

Relationship between Caregiving Burden, knowledge and stigma of Caregivers Caring for Older Adults with Alzheimer disease

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Abstract

Background: the level of burden is associated with severity of Alzheimer disease, frequency, and intensity of care, and absence of help. In many cases, mostly all members of the family become a stigma victim and could have feelings of shame about the disease. **Aim:** the aim of the study was to assess relationship between caregiving burden, knowledge and stigma of caregivers caring for older adults with Alzheimer disease. **Design:** the researchers used a descriptive-correlational cross sectional design to complete the study. **Subjects:** A convenience sample of 108 family caregivers of the older adults diagnosed with Alzheimer's disease covered a period of one year (from 1st of May 2019 till 1st of June). **Settings:** This study was carried out in the general hospital at patient clinic and Association of Alzheimer Patients at Mansoura city, Dekahlia governorate. **Tools:** Four tools were used to collect the data namely; Demographic and clinical data structure interview schedule sheet, The Zarit Burden Interview (ZBI), Alzheimer's Disease Knowledge Scale (ADKS) and The Stigma Impact Scale (SIS). **Results:** The mean age of caregivers was 44.93 ± 9.135 . And more than two-thirds of the study sample were females, while the mean age of elderly was (75.32 ± 5.901) . And above half of the study subject were male (69.4%). A strong positive correlation was found between caregiver's burden and stigma. **Conclusion:** A statistical significance relation was found between all sociodemographic characteristics of family caregivers and each of caregiving burden, stigma, and knowledge. A strong positive correlation was found between caregiver's burden and stigma. **Recommendations:** Educational program for family caregivers not only about the disease processes, but also the way to manage symptoms, experiences, detect resources that could lower the level of caregiving burden, improve their knowledge and reduce sense of stigmatization.

Keywords: Caregivers, Stigma, Knowledge, Alzheimer disease, caregiver burden and older adult.

Introduction:

There is a great increase in the prevalence of Alzheimer's disease (AD) worldwide and it is expected to increase from 44 million in 2013 to 135 million by 2050 according to international statistics. AD represents about 60 to 70% of dementias and is estimated that 13% of people above 65 years of age have Alzheimer in the USA (Melo, Champs, Goulart, Malta& Passos, 2020).

In Egypt, although there are only a few reports which provide prevalence rates of dementia in general and AD in particular, it was mentioned that the estimated number of Egyptian persons suffering from AD in 2013 is about 350000 persons; most of them are elderly. Unfortunately, in Egypt 20 million individual

will be categorized as elderly by the year 2050 also it is expected to possess the highest rank of old and oldest populations as well in the region (El Baqary, 2015).

The experience of AD in Egypt is surrounded by many misconceptions; Alzheimer's patients are suffering because they, their caregivers, and their families don't fully understand the disease experience. Efforts for risk reduction and early diagnosis of AD may be affected by perceptions and misconceptions. As a result of this lack of awareness, Alzheimer's patients go through a long journey of challenge, dependency, and weakness contributing to caregiver burden (El-masry, Elwasify & Khafagy, 2018).

As a result of caregiving, caregiver burden include physical, psychological, social,

and financial demands. Emotional stress and depression of dementia family caregivers is the result of deteriorating AD and other dementias, about 15.7 million persons assist patients diagnosed with AD or other dementia forms with daily needs in comfortable and familiar environments (**Alzheimer's Association, 2017**). Increased burden is related to the severity of the disease, frequency, lack of help and intensity of care. In many cases, family members specially caregiver converted to a stigma victim and can develop feelings of shame about AD (**Kahn, Wishart, Randolph & Santulli, 2016**).

Stigma is defined in sociology as a condition, attribute, trait, or behavior causing its bearer to be seen as "culturally unacceptable" or inferior. The stigma of the family about AD has received unexpectedly limited attention although it is assumed that people with AD and their family caregivers are stigmatization victims (**Werner, Goldstein & Heinik, 2011**). Some researches on stigma and AD revealed that stigma in the family causes caregivers to avoid seeking services that can decrease caregiver burden, also found that there is a strong relation between the stigma and disease characteristics (**Koschorke et al, 2017**).

The perceived burden of caring for AD family member is affected by many factors. These factors involve the caregiver's characteristics like kinship, sex, coping strategies and psychological resources; characteristics dementia patients with cognitive status, behavioral problems, and other characteristics as duration of care, support, and relationships quality within family. Furthermore, lack of caregivers knowledge about care of Alzheimer patients (**Baharudin, Subramaniam, & Razali, 2019**).

