### **Research Questions:**

This study is based on answering the following questions:

- 1) What are the levels of burden among family caregivers of patients with dementia?
- 2) What are levels of the psychological resilience among family caregivers of patients with dementia?
- 3) What are the relationships between care burden and psychological resilience among family caregivers of patients with dementia?

### **Subject and Methods**

#### **Research Design:**

A descriptive explorative design has been utilized to fulfill the aim of the study and answer the research questions.

#### **Setting of the Study:**

This study was conducted in memory clinic at the institute Al Yassin Specialized Medical Hospital affiliated to the Al-Baqiyat Al-Salihah Foundation, for Dr. Ablah Al-Kahlawi.

#### **Subjects:**

A sample of 100 family caregivers of patients with dementia who agreed to participate in the study .

### **Data Collection tools**

#### **1- Interview questionnaire sheet for dementia patient and their caregiver.**

**Part (1) General characteristics** it will be developed by the researcher and including characteristics for the patients and their relative such as (age, sex, religion, marital status, economic status, educational level, occupation, consanguinity etc...

**Part (2) Patient clinical data** will include age, gender, educational level, duration of illness, type of dementia, ect...

### **Zarit Burden Interview**

2-Burden interview scale adapted from Zarit Burden Interview (ZBI; Zarit et al., 1980) It is a self-report scale to measure caregiver burden such as' physical, psychological, social and financial burden attributable to care giving. The ZBI contains a 42-items checklist that requires participants to respond on a 3 -points Likert-type scale, ranging from 1 (rare) to 2 (sometimes), and 3(always).

Level of burden	Scores
Mild burden	0-45% (42-80)
Moderate burden	46-70% (81-101)
Sever burden	More than 70% (102-126)

### **3- Psychological resilience Scale for Adults (RSA).**

**Caregiver Resilience Scale (CRS) developed by ( Maneewat .T et al., 2016),** and composed of six domains which include: physical competence, relationship competence, emotional competence, moral competence, cognitive competence, and spiritual competence. The RSA These 3 0items which were arranged in a four point Likert scale, with the response choices ranging from 0 (not true) to 3(mostly true).

Total scores ranged from 0 to 90 points, with higher scores indicating higher levels of caregivers' resilience.

RSA level	scores
Mild resilience	Less than 50% (0-44)
Moderate resilience	50-75% (45-67)
High resilience	More than 75% (68-90)

### **Tools validity and reliability**

To achieve the criteria of trustworthiness of the tools of data collection in this study, the tools were tested and evaluated for their face and content validity, and reliability. Face and content validity are tested by three experts from faculty members in the nursing field from Ain Shams and University.

### **Pilot study**

A pilot study was conducted on10% of the total sample (10 family caregiver of patient

with dementia ) at the beginning at April 2021 (later excluded from the actual study subjects),it was conducted to evaluate the simplicity , applicability ,legibility ,understandability, feasibility ,validity and reliability of the research tools, in order to estimate the time needed to collect data .

### Field work

#### First step:

Before starting the data collection, the researcher met with the doctor and head nurses in the outpatient clinic after introducing the self, and then was explained the nature and purpose of the study to gain their oral consent and cooperation.

The researcher was introduced herself to the family caregiver of patient with dementia and explain the aim of the study in order to obtain family caregiver oral agreement to participate in the study.

Data were collected daily for 2 days/ week (Saturday –Tuesday) during the morning and afternoon shift (10.00 a.m:2.30.m) for 30-45 minutes at inpatient unit. Confidentiality of obtained information was assured, and the subjects were informed about their right to participate or not in the study and withdraw at any time without giving any reason. The participants were also assured about anonymity, and that data will only be used for the purpose of the study.

#### Second step:

The researcher individually interviewed the family caregiver of patient with dementia who agreed to participate in the study. After distributing the tools, the researcher explained the aim and objectives to them and assisted each family caregiver in filling in the tools. Filling in the tools took about 30- 45 minutes.

The study was conducted in waiting areas that near from Geriatric clinic. Through the place that was well ventilated, furnished, quiet as possible and had adequate lighting and adequate spacing for filling the interview questionnaire.

### Ethical considerations

The ethical research considerations in this study include the following:

The research approval was obtained from Scientific Research Ethical Committee in Faculty of Nursing at Ain Shams University before starting the study. The researcher clarified the objective and aim of the study to the family caregiver included in the study .the researcher assured maintaining anonymity and confidentiality of the subject data with reassurance about of the information given and that it will be used for scientific research only.

