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Burden of care and quality of life among informal caregivers to Alzheimer patients in Egypt

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Abstract

Background. Alzheimer's disease is a chronic neurodegenerative disorder that results in total cognitive impairment and functional decline. Family members are the most usual caregivers worldwide, resulting in an increasing total burden and a subsequent degradation of their quality of life.

Objectives. To evaluate the burden of care and quality of life among informal caregivers to Alzheimer patients in Egypt.

Methods. A descriptive research design was used. The study was conducted at outpatient clinics of El-Abbasya Mental Hospital in Cairo, Egypt. This study included 550 informal caregivers of Alzheimer patients. Data were gathered through questionnaires using the Sociodemographic Profile of Family Caregivers, an adopted version of the Montgomery Borgatta Caregiver Burden scale, and Health-Related Quality of Life Scale.

Results. Nearly three quarters (73.5%) of the informal caregivers were female. Additionally, the physical burden among the informal caregivers was the highest (21.58 ± 8.13), while the psychological burden was the lowest (7.48 ± 25.35). Besides, around one-third (30%) of the informal caregivers had a total poor quality of life.

Significance of results. Total burden among informal caregivers of Alzheimer patients was relatively high (64.71 ± 26.86). Moreover, less than one-tenth (8%) of the informal caregivers for Alzheimer's patients had a good quality of life, whereas more than half (62%) of them had an average quality of life. In the Egyptian context, ongoing health education initiatives for those who care for Alzheimer patients are essential, and additional research employing large study sample sizes in varied contexts is strongly advised.

Introduction

According to estimates, 6.5 million American individuals aged 65 and older suffer from Alzheimer's disease (AD). By 2060, this number could reach 13.8 million if no medical advances are made to prevent, slow down, or cure AD. In total, 121,499 deaths from AD were recorded on official death certificates in 2019, the most recent year for which data are available. AD was the sixth-leading cause of death in the US in 2019 and the seventh-leading cause in 2020 and 2021 when COVID-19 entered the top 10 causes of death. AD is still the fifth-leading cause of death for Americans aged 65 and over. Fatalities from heart disease, HIV, and stroke all dropped between 2000 and 2019, while reported deaths from AD rose more during that time (Alzheimer's disease facts and figures 2022).

This increase may be linked to both an increase in life expectancy and population growth overall. Another factor in the demographic transition toward an elderly population is a lower birth rate. The number of older people is estimated to rise by 56% in higher-income nations between 2015 and 2050, by 138%–185% in middle-income countries, and by 239% in low-income countries. It is also anticipated that the prevalence of dementia will rise in the Arab world as a result of these changes in population dynamics (Wimo et al. 2015).

However, there are gaps in the epidemiological data on the prevalence of AD in Egypt. Due to the significant amount of young people in the community, it is suggested that Alzheimer is not seen as a health threat. Additionally, the public's perception of Alzheimer as a symptom of healthy aging undervalues its importance. However, the current demographic shift makes Alzheimer a future issue that needs to be considered. In 2013, there were around 4 million people in Egypt who were 65 or older. The effects of Alzheimer will also rise as this age group is projected to grow to 13.3% of the population by 2050. When compared to other nations

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in the North African and Middle Eastern region, Egypt has a significantly lower frequency of Alzheimer (Elshahidi et al. 2017).

By definition, providing care is a very demanding activity, particularly when the patient has a chronic, degenerative illness that offers many difficulties, like AD. Although 1 of the early signs of the disease is a loss of recent memory, higher degrees of supervision and personal care are needed as decision-making, orientation, and ultimately communication skills gradually deteriorate. Patients who are suffering from advanced disease may be totally reliant on their carers, even for simple everyday tasks like eating and taking a shower (Arvanitakis et al. 2019).