Dementia knowledge gaps have been identified in family caregivers, the general public, doctors, and nurses, or other healthcare members. Caring for an individual with dementia needs knowledge of the trajectory and appropriate dementia care. Being knowledgeable about dementia is linked with decreased caregiver burden levels, depression of caregiver, and enhanced quality of care for dementia older adults (**Scott, Clay, Epps, Cothran & Williams, 2020**).in order to offer suitable ongoing care, both formal and informal

dementia caregivers need to increase knowledge about dementia through continuing education and advanced training (**Resciniti et al., 2020**).

Caregivers is the person who live daily with stigmatic beliefs and is mostly a close relative, parent, or spouse. Even so, there is a lack of researches in the area of stigma and AD, especially in the area of the family (**Werner, Goldstein & Buchbinder, 2010**). Therefore, the aim of the study was to assess relationship between caregiving burden, knowledge and stigma of caregivers caring for older adults with Alzheimer disease

Research questions

1. What is the caregiving burden, knowledge, and stigma of caregivers caring for older adults with Alzheimer disease?
2. What is the relation between demographic characteristics and caregiving burden, knowledge, and stigma of caregivers caring for older adult's Alzheimer disease?

Subjects and Methods

Study design:

The researchers used a descriptive-correlational cross sectional research design.

Settings:

This study was carried out in the general hospital (outpatient patient clinic) and Association of Alzheimer Patients at Mansoura city, Dakahlia Governorate.

Subjects:

A convenience sample of 108 family caregivers of the older adults diagnosed with AD attending in the above mentioned settings within a period of one year (from 1st of May 2019 till 1st of June, 2020) and fulfilling these criteria; Aged 18 years or more, both gender, responsible for providing care for older adults and able to communicate and willing to participate in the study. Exclusion criteria: Paid caregivers.

Tools of data collection:

The researchers used four tools for collecting the necessary data:

Tool I: Demographic and clinical data structure interview schedule sheet:

Part I: Data about older adults with Alzheimer disease. It included item related to; Socio-demographic characteristics of the elderly such as age, gender, marital status, educational level, occupation, and income. Clinical data about severity of disease and chronic disease.

Part II: Data about older adult's caregiver. It included items related to; Socio-demographic characteristics of the care giver such as age, gender, level of education, occupation, relation to elderly, marital status, and income. Clinical data about chronic disease.

Tool II: The Zarit Burden Interview (ZBI):

It was developed by **Zarit, Reever and Bach-Peterson (1980)**. The interview provides a global, unidimensional measure of the caregiving burden. 22-item rating scale measuring burden in health, psychological well-being, finances, social life, and relationship with the patient. The caregiver answers are endorsed using a 5-point Likert scale. Response options range from 0 (Never) to 4 (Nearly Always). Scoring key: 0 to 20 = little or no burden; 21 to 40 = mild to moderate burden; 41 to 60 = moderate to severe burden; 61 to 88 = severe burden. The reliability was assured using Cronbach's alpha (r) = 0.85 (**Ali, 2015**).

Tool III: Alzheimer's Disease Knowledge Scale (ADKS):

It was used to assess caregivers' knowledge of Alzheimer's disease. The scale comprises 30-items having true or false answers taking around 5-10 minutes to complete with the resulting score being the number answered correctly, giving a total score with a range of 0-30. Although, the ADKS is split into 7 subscales: life impact, risk factors, symptoms, treatment & management, assessment & diagnosis, caregiving, and course of the disease; it is best expressed by the overall knowledge score rather than separately scored subscales,

with higher scores indicating good caregiver knowledge of Alzheimer's (**El-masry et al., 2018**).

Tool IV: The Stigma Impact Scale (SIS):

Perceived stigma was measured by this tool. It consists of 4 subscales: social rejection (9 items), financial insecurity (3 items), internalized shame (5 items), and social isolation (7 items) with a total score of 24 items and are rated on a 0 to 4-point Likert-type scale. Higher scores from 0-96 indicate elevated perceived stigma level (**Burgener & Berger, 2015**).