The family caregiver informed that they are allowed to choose to participate or not in the study and that they have the right to withdraw from the study at any time. Oral consent was obtained from each family caregiver to participate in the study sample.

### Statistical Design

The statistical analysis of data was done by using the Statistical Package for Social Science (SPSS), version 22. The first part of data was descriptive data which was revised, coded, tabulated and statistically analyzed using percentage, arithmetic mean(x) and standard deviation (SD) for quantitative data. Qualitative variables were compared using chi square test (X)<sup>2</sup> , P-value to test association between two variables and R- test to the correlation between the study variables .

Degree of significance results were:-

- P. Value>0.05(Not Significant)
- P.Value≤0.05(significant)
- P.Value≤0.001(Highly Significant)

### Results:

**Table (1):** reveals that, more than three fifth of studied caregivers of patients with dementia (65%) were female. Also, more than one third of the studied family caregivers (33%) with mean age were score  $40.69 \pm 4.23$  and more than three fifth of them (66%) were married.

This table also show that, two fifth of the studied caregivers of patients with dementia (41%) their relation to the patient were Daughter. also the educational level of the studied caregivers of patients with dementia, more than two fifth (46%) of them were university education. Furthermore, one half (52%) of the studied family caregivers were worked. and the majority (85%) of the studied family caregiver caring their patient from 1-5 years. Meanwhile, slightly less than three quarters (74%) of the studied family caregivers had another person assist them in caring of their patients.

**Table (2):** shows that, more than three quarters of the studied patients (77%) with mean age were score  $68.31 \pm 6.44$ . As regard gender and educational level, more than three fifth and slightly less than one half (69%&49%) of the studied patient were female and Illiterate respectively. Moreover, the majority (84%) of the studied patient their duration of illness ranged from 1-5 years.

**Figure (1):** shows that, more than two fifths (46%) of the studied family caregivers had severe level of total burden. Also, more than one third (36%) of the studied family caregivers had moderate level of total burden. While, less than one quarter of them (18%) had mild level of total burden.

**Figure (2):** shows that about more than four fifths (88%) of the studied family caregivers had Moderate levels of Psychological Resilience. While (8%) of them had high levels of Psychological Resilience and only (3%) of the studied family caregivers of patients with dementia had mild levels of Psychological Resilience.

**Table (3):** shows that, there were highly significant negative correlation between caregiver psychological resilience and their burden levels among family caregivers of patient with dementia in which ( $r = -0.92$ ) at  $p=0.000$  respectively.

**Table (1):** Number and percentage distribution of family caregivers of patient with dementia according to their socio-demographic data (n=100).

Socio-Demographic data	N	%
<b>Gender</b>		
Male	35	35
Female	65	65
<b>Age (in years)</b>		
18 – 25	7	7
26 – 35	33	33
36 – 49	31	31
More than 50	29	29
	Mean $\pm$ SD	40.69 $\pm$ 4.23
<b>Marital status</b>		
Married	66	66
Widowed	5	5
Single	26	26
Divorced	3	3
<b>Relation to patient</b>		
Son	26	26
Daughter	41	41
Wife	8	8
Husband	5	5
Sister	3	3
Brother	3	3
Son Wife	12	12
Grand Son	2	2
Others	0	0
<b>Educational level</b>		
Illiterate	6	6
Read and write	5	5
Secondary	43	43
University degree	46	46