A controlled environment like a nursing home with the assistance of "official" caregivers like nurses and doctors is one way to regularly provide this level of care. However, family members (informal caregivers) often provide care in an "informal" and unpaid capacity (mostly spouses and adult children). These caregivers, who lack professional training, may become emotionally and physically exhausted due to their continual interaction with the patient. They have been referred to as "the secret victims" of AD so frequently (WHO 2019).

The term "caregiver's burden" was used to indicate the buildup of issues that could eventually impair a caregiver's own professional and social life, emotional well-being, and profitability. These problems can include everything from social isolation and money troubles to the stress associated with caring for AD patients. Although caring for a loved one who has AD can be challenging, too much stress can be harmful to both parties and lead to caregiver burnout. Compared to other chronic conditions, Alzheimer patients' caregivers report a heavier burden. Additionally, several professions have found that providing care for someone with AD negatively impacts their health, work, income, and financial security (Andreakou et al. 2016).

In addition, there are not enough Alzheimer's associations, medical professionals, or care facilities to handle this illness. Furthermore, a lack of information on AD may result in caregivers' ignorance of the condition, unfavorable attitudes toward Alzheimer patients, and an increase in their subjective burden. Because they are unable to properly care for the patients' bodily and psychological needs, this issue has a negative impact on the patients (Khalil et al. 2020).

Egypt lacks specialist nursing and residential facilities, home-visiting programs, as well as a support structure for families of Alzheimer patients. In other words, family/informal caregivers, in particular, are required to assume full responsibility for caring for their loved ones with AD. Due to this circumstance, the risk of care load on Egyptian carers is increased. Additionally, past research have shown that caregivers in wealthy nations with excellent home health-care and rehabilitation services frequently experience care strain. Therefore, by offering community-integrated therapies that take into account the ongoing assistance, the caregivers of Alzheimer survivors in Egypt should be assisted (Ashrafizadeh et al. 2021).

It has been demonstrated that the quality of life (QoL) of family/informal caregivers for people with AD is poorer than that of those without the condition. Important factors for the QoL of Alzheimer patients include the family caregiver's QoL and capacity to manage the disease's progression, symptoms, and other issues related to caregiving, which may postpone the individual's decline or the need to enter institutional long-term care facilities (Hazzan et al. 2022).

Aim of the study

This study aims to evaluate burden of care and QoL among informal caregivers to Alzheimer patients in Egypt.

Methods

To meet the objectives of the study, a cross-sectional descriptive design was used. The study was conducted at the outpatient clinics of the Abbasiya mental hospital in Nasr City, Cairo, Egypt. Abbasiya Hospital for Mental Health is located in Cairo Governorate, and it is the first mental hospital in Cairo. The hospital involves specialized outpatient clinics: pediatric psychiatry clinic, adolescent psychiatry clinic, clinic for autistic children, trauma clinic for children and adolescents (Waha), evening addiction treatment clinic for teens, addiction and substance abuse treatment clinic, evening addiction treatment clinic, geriatric psychiatry clinic, smoking cessation clinic, and Oasis clinic for adults.

Participants

Total number of the study participants was 550 informal family caregivers of the Alzheimer patients. A purposive sample of all family caregivers of the Alzheimer patients attending the previous mentioned setting was included. The primary caregiver for an Alzheimer patient is described as his/her family. The caregiver could be a son, a daughter-in-law, a spouse, a grandson, or a spouse. The following inclusion criteria must be met by the caregivers to be included: (1) Caregivers' age must be at least 18 years, (2) patient with AD within 6 months, and (3) patient should have a modified Rankin Scale score of 3–5 at enrollment. If a patient has met either of the following criteria, the caregivers were excluded: (1) Other forms of immobility, such as fractures, dislocations, spinal cord, or vertebral injuries and (2) terminal illnesses, such as cancer, liver or renal disease, as well as any other illnesses. Cognitively impaired caregivers are not included in the study.