Methods:

1. The director of the general hospital in Mansoura city and board director of Alzheimer disease association was informed about the purpose of the study, the date and the time for data collection to obtain an approval to interview the family caregivers of AD.
2. After a thorough review of literature, tool I (Demographic and clinical data structure interview schedule sheet was developed by the researcher and reviewed by the specialists.
3. Arabic versions of Tool II (The Zarit Burden interview and Tool III (Alzheimer's disease knowledge scale) were used to assess burden of the caregiver and their knowledge about Alzheimer's disease.
4. Tool IV (The Stigma Impact Scale) was translated by the researchers into Arabic language and tested using test – retest method. The reliability was assured by means of Cronbach's alpha (r) = 0.85.
5. Tools of the study were reviewed by seven experts in Gerontological Nursing, Psychiatric Nursing and Community health Medicine fields to test the validity, feasibility of the content and the researchers did the necessary modifications.
6. A pilot study was carried out on 12 family caregivers from outpatient clinics at Mansoura General Hospital in outpatient clinic before starting the data collection to test the feasibility of the tools and to identify the approximate time needed to answer all sheet. The family caregivers

participated in the pilot study were excluded from the sample. The data obtained from the pilot study was analyzed and according to the results, the recommended changes were done.

7. The researchers send the structured sheet to the (highly educated) family caregivers on WhatsApp application as a Google form to answer and sent again within one week to reduce (direct contact) in this pandemic period of COVID -19, while the caregivers not able to filling the Google form were interviewed individually by the researchers in the waiting room of outpatient clinic starting from 9 am to 1 pm to collect the baseline elderly patients and family caregivers data. The researcher interviewed 3 to 4 of them daily 2 days /week (Saturday and Wednesday) according to routine outpatient clinic in the General Mansoura, Hospital. The interview time ranged from 30-45 minutes.

Ethical considerations:

The protocol was approved by the Ethics and Research Committees of the faculty of nursing, Mansoura University, General hospital and Alzheimer patients association in Dakahlia, and the committee of human rights. Verbal consent of the study subjects was obtained after clarification of the purpose of the study. Privacy and confidentiality of the subjects and collected data was assured.

Statistical analysis

Data were analyzed using the Statistical Package for Social Sciences "SPSS" statistical program version 22. Descriptive statistics: Count and percentage were used for describing and summarizing qualitative data. Arithmetic mean (X), Standard deviation (SD) were used as measures of central tendency and dispersion respectively for normally distributed quantitative data. Independent t-test was used for two groups comparison and analysis of variance (F) test was used for more than two groups comparison with Bonferroni post-hoc multiple comparisons. Spearman's correlation coefficient (r) was used to calculate the correlation between different

variables. The 0.05 level was used as the cut-off value for statistical significance. Additionally, Graphs were done for data visualization and using SPSS and Microsoft.

Results

Demographic characteristics of elderly patient with AD, the majority of the elderly patient with AD (81.5%) were 70 years and older, with a mean of 75.32 ± 5.901 years. It can be noticed that 69.4% of the study sample were male, the majority of them 52.8% were Widow and 22.2 % were illiterate. 58.3% of the elderly were in the fourth stage of the disease, 67% of elders didn't have enough income and 73% have at least one chronic disease. (Data not shown in tables).

Table (1) shows the demographic data of elderly family caregivers. It can be noticed that 66.67 % of the study sample were females and the mean age of them was 44.93 ± 9.135 years. The majority of the study subjects 96.3% were married and 50.0 % of them had just finished the secondary education and the highest percentage of the subjects were working as governmental employee ; while 66.7 % of caregivers reported had not enough income. According to relation with the elderly, daughter was the uppermost percentage 46.3 % and 69.4 % do not live with elderly. About 96.3% found others providing help in caring for the elderly. Finally, 51.9% of them spent more than 5 hours per day with the elderly with a mean \pm SD of 7.56 ± 4.909 hour.

Table (1): Distribution of family caregivers according to their demographic characteristics