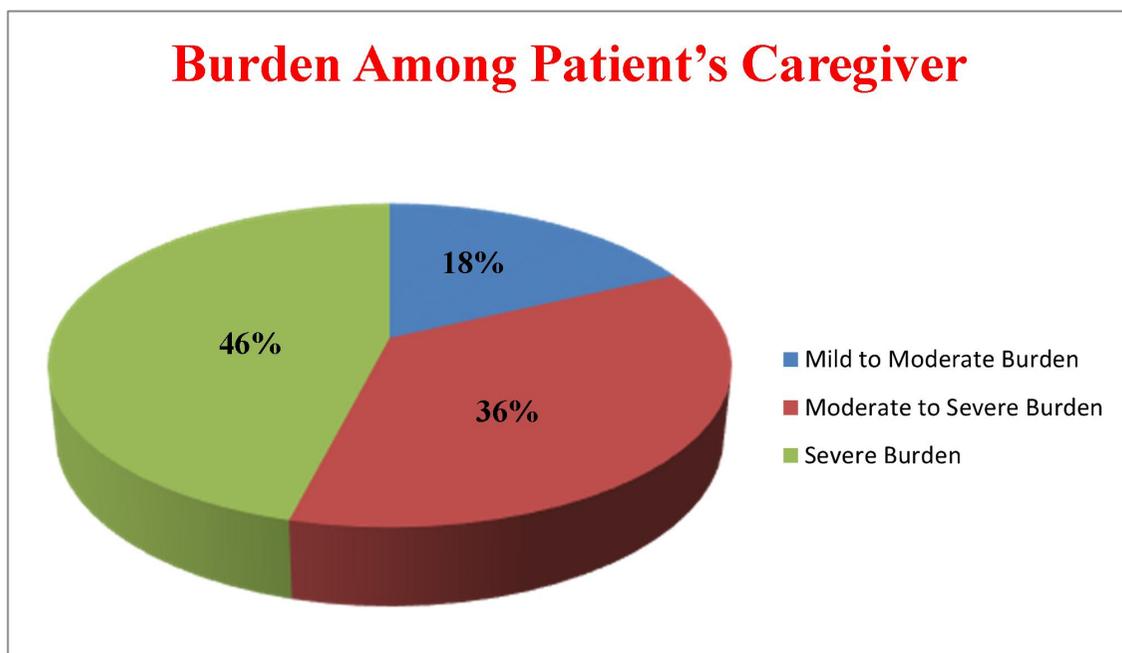
Continue.....

**Table (1):** continues: Number and percentage distribution of family caregivers of patient with dementia according to their socio-demographic data (n=100).

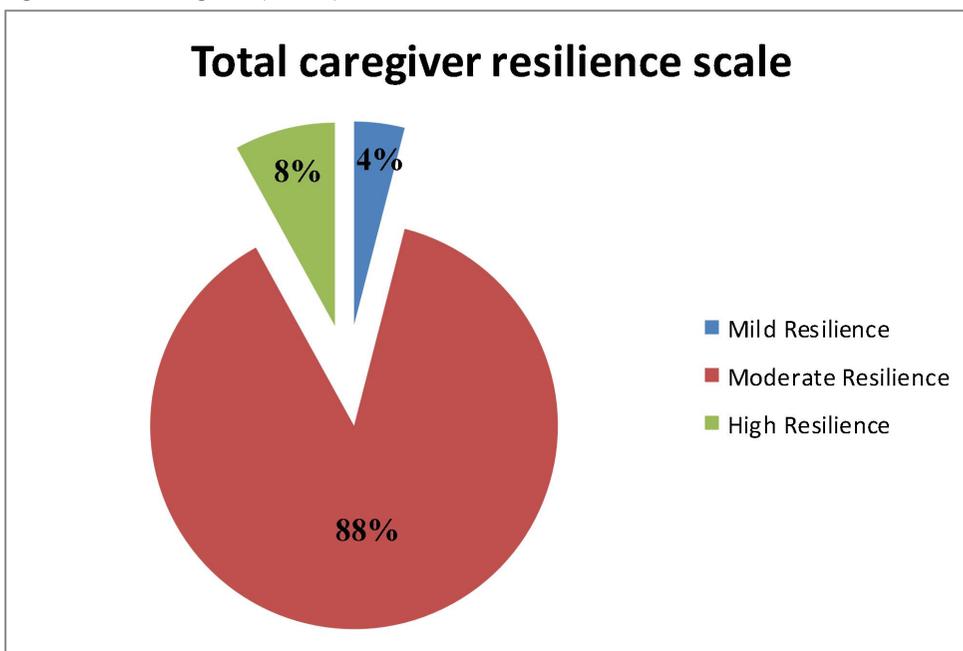
Socio-Demographic data	N	%
<b>The job</b>		
<b>Work</b>	48	48
<b>Does not Work</b>	52	52
<b>Monthly Income</b>		
<b>Enough</b>	22	22
<b>Not enough</b>	24	24
<b>Fairly enough</b>	54	54
<b>Residence area</b>		
<b>Urban</b>	73	73
<b>Rural</b>	27	27
<b>Duration of patient care</b>		
<b>1 - 5 years</b>	85	85
<b>6 - 10 years</b>	13	13
<b>More than 10 years</b>	2	2
<b>Did you Another person helping in caring of patient</b>	74	74
<b>Yes</b>	26	26
<b>No</b>		

**Table (2):** Number and percentage distribution of the studied patients with dementia according to their socio-demographic data (n=100).