Tools for data collection

Data was collected for this study by using the following tools:

Tool (I): Questionnaire on the Sociodemographic Profile of Family Caregivers
Toledano-Toledano et al. (2019) adopted and created this instrument. It included information on the demographics of both patients and caregivers that was related to personal characteristics (age, sex, marital status, employment status, level of education, monthly income, genetic and present health problem, number of family member, number of children of the family, relation to the patient, number of years diagnosed with Alzheimer, hours of daily care needed, number of years provide care of the patient, family support for care giving activities, and the formal support services).

Tool (II): Montgomery Borgatta Caregiver Burden Scale
Caregiver Burden Scale was first created by Monteiro et al. (2018). The 3 types of informal family caregiver burden that this instrument was designed to measure are as follows: The first part was objective (Physical Burden), which included 6 items that caused a caregiver's life to be disrupted while doing caregiving duties (1:6). The relationships between the caregiver and care recipient were based on the demands of caregiving responsibilities, and this

second part, relationship and economic (Social Burden), included 5 items (7:11). There were 5 items in the third part, which was stress and emotional (Psychological Burden), which examined the emotional toll of providing care (12:16).

On a 5-point Likert scale, from 1 (not at all) to 5, family caregivers' responses were scored according to the Caregiver Burden Scale (a great deal). Each subscale's burden ratings are added up, with higher scores indicating heavier loads. The total score was divided by the number of items, yielding a mean score for the different components of caregiver burden. The researcher computed means and standard deviations. It would be good if the % score was greater than 70, average if it was between 50 and 70, and poor if it was less than 50.

Tool (III): Health-Related Quality of Life (HRQOL) Scale

Al Abdulmohsin et al. (1997) adopted and created the scale with the intention of evaluating HRQOL. HRQOL scale included multi-item scales to measure 8 aspects of health: physical functioning (items 1, 2), bodily pain (items 7, 8), role limitations brought on by physical health issues (items 3, 4), limitations brought on by emotional problems (item 6), emotional well-being (item 5), social functioning (item 10), energy/fatigue (item 9), and general health perceptions (item 11).

A score of 100 correlates to a high level of functioning, and a score of 50 is considered to be ordinary or normal on the Short-Form Health-Related Quality of Life Translated Scale (HRQOL). Higher values denote a higher HRQOL. The sum of the item scores was divided by the number of items to produce the mean score for HRQOL. We computed means and standard deviations. It is regarded as good if the % score was greater than 70, average if it was between 50 and 70, and poor if it was less than 50.

The modified tool (I) was evaluated for validity by a jury of 5 nursing and public health professionals to see if it met the study's goals and to ensure that the measuring instrument appeared to be measuring what it was intended to measure. The appropriate adjustments were then made. This phase took place over a 2-month period, during which the instrument was examined for clarity, relevance, thoroughness, understanding, and applicability. They were asked for feedback on the consistency, format, and layout of the tool. The appropriate adjustments were made as a result. By measuring the internal consistency of the produced tools, the Cronbach's alpha was calculated to evaluate their dependability. The Caregiver Burden Scale for Montgomery Borgatta caregivers had a reliability score of 0.79, and the Short-Form Health-Related Quality of Life Translated Scale (HRQOL) had a Crohnbach's alpha value of 0.82) on the cognitive evaluation questionnaire for Alzheimer patients.

Procedure

The researcher began collecting data after acquiring permission from responsible and authorized authorities to proceed with the current study. He also contacted each potential family care provider to explain the study's objectives and methodology. Participants in the study were provided the tools for collecting data once the objective was explained to them. Each participant was given a time limit of 30 to 45 minutes.

Statistical analysis

Statistical analysis was conducted using SPSS software version 23 (IBM Corporation, Chicago, IL, USA). The demographic

characteristics of the Alzheimer patients and informal family caregivers who participated were quantified using numbers and percentages. The study variables' means and standard deviations were calculated. To find variations in the study results based on demographic factors, an independent sample t-test and 1-way analysis of variance (ANOVA) were performed. The total burden scale and QoL of the informal family caregivers were calculated using the Pearson's r correlation coefficient. Multiple linear regression analysis and ANOVA for the complete regression models were used to determine the independent predictors of the burden scale and QoL scores. Statistical significance was set at $p < 0.05$.