Variables	No. (n=108)	%
Age of caregiver		
30 -	48	44.4 %
45 +	60	55.6 %
(Mean \pm SD)	44.93 \pm 9.135	
Gender		
Female	72	66.67 %
Male	36	33.33 %
Marital Status		
Married	101	93.5
Widow	4	3.7
Divorced	3	2.8
Educational level		
Illiterate	4	3.7
Secondary	54	50.0
University	43	39.8
Postgraduate	7	6.5
Working		
Governmental employee	49	45.4
Private work	27	25.0
Farmer	13	12.0
House Wife	19	17.6
Income		
Enough	36	33.3
Not enough	72	66.7
Caregiver relation to older adult		
Son	48	44.4
Daughter	50	46.3
Partner	3	2.8
Relative	7	6.5
Living with older adult		
Yes	33	30.6
No	75	69.4
Others helping caregiver		
Yes	104	96.3
No	4	3.7
Duration of Alzheimer' Disease		
5 years and less	62	57.4 %
More than 5 years	46	42.6 %
Chronic disease of caregivers		
No	47	43.5 %
Yes	61	56.5 %
Severity of disease		
Moderate	45	41.7
Sever	63	58.3
Number of daily hours of caring		
< 5 hrs. / day	52	48.1
\geq 5 hrs./ day	56	51.9
(Mean \pm SD)	7.56 \pm 4.909	

It's apparent from **figure (1)** that-70.4% of caregivers reported that they have a moderate to severe burden and 29.6% of them with a severe burden.

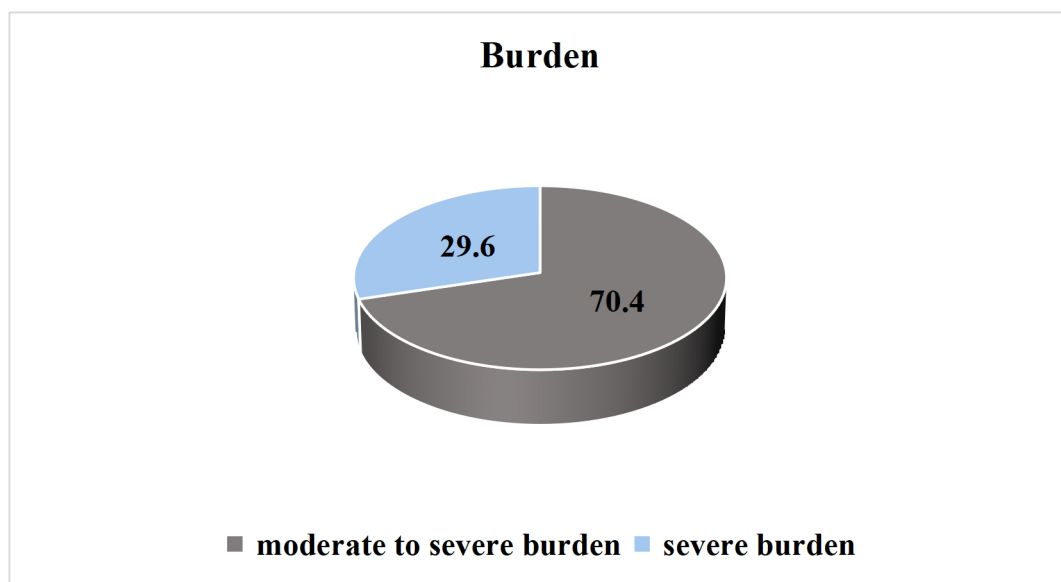


Figure (1): Caregiving burden of the studied family caregivers

Table (2) show that the total mean scores of Burden and knowledge with mean and standard deviation (mean \pm SD) were 65.18 ± 9.94 and 38.69 ± 5.94 respectively and represent the higher mean score of stigma (mean \pm SD) was 70.3796 ± 10.59335 . Also, clarifies that there were statistical significance relation was found between all demographic characteristics of family caregiver and caregiving burden, stigma, and knowledge ; while no statistical significance relation was observed between burden and severity of disease and between severity of disease and stigma.

Table (2): Relation between Demographic characteristics of family caregiver and Cargiving Burden, Stigma and Knowledge.

Items	Burden		Stigma		Knowledge	
Total score	65.18 \pm 9.94		70.38 \pm 10.598		38.69 \pm 5.94	
Mean \pmSD						
-	F	P.vlaue	F	P.vlaue	F	P.vlaue
Age of caregiver	4.211	0.000***	10.143	0.000***	4.178	0.000***
Gender	10.607	0.000***	6.401	0.000***	5.385	0.000***
Marital Status	1.362	0.164	19.263	0.000***	4.789	0.000***
Educational level	11.205	0.000***	25.657	0.000***	12.053	0.000***
Working	7.298	0.000***	28.211	0.000***	12.588	0.000***
Income	55.881	0.000***	17.558	0.000***	5.788	0.000***
Caregiver relation to older adult	3.765	0.000***	39.786	0.000***	2.716	0.003**
Living with older adult	40.963	0.000***	8.028	0.000***	6.507	0.000***
Others helping caregivers	17.215	0.000***	7.724	0.000***	11.506	0.000***
Number of daily hours of caring	8.866	0.000***	9.601	0.000***	55.431	0.000***
Severity of disease	0.419	0.519	1.582	0.211	12.097	0.001**