Socio-Demographic data	N	%
<b>Patient Age (in years)</b>		
<b>50 – 60</b>	18	18
<b>61 – 80</b>	77	77
<b>More than 80</b>	5	5
	<b>Mean ± SD</b>	<b>68.31± 6.44</b>
<b>Patient Gender</b>		
<b>Male</b>	31	31
<b>Female</b>	69	69
<b>Education level</b>		
<b>Illiterate</b>	49	49
<b>Read and Write</b>	26	26
<b>Secondary</b>	14	14
<b>University</b>	11	11
<b>Duration of illness (in years)</b>		
<b>1 - 5</b>	84	84
<b>6 - 10</b>	14	14
<b>More than 10</b>	2	2



**Figure (1):** Number and percentage distribution of patient's caregiver according to Total Burden Among dementia Caregiver (n=100).



**Figure (2):** Number and percentage distribution of the caregivers of patients with dementia according to their Total Caregiver Resilience Scale (n=100).

**Table (3):** Correlation between family caregivers psychological resilience and care burden among the studied of family caregivers of patient with dementia (n=100).

Variables	Psychological Resilience	
	r	P-value
Care Burden	-.092	0.000* (HS)

## Discussion

Dementia is a latent and progressive disease that prevents people from continuing their daily life activities as a result of the deterioration of mental functions, (WHO 2018). Caregiving is usually performed with the essence of volunteering by family members due to the sense of duty, spiritual satisfaction, love, feeling guilty if they does not care for the patient. (Oğlak .S & et al., 2017).

Family caregivers can have a positive experience of caring for persons with dementia, but they are also at increased risk for stress, depression, burden and other health complication which not only imposes great challenges to their physical and mental health, but also harms dementia patients' quality of life in turn. (Lethin .C & et al, 2020).

Caregiver burden is defined as the strain borne by a person who cares for a chronically ill, disabled or elderly person . It is also the caregiver's personal perceptions about the extent of caregiving having an impact on their emotional, social, financial, physical and spiritual functioning Titova. N, (2019)

Studies have shown that the age of patient with dementia, the diagnosis, stage, duration of the disease and the time spent on care for the patient have significantly impacted the burden of care of caregivers (Eğilli CS et al., 2017).

Resilience can also be defined as a dynamic process through which individuals- are able to regain or preserve their mental health while being exposed to significant adversity (Moeller-Saxone et al., 2015). In this sense, resilience also appears to be particularly instrumental for caregivers of patients with

dementia who are often overburdened with physical and emotional challenges Moeller-Saxone, K. (2015).

### Part I. Socio-demographic characteristics of the studied family caregivers and their patients with dementia.

Regarding age of the studied family caregivers, the current findings illustrated that more than two fifths of the studied family caregivers with mean age  $40.69 \pm 4.23$ ; this could be due to that the majority of them were daughter, became more involved with care for their patients with dementia related to their feeling the responsibility toward them.

This result are agreed by Srivastava .G & et al.(2016) who stated,, Caregiver Burden and Quality of Life of Key Caregivers of Patients with Dementia'' who indicated that the average age of the family caregivers of patients with dementia was  $42 \pm 8.44$  years.

Also, the present study findings revealed that, more than three fifth of studied caregivers of patients with dementia were female, this may be due to nature of the female and less likely to be employed outside the home and they take care of their ill family member.

These findings agreed with the study accomplished by James .K & et al ,(2021), who studied „Caregivers of Older Persons in Jamaica Characteristics, Burden, and Associated Factors'' and found that the majority of the studied caregivers were female .

According to marital status ,the findings of the current study indicated that more than three fifth of the studied sample were married this may be due to the mean age of the studied family caregivers was  $42 \pm 8.44$  years

and this age indicated to married age according to social culture .

These results similar to the result of study performed by **Zahed .S& et al (2021)**. Who carried out a study to assess “Stress as a challenge in promoting mental health among dementia caregivers” and indicated that the majority of the studied sample were female and married.

**Concerning the relation to the patient**, found that two fifth of the studied caregivers of patients with dementia their relation to the patient were Daughter. May be due to some adult daughters experienced role reversal, in which they became the parent and their parent became the child. Role reversal was frequently drawn upon as motivation to carry on caregiving, as some adult daughters viewed this as an opportunity to reciprocate everything their parent had done for them when they were younger.

These findings in agreement with the study of **Sara Moreno-Cámara & et al (2019)**, who studied” Perceived Needs of The Family Caregivers of People with Dementia in a Mediterranean Setting” who reported that more than three quarter of the studied caregivers were daughter .