Results

Table 1 describes the demographic data of the informal caregivers and reveals that 40% of the informal caregivers were aged between 30 and 40 years with a mean standard deviation of 43.13 ± 7.09 years, 73.5% of the informal caregivers were female, 43% of them had a moderate educational level, and 65% were married. The data also showed that 50.9% of the informal caregivers were working (part time only). Ultimately, the findings showed that 64.5% of the informal caregivers claimed to have a sufficient income.

Besides, first-degree relatives of the informal caregivers made up 45.1% of the patients. In addition, 80% of the informal caregivers claimed to reside with their patients, and 58% of them had been the patients' primary caregivers for more than 5 years. The data also showed that 55.5% of the informal caregivers reported they spent fewer than 6 hours a day with their patients, and 58% of the patients of the caregivers had been diagnosed with AD and/or dementia for more than 5 years. This table also showed that 39.1% of the informal caregivers engaged the patients in routine daily activity.

Table 2 reveals that 53.6% of the Alzheimer patients aged 70 years and more had a mean standard deviation of 67.17 ± 8.12 years, 61.8% of informal caregiver's patients were female, and 54% of Alzheimer patients had a low educational level. The results also showed that 55% of the patients were unmarried and 75% of them not working. Ultimately, the findings showed that 69.1% of the patients claimed to have not enough income.

According to Table 3, the physical burden of the informal caregivers of Alzheimer patients was the highest (21.58 ± 8.13), while the psychological burden was the lowest (7.48 ± 25.35). In addition, the data showed that the total burden scale for Alzheimer patient caregivers was 64.71 ± 26.86. Besides, only 8% of the Alzheimer patient caregivers reported an overall good QoL, compared to 62% who had an average QoL.

Table 4 shows the correlation between the burden scale and the QoL of the caregiver. As shown in the table, there was a highly statistically significant positive association between caregivers' overall burden rating and the quality of care provided to Alzheimer patients at $p = 0.05$.

Table 5 presents the relationship between informal caregivers' burden scale and their personal characteristics. As shown in the table, there were highly statistically significant disparities in the informal caregivers' employment status, and yearly income, with their total burden scale.

Table 6 shows the relationship between informal caregivers' QoL and their personal characteristics. This table illustrates a highly statistically significant relationship between caregivers' QoL

Table 1. Informal caregivers distribution based on sociodemographic personal characteristics (*n* = 550)

Variable	N	%
Age		
<30 years	160	29.1
30–40 years	220	40
≥40 years	170	30.9
Mean ± SD	43.13 ± 7.09	
Sex		
Male	146	26.5
Female	404	73.5
Educational level		
Low	165	30
Moderate	237	43
High	148	27
Marital status		
Unmarried	193	35
Married	357	65
Employment status		
Not working	270	49.1
Working (part time only)	280	50.9
Monthly income		
Enough	355	64.5
Not enough	195	35.5
Degrees of kinship with patients		
(Spouse, son, daughter…) First	248	45.1
Second	204	37.1
Third	98	17.8
Live with the patient		
Yes	440	80
No	110	20
Number of years provide care for the patient		
<5	231	42
≥5	319	58
Period since the patient's Alzheimer's diagnosis		
<5 years	231	42
≥5 years	319	58
Time spent each day by caregivers providing care for the patient		
<6 hours	305	55.5
≥6 hours	245	44.5
Kinds of assistance the caregiver can offer the patient		
Routine daily activity	215	39.1
Indicative activates	190	34.5
Recreational/supportive	145	26.4

Table 2. Distribution of informal caregivers, Alzheimer patients according to personal characteristics (*n* = 550)