*, **, & *** significant at $P \leq 0.05$, $P \leq 0.01$, & $P \leq 0.001$

Table (3) illustrates that there were a statistical significant relation between all demographic characteristics of family caregivers and Stigma subscales except relation between severity of disease and each of social rejection, financial insecurity, and social isolation. In the same manner, there were no statistically significant relation between financial insecurity and both marital status

and relationship with the elderly. On the other hand, table show the higher mean scoring regarding to stigma subscales was social rejection with (mean \pm SD) 26.06 \pm 4.18.

Table (3): Relation between demographic characteristics of family caregiver and stigma subscales.

Items	Social Rejection		Financial Insecurity		Internalized Shame		Social Isolation	
Scoring subscales Mean \pm SD	26.06 \pm 4.18		8.56 \pm 1.72		14.87 \pm 2.64		20.87 \pm 3.22	
-	F	P.vlaue	F	P.vlaue	F	P.vlaue	F	P.vlaue
Age of caregiver	5.469	0.000***	2.558	0.018*	5.364	0.000***	5.095	0.000***
Gender	6.650	0.000***	6.956	0.000***	5.829	0.000***	4.743	0.000***
Marital Status	10.882	0.000***	1.863	0.084	4.840	0.000***	2.310	0.018*
Educational level	20.603	0.000***	6.367	0.000***	5.434	0.000***	2.018	0.039*
Working	31.064	0.000***	2.970	0.007**	6.079	0.000***	4.655	0.000***
Income	23.737	0.000***	18.095	0.000***	27.073	0.000***	15.169	0.000***
Caregiver relation with older adult	11.642	0.000***	1.858	0.084	8.338	0.000***	2.989	0.003**
Living with older adult	50.009	0.000***	2.360	0.028*	6.042	0.000***	7.643	0.000***
Others helping caregivers	10.028	0.000***	8.324	0.000***	2.987	0.003**	3.785	0.000***
Number of daily hours of caring	10.572	0.000***	7.708	0.000***	6.123	0.000***	9.732	0.000***
Severity of disease	0.866	0.354	3.170	0.078	9.487	0.003**	2.064	0.154

*, **, & *** significant at $P \leq 0.05$, $P \leq 0.01$, & $P \leq 0.001$

Table (4) Shows that negative correlations were found between all of the following knowledge and burden and stigma. A negative correlation was found also between burden and knowledge. On the other hand, a positive correlation was found between stigma and burden.

Table (4): Correlation between caregiving burden, stigma and knowledge

Variables	Burden		Stigma	
	R	P.vlaue	R	P.vlaue
Burden			0.806	0.000***
Stigma	0.806	0.000***		
Knowledge	-0.414	0.000***	-0.442	0.000***

*, **, & *** significant correlation at $P \leq 0.05$, $P \leq 0.01$, & $P \leq 0.001$

Table (5): Logistic regression table reveals that independent predictors of burden were the fourth stage of diseases, female sex, married caregiver, organizational employee, not enough income and no others help the caregiver. While related to stigma, the independent predictors are the fourth stage of disease, illiterate, and governmental employee.

Table (5): Logistic regression analysis of independent predictors of caregiving burden and stigma in caregivers of elderly with Alzheimer:

Item	Burden			Stigma		
	β	P	OR (95 % CI)	β	P	OR (95 % CI)
Fourth stage of Alzheimer	1.3	0.001	6.1 (2.2 – 7.5)	2.4	0.000	6.8 (2.5–18.9)
Female	2.2	0.040	5.4 (2.4–12.2)			
Married caregiver	5.6	0.021	4.2 (1.9–9.1)	---		
Illiterate	---			11.3	0.047	10.2 (4.3–24.2)
Governmental employee	---			14.7	0.031	6.8 (2.5–18.9)
Organizational employee	4.3	0.001	7.4 (3.3–11.8)	---		
Not enough Income	1.7	0.007	4.3 (1.7–10.5)	---		
No others help you	7.2	0.010	8.4 (3.3–21.3)	---		

Discussion

Caregivers' stigma perception has an effect on burden. However, this effect among those caring for a relative with Alzheimer's disease (AD) has yet to undergo theoretical and empirical analysis **Perla et al., (2011)**. So, the aim of our study was to assess relationship between caregiving burden, knowledge and stigma of caregivers caring for older adults with Alzheimer disease.