**Regarding the educational level of the studied caregivers**, the findings of the current study revealed that, more than two fifth of the studied caregivers were university education this may be due to the majority of the studied family caregivers were lives in moderate and high class environment.

These results agreement with the study achieved by **Kai-Ming Jhang & et al, (2021)**. Who carried out the study to assess “Characteristics Predicting a High Caregiver Burden in Patients with Vascular Cognitive Impairment” and mentioned that about two thirds of studied family caregivers were university education and above .Also these results are supported by **Sanchez-Teruel & et al(2021)** that entitled” Exploring resilience and

well-being of family caregivers of people with dementia exposed to mandatory social isolation by COVID-19”and found that the majority of the studied family caregivers have high level of education.

**Regarding duration of patient care**, the findings of the current study demonstrated that the majority of the studied family caregivers caring their patient from 1-5 years .may be due to the onset the disease process for studied patients start from 1-5years at that time the family caregivers providing care for their ill family member with beginning of dementia disease.

These results is in accordance with **Aram Cho ,Chiyong Cha, (2021)**. And entitled” Health Promotion Behavior among Older Korean Family Caregivers of People with Dementia” and mentioned that more than one third of the studied caregivers caring their patients with dementia from 1-5 years.

Also the present study findings revealed that, slightly less than three quarters of the studied family caregivers had another person assist them in caring of their patients. These results could be due to family members for patients with dementia cooperate with them to provide complete care for their ill member and reduce care burden among family caregivers.

These findings were in agree with the study accomplished by **Joanna Kowalska &et al , (2017)** ,who studied “Assessment of the Burden on Polish Caregivers of Patients With Dementia “and found that the majority of the studied sample had another person assist them in caring of their patients and usually from family member . Also, these findings were in agreed with the study done by **Joanna. S .Gieracha &et al (2020)**, who conducted a study entitled “Nonpharmacological Forms of Therapy to Reduce the Burden on Caregivers of Patients with Dementia” they stated that more than two thirds of the studied caregivers were have another person from their family assist them in their patient care.

**Regarding to the sociodemographic characteristics of the studied patients**, the current findings illustrated that the mean age for the studied patients were ( $68.31 \pm 6.44$ ), and this results may be due to dementia disease common in old age , genetic factors, socioeconomic characteristics of the population.

These results are supported with the study done by **Jufang. Li , et al(2021)** ,and entitled ‘‘ Perceived social support in Chinese family caregivers of patients with dementia’’ and mentioned that the average age of the studied patients with dementia  $69.05 \pm 8.89$ .

Also the present study findings revealed that, more than three fifths of the studied patients with dementia were female. . May be based in biology such as chromosomal or hormonal differences (i.e., sex differences) or differences in environmental, social and cultural influences on women (i.e., gender differences), or the combination of the two.

**These findings were in agreement with Stansfeld .J , &et al (2019)** ,who conducted a study about ‘‘Sense of coherence in family caregivers of people living with dementia: a mixed methods psychometric evaluation’’ and they reported that more than three fifths of the studied patients with dementia were female.

**Regarding the educational level**, slightly less than one half of the studied patients were Illiterate. This could be due to People have lower years of formal education are at more risk for dementia than educated people. These results may be due to the brain’s ability to make flexible and efficient use of cognitive networks (networks of neuron-to-neuron connections) to enable a person to continue to carry out cognitive tasks despite brain changes this process called cognitive reserve.

These results is in accordance with **Alba Pérez-González, Josep Vilajoana-Celaya &et al (2021)** who carried out a study entitled ‘‘ Alzheimer’s Disease Caregiver Characteristics

and Their Relationship with Anticipatory Grief’’ and they mentioned that more than two fifths of the studied family caregivers were illiterate.

**Regarding to the duration of illness** of studied patients with dementia, the finding of the present study revealed that the majority of the studied patient their duration of illness were ranged from 1-5 years.

This result similar with the result of study performed by **Gonen .S. S, et al (2018)** who conducted a study to assess ‘‘The Relationship between Caregiver Burden and Psychological Resilience in Caregivers of Individuals with Dementia’’ reported that slightly less than one half of the studied patients with dementia their duration of illness were ranged from 1-5 years.

Also these result are in agreement with the study achieved by **Verkaik .R& et al. (2016)** ‘‘ Self-management by family caregivers to manage changes in the behavior and mood of their relative with dementia’’. reported that one half of the studied patients with dementia their duration of illness were ranged from 1-5 years.