Variable	N	%
Age		
<60 years	255	46.4
≥70 years	295	53.6
Mean ± SD	67.17 ± 8.12	
Sex		
Male	210	38.2
Female	340	61.8
Educational level		
Low	297	54
Moderate	176	32
High	77	14
Marital status		
Unmarried	319	58
Married	231	42
Employment status		
Not working	413	75
Working	137	25
Monthly income		
Enough	170	30.9
Not enough	380	69.1

Table 3. Distribution of Informal caregivers based on their total burden scale and quality of life (*n* = 550)

Burden assessment categories	Scores	*p*-Value
Social Burden	17.78 ± 2.05	0.001*
Physical Burden	21.58 ± 8.13	0.001*
Psychological Burden	7.48 ± 25.35	0.001*
Total	64.71 ± 26.86	0.001*
Total quality of life	N	%
Poor	165	30
Average	341	62
Good	44	8

*significant at *p*-value 0.001.

Table 4. Correlation between quality of life and Burden scale for informal caregivers (*n* = 550)

Items	*r*-Value	*p*-Value
Quality of life vs Caregiver Burden Scale	0.186	0.015*

r = Pearson correlation test. *Significant ($p < 0.05$).

and age. No other statistically significant relationships could be found.

In Table 7, female gender and job are shown to be statistically significant independent positive predictors of burden scale.

Table 5. Relation between personal characteristics of the informal caregivers and their total burden scale ($n = 550$)

Variables	Scores	F-Value	p-Value
Age			
<30	49.52 ± 10.92	0.185	0.798
30–40	49.34 ± 9.29		
≥40	52.38 ± 8.15		
Marital status			
Unmarried	53.02 ± 12.77	0.111	0.865
Married	52.58 ± 5.28		
Educational level			
Low	52.90 ± 11.19	1.744	0.165
Moderate	50.48 ± 10.85		
High	48.59 ± 6.38		
Employment status			
Not working	47.33 ± 10.92	2.571	0.025*
Working	52.93 ± 8.01		
Sex			
Male	52.73 ± 8.17	2.611(t)	0.106
Female	51.58 ± 11.07		
Annual income			
Enough	50.53 ± 7.91	4.018	0.005*
Enough and more	51.68 ± 4.10		

*Significant at P-Value <0.05.

Table 6. Relation between personal characteristics of the informal caregivers and their total quality of life ($n = 550$)

Variables	Scores	F-Value	p-Value
Age			
<30 years	76.45 ± 3.85	1.862	0.013*
30–40 years	79.62 ± 4.67		
≥40 years	65.82 ± 6.32		
Marital status			
Unmarried	83.51 ± 11.71	0.535	0.694
Married	77.42 ± 4.49		
Educational level			
Low	78.20 ± 7.39	0.641	0.669
Moderate	75.05 ± 5.52		
High	75.35 ± 7.04		
Employment status			
Not working	77.22 ± 4.84	0.992	0.435
Working	76.02 ± 5.80		
Sex			
Male	74.31 ± 6.61	1.518 (t)	0.221
Female	75.77 ± 5.18		
Annual income			
Enough	74.97 ± 5.34	0.443	0.643
Enough and more	76.17 ± 5.55		

F = ANOVAs test, t = t-test *Significant ($p < 0.05$).

The model also showed that 28% of the burden score's volatility. The optimal multiple linear regression models for the QoL score are shown in Table 8. The model accurately captured 8% of the volatility in the quality score, as seen. None of the traits had a discernible impact on this score.