A recent national survey in 2020 suggested that approximately two in every three caregivers are women (**Prudencio & Young, 2020**). This fosters our results as the present study showed that more than two thirds of the study sample were females, and this can be attributed to being the primary care providers and usually accompany the elderly during the hospital visits. This finding is consistent with the study by **Schulz et al., (2016)** as more than two-thirds of their caregivers in their study were females. A study in 2008 revealed that 81% among Vietnamese and Chinese AD Caregivers were daughters and daughters-in-law.

In this study, more than half of the caregivers aged more than 45 years old. This may be due to the mean age of marriage in Egypt is 20 to 25 years old, thus the difference between the ages of the parent and his first child is 25 years. Previous studies by **Tan et al., (2021)** found that the mean age of their participant caregivers was 55.6 years, and **Alhasan et al., (2021)** showed that the mean age of their participant caregivers was 58.9 years. In the same line, **Sharma et al., (2016)** claimed that the female caregivers have higher levels of burdens than males and explained that

they are elderly persons' wives or adult daughters, and they are at their middle age. They are also more likely to be employed outside the home. More recently, researchers reported that there is an increase in the proportion of men who deliver care for the elderly, men may constitute approximately half of the elderly primary caregivers (**Akpinar et al., 2011**).

Caring for an elderly with AD may have additional challenges, and this may put family caregivers at particularly elevated risk of burden. The present study, reported that the majority of the studied caregivers had moderate to severe burden. This result may be justified by despite of caregiving being a satisfying experience some times in our culture it is still emotionally draining, physically demanding and distracting the caregiver from taking care of self. Also, in Egypt there are limited social services and respite centers along with poor health delivery system. This result agrees with a study done by **Springate and Tremont, (2014)** they found that the majority of their participant caregivers endorsed high levels of burden. That's evidenced by the longitudinal study by **Dauphinot et al., (2016)** who stated that the Alzheimer patient's concomitant reduction in cognitive performance, functional impairment increase, and neuropsychiatric symptoms worsening over time were independently linked with increased caregiver burden. In the same line, caregivers in the study by **Gibbons et al., (2014)** continued to report higher levels of burden and stress.

Moreover, **Penning and Wu, (2016)** found that higher levels of burden were conveyed by younger, employed primary caregivers or whom engaged in other work-related activities rather than retired. In the same

study, burden levels were to some extent increased among female than male caregivers, but in our study, no differences were found regarding gender. That's in contrast to **Werner et al., (2012)** as they found four significant factors that affect caregiver burden: caregiver sex, length of time since diagnosis, number of years involved in caregiving, and number of hours consumed in providing care. They interpreted these results as meaning that females, caring for a recently diagnosed parent, who stated that they had spent more hours per week for caregiving for a longer duration, were more expected to report elevated levels of caregiver burden than others. There is no agreement in the literature by **Fekadu et al., (2019)** about burden level concerning the duration of time spent on caregiving. **Crowe, and Brinkley, (2015)** in their study related the burden level with time spent for caregiving. While **Tirfessa et al., (2019)** evaluated the burden at the household level. Additionally, **Weissman et al., (2016)** measured illness impact on extended families as grandparents and family members who live in separate houses without any direct contact with the elderly person. Furthermore, found a statistical significant difference between the caregiver burden and increased number of daily hours caring in our study. This result may be due to the decline in physical functioning occurs with increasing with Alzheimer elderly, and become more dependent on others to meet their needs and also, most of them had advanced disease stages. Therefore, increased caregiver burden is expected. This result is consistent with other studies (**Loureiro et al., 2013** and **Garlo, 2010**).

Regarding income, the present study revealed that caregivers who didn't have enough income had a significant relation with burden, stigma and knowledge. This result may be due to that the majority of the older adults and caregiver's didn't had enough income, therefore caregivers were more likely to feel the expenses of treatment, transportation, follow up in physicians' special clinics and so on. Also low income can impact to some degree caregivers' social function such as leisure activities and become more stressed. This results in line with the study done in Germany by **Götze et al (2014)** who reported

higher family caregivers' risk of psychological distress if there is high financial burden. Furthermore, the results of the study carried out in Egypt by **Salama & Abou ElSoud (2012)** and in Thailand by **Limpawattana et al (2012)** in which income was a predictor of burden. Contrary to this finding, the study of **Alacacioglu (2013)** in Turkey who found that income was not significant with caregiver's level of burden and anxiety.