**According to Total Burden among dementia Caregivers** more than two fifths of the studied family caregivers had sever level of total burden. Also, more than one third of the studied family caregivers had moderate level of total burden. While, less than one quarter of them had mild level of total burden.

These results are similar to the results of study performed by **Souza .C, Manzini .S, (2020)**,who carried out study to assess’’ Emotional disorders evidenced by family caregivers of older people with Alzheimer’s disease’’ who stated that more than two fifths of the studied caregivers had sever burden , while less than one quarter had moderate burden and only Less than one quarter of them had mild burden.

These results are similar to the results of study performed by **Souza .C, Manzini .S,**

(2020), who carried out study to assess "Emotional disorders evidenced by family caregivers of older people with Alzheimer's disease" who stated that more than two fifths of the studied caregivers had severe burden, while less than one quarter had moderate burden and only less than one quarter of them had mild burden.

Also, **Nadia M. Tawfik, Noha A. Sabry & et al, (2021)**, who conducted a study to assess "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" and stated that there is a consistently high level of family caregiver's perceived burden.

**Regarding Total Caregiver Resilience** the majority of the studied family caregivers had Moderate levels of Psychological Resilience. While less than one fifth of them had high levels of Psychological Resilience and mild levels of Psychological Resilience. May be due to the majority studied family caregivers have moderate to high socioeconomic status, highly educated, experience in patients care and found of another person help them in patients care and moral, spiritual factors that assist the family caregivers to cope with their patient's needs and care.

These results supported by the study done by **Hemalatha .M and Dr. Nasreen Banu, (2018)** who carried out study about "Impact of perceived stress on resilience of the caregivers attending to Alzheimer's patients" who found about one half of the studied caregivers reported that they were having moderate resilience, and more than one third of them having high resilience while 10% of the studied caregivers were having low resilience.

**Regarding the correlation between psychological resilience and care burden among family caregivers of patients with dementia.** The current findings illustrated that there is highly significant negative correlation

between burden level of the studied caregivers and their psychological; this may be due to promote caregiver resilience and positive growth, that may be targeted to help reduce distress, care burden and improve overall well-being, the quality of caregiving and care recipients' outcome.

These results are supported with the study done by **Pradana .A, Rohayati, (2021)**. Who studied "Family's Resilience In Caregiving Elderly With Dementia: A Systematic Review" and mentioned that there was there is highly significant negative correlation between burden level of the studied caregivers and their psychological.

In the same field, **Serra .L, Contador .C & et al (2018)**, reported that the effect of resilience to decrease caregiver burden continued to be significant. Should be noted that resilience was associated with a lower probability of care burden. Also, **Karlijn J. Joling & et al (2016)** who carried out study to assess "Factors of Resilience in Informal Caregivers of People with Dementia from Integrative International Data Analysis" and stated that low caregiver burden were clearly related to high level of caregiver resilience.

### **Conclusion**

**The findings of the present study reached to the following conclusion:**

More than two fifths of the studied family caregivers had severe level of total burden. Also, more than one third of the studied family caregivers had moderate level of total burden. While, less than one quarter of them had mild level of total burden. Regarding Caregiver Resilience Scale About more than four fifths of the studied family caregivers had Moderate levels of Psychological Resilience. While eight of percentage of them had high levels of Psychological Resilience and only three of percentage of the studied family caregivers of patients with dementia had mild levels of Psychological Resilience. There were highly significant negative correlation between caregiver psychological resilience and their burden levels among family caregivers of patient with dementia.

### Recommendations

Based upon the results of the current study, the following recommendations were suggested:

- Development of psychosocial care program to provide psychosocial support for patients with dementia and their family caregivers.
- Further study should be applied to assessing factors related to increasing the level of burden among family caregivers of patients with dementia.
- Future research to assess level of psychological resilience among family caregivers of patients with dementia.
- Providing psychoeducational program for family caregivers of patients with dementia to reduce their burden and improve their psychological resilience to deal with the stress and burden resulting from completely care and dependence of the patients with dementia and improve quality of care for patients with dementia.
- Establishment of counseling program for family caregivers of patients with dementia to improve psychosocial wellbeing.
- Establishing of rehabilitation program for family caregivers of patients with dementia through multidisciplinary team for successful community integration for enhancing their quality of life.
- Educational program should be provided for nurses to provide psychosocial support throughout their routine work as health care setting.