Discussion

A caregiver burden is a complicated phenomenon that has diverse effects on both patients and caregivers. It is critical to not neglect or disregard the needs and concerns of the caregiver in the desire to provide the sick person with more comfort. The purpose of this study was to evaluate burden of care and QoL among informal caregivers to Alzheimer patients in Egypt. The current study's findings revealed that two-fifths of the informal caregivers aged between 30 and 40 years with a mean standard deviation of 43.13 ± 7.09, and slightly more than two-fifths of the caregivers had a modest educational level. Besides, slightly less than three-quarters of the informal caregivers are female. Additionally, around two-thirds of the informal caregivers were married, and half of them held jobs.

According to the researcher, as for female caregivers, half of them work "part time", they may have time to take care of their families of Alzheimer patients. Two-third of them are married, as this is one of the Egyptian people's customs and traditions to marry during that period or before, and about half of the sample are employees, which may result in an increase in the burden they bear while they work and care for family members with AD, in addition to the stresses of marriage and raising children.

In the same context, the findings clarified that more than two-fifths of the Alzheimer patients were cared by the caregivers' first-degree kinship. This demonstrates the strong bond that exists between family members and their parents and relatives, as well as the extent of belonging and solid family bonding for family members, as they adhere to the teachings of the tolerant Islamic religion, which calls for benevolence to parents, good kinship ties, and supervision of their services and care, particularly between children and their families. Kindness to children at a young age results in kindness toward parents in old age. This result was supported the study conducted by Mas et al. (2021), and reported that most of the Alzheimer patients were served by their off springs.

Also, the study showed that more than half of the informal caregivers had cared for the patients as their primary caregivers for more than 5 years. Additionally, the data revealed that more than half of the patients of the caregivers had been diagnosed with AD and/or dementia for more than 5 years, and 55.5% of the caregivers said they only spent less than 6 hours a day with their charges. According to the researcher, the first 3–5 years of caring for a person with Alzheimer's are particularly challenging for the caregiver, especially since they spend an average of 6 hours a day with the patient in addition to their regular jobs.

The informal caregivers may feel a heavy load from all of these, which has an impact on their social, financial, and psychological well-being. This finding was supported by Montgomery et al. (2018), and showed that nearly two-fifths provided care to the Alzheimer patients for a period ranged from 2 to 4 years for period ranged from 1 to 5 hours daily and more. Besides, Margelaki and

Table 7. Best fitting multiple linear regression model for the burden score

	Unstandardized coefficients		Standardized coefficients	*t*-Value	*p*-Value	95% Confidence interval for *B*	
	B	Std. error				Lower	Upper
Constant	−52.51	15.85		−3.313	0.001	−83.68	−21.35
Age	2.02	0.92	0.12	2.190	0.029	0.21	3.83
Female gender	12.93	2.00	0.36	6.462	<0.001	9.00	16.86
Education	−3.86	1.61	−0.11	−2.402	0.017	−7.02	−0.70
Employment	1.44	0.15	0.48	9.485	<0.001	1.15	1.74

r-square = 0.28.
Model ANOVA: $F = 21.87$, $p < 0.001$.

Table 8. Best fitting multiple linear regression model for the quality score

	Unstandardized coefficients		Standardized coefficients	*t*	*p*	95% Confidence interval for *B*	
	B	Std. error				Lower	Upper
Constant	92.27	11.74		7.860	<0.001	69.19	115.35
Age	−2.20	0.65	−0.21	−3.361	0.001	−3.49	−0.91
Female gender	−3.63	1.42	−0.16	−2.561	0.011	−6.42	−0.84
Education	4.84	2.84	0.09	1.706	0.089	−0.74	10.43
Employment	−0.26	0.11	−0.14	−2.382	0.018	−0.47	−0.05

r-square = 0.08.
Model ANOVA: $F = 5.68$, $p < 0.001$.

Katharaki (2021), indicated that the mean years of experience of the caregivers toward caring of Alzheimer patients was 4.9 years and spending not less than 4 hours in their caring and supervision. Additionally, Queiroz et al. (2018) revealed that, slightly less than half of caregivers share the same habitat with dementia/Alzheimer patients.