In the present study, regarding the stigma subscales in the SIS, there were statistically significant relations between all demographic characteristics of caregivers and stigma subscales except in the relationship between disease stage and each of social rejection, financial insecurity, and social isolation. In the same manner, there were no statistically significant relations between financial insecurity and both marital status and relationship to the elderly. This may be contributed as the individuals tend to avoid activities with limited access or avoid social contacts altogether and the extended duration of medical treatment and daily life activities expend more finances. A study of **Hartini et al., (2018)** supporting the previous findings, reported that some stigma level score differences across groups of gender, and level of income. Meanwhile, educational level has no marked effect to the stigma score difference toward mental health patients. This is in line with the study by **Corrigan et al., (2011)** that revealed that sociodemographic factors contribute significantly to the attitude of persons with mental disorders. Also, in Israel **Werner and Heinik, (2008)** illustrated that family stigma might hinder adult children, spousal, and other family caregivers from looking for services for their loved ones.

On completing the present study and regarding the correlation between burden, stigma, and knowledge, it's shown that negative correlations were found between all of the following knowledge and burden and stigma. A negative correlation was found also between burden and knowledge. On the other hand, a positive correlation was found between stigma and burden. Similar to our findings and regarding the correlation between knowledge, stigma, and burden, **Yu et al., (2015)** found that low levels of knowledge or awareness

regarding AD as a chronic degenerative brain syndrome, caregiving experience, and the absence of supportive health and welfare service. Additionally, Cahill et al., (2015) concluded that elevating the levels of knowledge for the general population will help to decrease the dementia stigma and open up a better-informed debate about patients' needs. Roberts et al., (2014) found that elevated AD knowledge levels were found among higher educated persons, and this correlation applied to both overall levels of knowledge about dementia and Alzheimer disease. Studies by Chang et al., (2015) and Werner et al., (2011) found that stigma would be positively correlated with the caregiver burden. They explained that as families and caregivers may experience social consequences from stigmas as elevated burden and judgment and completed that this can cause interpersonal consequences, as to avoid social relationships or move to another place. Therefore, social and psychological effects of stigma as isolation can be experienced by caregiver is act as great burdens of the family or the caregivers of those patients.

In the case of the stigma of AD, Rosin et al., (2020) stated that in late stages of the disease once all symptoms of the disease are realized. Increased stigma for the caregiver at this stage can increase caregiver burden. The results of this study also proved the same result as through the use of Logistic regression test revealed that independent predictors of *burden* were the fourth stage of diseases, female sex, married caregiver, organizational employee, not enough income and no others help the caregiver. Additionally, Springate and Tremont, (2014) found that gender, marital status caregivers, and their working status. Their burden had a more direct correlation with dementia impact on their lives and feelings of guilt. While the independent predictors related to stigma among AD caregiver were the fourth stage of the disease, being illiterate, and the governmental employees. This can be explained by when AD symptoms become too severe, the caregiver need to manage situations including increasing social isolation for elderly, and the caregiver isolating themselves from the elderly and realigning with other member of the family.

Our findings highlight the importance of reducing family caregivers' burden and sense of stigmatization and help them to cope with their caregiving role. Caregivers and other healthcare teams should acknowledge informal caregivers and older adult patients as one unit of care, need for information, support, and a sense of medical partnership.

Conclusion:

Based on findings of our study, we can conclude that moderate and severe caregiving burden was common among family caregivers who care for older Alzheimer patient associated with high mean score of stigma. A statistical significance between all demographic characteristics of family caregivers and each of caregiving burden, stigma, and Knowledge. A strong positive correlation was found between caregiver's burden and stigma. On the other hand, a positive correlation was found between stigma and burden.

Recommendations:

- The longitudinal effects of stigma on social support and other caregiver outcomes should be evaluated.
- Educational program for family caregivers about AD processes, the way of symptoms management and experiences and finding resources to reduce the caregiving burden and improve their knowledge and reduce sense of stigmatization.
- Formal caregiver should be involved in caring of Alzheimer patients to minimize burden in family caregivers.

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