### References

- Alfakhri AS, Alshudukhi AW, Alqahtani AA, Alhumaïd AM, Alhathlol OA, Almojali AI, Alotaibi MA, Alaqeel MK. Depression Among Caregivers of Patients With Dementia. *Inquiry*. 2018 Jan-Dec;55:46958017750432. doi: 10.1177/0046958017750432. PMID: 29345180; PMCID: PMC5798670.
- Dove E, Astell A. The Kinect Project: Group motion-based gaming for people living with dementia. *Dementia*. 2019;18(6):2189-2205. doi: [10.1177/1471301217743575](https://doi.org/10.1177/1471301217743575)
- Roberts, E., & Struckmeyer, K. M. (2018). The Impact of Respite Programming on Caregiver Resilience in Dementia Care: A Qualitative Examination of Family Caregiver Perspectives. *Inquiry : a journal of medical care organization, provision and financing*, 55, 46958017751507. <https://doi.org/10.1177/0046958017751507>
- Kim, B., Noh, G.O. & Kim, K. Behavioural and psychological symptoms of dementia in patients with Alzheimer's disease and family caregiver burden: a path analysis. *BMC Geriatr* 21, 160 (2021). <https://doi.org/10.1186/s12877-021-02109-w>
- Tretteteig, S., Vatne, S. & Rokstad, A.M.M. The influence of day care centres designed for people with dementia on family caregivers – a qualitative study. *BMC Geriatr* 17, 5 (2017). <https://doi.org/10.1186/s12877-016-0403-2>
- Oğlak, S. (2017): The value of Informal caregiving on elderly care: As a shadow workforce. *Istanbul Gelisim University Journal of Social Sciences*, 4 (2),73-87.
- WHO. (2018). The global dementia observatory reference guide. World Health Organization
- Lethin .C & Leino-Kilpi. H , Stephan .A , Martin.M, Nilsson.K, Zabalegui.A, Karlsson.S ,( 2020). Predicting caregiver burden in informal caregivers caring for persons with dementia living at home – A follow-up cohort study. 2020, 19(3) 640–660. DOI: 10.1177/1471301218782502 [journals.sagepub.com/home/dem](https://journals.sagepub.com/home/dem)
- Eğilli, C.S., Sunal, N. (2017). Determination of careload of the caregivers of demented patient and relevant affecting factors. *Journal of Academic Research In Nursing*,3(2),83-91.

- Connors .M, Seeher1 .K, | Teixeira-Pinto .A, Woodward .M | Ames .D, Brodaty .H, (2019): Dementia and caregiver burden. DOI: 10.1002/gps.5244. *Int J Geriatr Psychiatry*. wileyonlinelibrary.com/journal/gps 2020;35:250–258.
- Chaudhuri KR, Titova. N, (2019) Societal Burden and Persisting Unmet Needs of Parkinson's Disease . *Eur Neur Rev.*:14(1):28–35
- Moeller-Saxone, K., Davis, E., Stewart, D. E., Diaz-Granados, N., & Herrman, H. (2015). Promoting resilience in adults with experience of intimate partner violence or child maltreatment: A narrative synthesis of evidence across settings. *Journal of Public Health*, 37, 125–137.
- Srivastava .G, Tripathi ,R ,(2016): Caregiver Burden and Quality of Life of Key Caregivers of Patients with Dementia. *Indian J Psychol Med* 2016;38:133-6., DOI 10.4103/0253-7176.178779
- James.K., Thompson.C (2021): Caregivers of Older Persons in Jamaica: Characteristics, Burden, and Associated Factors. *Journal of Applied Gerontology* 2021, 40(7) 713–721 © The Author(s) 2020 Article reuse guidelines: sagepub.com/journals-permissionsDOI: 10.1177/0733464819898315 journals.sagepub.com/home/jag
- Zahed S, Emami M, Eslami AA, Barekatin M, Hassanzadeh A, Zamani-Alavijeh F. Stress as a challenge in promoting mental health among dementia caregivers. *J Educ Health Promot.* 2020;9:65. Published 2020 Mar 31. doi:10.4103/jehp.jehp\_445\_19
- Cámara,S ,Pedro Ángel Palomino-Moral,Lourdes Moral-Fernández,Antonio Frías-Osuna,Laura Parra-Anguita,Rafael Del-Pino-Casad *International Journal of Environmental Research and Public Health* (IF3.39), Pub Date : 2019-03-22, DOI: [10.3390/ijerph16060993](https://doi.org/10.3390/ijerph16060993)
- Jhang KM, Wang WF, Chang HF, Chang MC, Wu HH. Characteristics Predicting a High Caregiver Burden in Patients with Vascular Cognitive Impairment: Using the Apriori Algorithm to Delineate the Caring Scenario [published correction appears in *Risk Manag Healthc Policy*. 2021 Aug 02;14:3195]. *Risk Manag Healthc Policy.* 2021;14:1335-1351. Published 2021 Mar 30. doi:10.2147/RMHP.S297204
- Sánchez-Teruel, Robles-Bello, Sarhani-Robles M, Sarhani-Robles A. Exploring resilience and well-being of family caregivers of people with dementia exposed to mandatory social isolation by COVID-19. *Dementia*. September 2021. doi:[10.1177/14713012211042187](https://doi.org/10.1177/14713012211042187)
- Cho, A.; Cha, C. Health Promotion Behavior among Older Korean Family Caregivers of People with Dementia. *Int. J. Environ. Res. Public Health* 2021, 18, 4123. <https://doi.org/10.3390/ijerph18084123>
- Kowalska J, Gorączko A, Jaworska L, Szczepańska-Gieracha J. An Assessment of the Burden on Polish Caregivers of Patients With Dementia: A Preliminary Study. *American Journal of Alzheimer's Disease & Other Dementias®*. December 2017:509-515. doi:[10.1177/1533317517734350](https://doi.org/10.1177/1533317517734350)
- Szczepańska-Gieracha, Joanna, Lilianna Jaworska-Burzyńska, Krystyna Boroń-Krupińska, and Joanna Kowalska. 2020. "Nonpharmacological Forms of Therapy to Reduce the Burden on Caregivers of Patients with Dementia—A Pilot Intervention Study" *International Journal of Environmental Research and Public Health* 17, no. 24: 9153. <https://doi.org/10.3390/ijerph17249153>

[Jufang Li PhD,Gexin Gao MSN,Yawei Zeng MSNc,Yuping Wu BSNc,Xiaoling Zhu MSN,Hongbo Xu MSN\(2021\) Perceived social support in Chinese family caregivers of patients with dementia](#)

<https://doi.org/10.1111/ijn.12945>

Stansfeld, J., Orrell, M., Vernooij-Dassen, M. et al. Sense of coherence in family caregivers of people living with dementia: a mixed-methods psychometric evaluation. *Health Qual Life Outcomes* 17, 44 (2019). <https://doi.org/10.1186/s12955-019-1114-0>

Pérez-González A, Vilajoana-Celaya J, Guàrdia-Olmos J. Alzheimer's Disease Caregiver Characteristics and Their Relationship with Anticipatory Grief. *International Journal of Environmental Research and Public Health*. 2021; 18(16):8838. <https://doi.org/10.3390/ijerph18168838>

Huis in het Veld, J., Verkaik, R., van Meijel, B. et al. Self-management by family caregivers to manage changes in the behavior and mood of their relative with dementia: an online focus group study. *BMC Geriatr* 16, 95 (2016). [https://doi.org/10.1186/s12877-016-0268-448\(3\):865-867](https://doi.org/10.1186/s12877-016-0268-448(3):865-867),

Manzini, Carlene Souza Silva and Vale, Francisco Assis Carvalho do Emotional disorders evidenced by family caregivers of older people with Alzheimer's disease. *Dementia & Neuropsychologia* [online]. 2020, 14, n. 1 [Accessed 9 January 2022] , pp. 56-61. Available from: <<https://doi.org/10.1590/1980-57642020dn14-010009>>. Epub 16 Mar 2020. ISSN 1980-5764. <https://doi.org/10.1590/1980-57642020dn14-010009>.

Tawfik NM, Sabry NA, Darwish H, Mowafy M, Soliman SSA. Psychoeducational Program for the Family Member Caregivers of People with Dementia to Reduce Perceived Burden and Increase Patient's Quality of Life 2021: A Randomized Controlled Trial. *Journal of Primary Care & Community Health*. January doi:[10.1177/21501327211014088](https://doi.org/10.1177/21501327211014088)

Anung Ahadi Pradana, Rohayati *medRxiv, (2021) FAMILY'S RESILIENCE IN CAREGIVING ELDERLY WITH DEMENTIA: A SYSTEMATIC REVIEW*. .06.16.21259058; doi: <https://doi.org/10.1101/2021.06.16.21259058>