According to the current study's findings, the physical burden among the informal caregivers was the highest, while the psychological burden experienced among them was the lowest. According to the researcher, the majority of informal caregivers' experience physical strain since Alzheimer patients require assistance with all areas of daily life, including eating, drinking, using the restroom, and lifting objects from one location to another. After a while, Alzheimer patients fully depend on the informal caregivers which wears the caregivers out physically, especially because the majority of them are women. Since the informal caregivers are relatives of the patients and their families, psychological stress may not be as common among them.

Abdollahpour et al. (2012), Ghezeljeh et al. (2020), Seidel and Thyrian (2019), Tsai et al. (2020), and Ohno et al. (2021) all agreed with this study's findings that the majority of caregiver's experience physical exhaustion and burden while taking care of Alzheimer patients, with only a small percentage of them being vulnerable to emotional, social, and psychological distress. In addition, when patients had more severely decreased functional autonomy and the presence of signs of apathy and irritability, the majority of elder caregivers of older demented patients experienced a higher physical care load.

The results of this study revealed that only a small percentage of Alzheimer patient caregivers had a good QoL. According to the researcher, a large percentage of caregivers have an average or poor QoL, which is logical given that they are constantly caring for families with Alzheimer patients and are completely dependent on them for all of their daily activities. Only a small proportion of caregivers have a good QoL, however.

This conclusion was reinforced by Dawood (2016), Jones et al. (2015), Froelich et al. (2021), Maldonado et al. (2017), and Andreakou et al. (2016), who found that AD patients' caregivers experience lower HRQOL compared to the general Greek urban population practically across the board. This outcome was influenced by the social roles of the carers, the presence of emotional issues, and the state of their mental health. In addition to health-related factors, caregivers of AD patients experience lower QoL over time than those of same age and sex in the general population.

The results of the current study showed a highly statistically significant positive association between overall QoL and Caregiver Burden Scale. According to the researcher, this result shows that informal caregivers' overall QoL improved when their burden and load was reduced. Kuzu and Aydin et al. (2022) concluded that there was a significant and adverse connection between care burden and QoL, negated this finding. QoL improved as care burden reduced ($p = 0.05$). According to Adelman et al. (2014), the QoL score of caregivers declined significantly 12 months after hospitalization. This study examined caregivers of patients diagnosed with AD both during and 12 months after hospitalization.

The findings of the current study puzzled out that there were highly statistical significant differences between employment status and annual income of the informal caregivers with their total burden scale. Also, there was a highly statistical significant difference between age of the informal caregivers and their QoL. From the researcher point of view, employment status and annual income and sex play an important role in occurrence and reduction of the total burden especially among the caregivers of Alzheimer patients, whereas no employment, and female gender, the more the burden acquisition. Besides, these findings donate the effectiveness of

personal characteristics of the caregivers particularly age which is the basics of life and affect strongly on their QoL.

No changes were found in the informal caregiver's relationship to the patient, marital status, sex, or employment position, according to Babarro et al.'s (2019) research. Additionally, Villars et al. (2021) came to the conclusion that factors such as age, marital status, educational attainment, and employment status are strongly related to and affect the overall QoL of those who informally care for Alzheimer patients.

Findings of the present study revealed that there was a highly statistical significant positive correlation between total QoL and burden assessment for caregiver. From the researcher point of view, this finding means that when burden reduced, total QoL of the caregivers increased. This result was contraindicated by Aydin et al (2022), Cengiz et al. (2021), and Srivastava et al. (2016), who concluded that there was a significant and negative correlation between care burden and QoL. As care burden decreased, QoL increased ($p < 0.05$).

Conclusion

Based on the findings of the present study, it can be concluded that, the physical burden was the most prevalent among the informal caregivers of Alzheimer patients, while the psychological burden was the lowest among the informal caregivers of Alzheimer patients. Besides, total burden assessment scale among the informal caregivers of Alzheimer patients was 64.71 ± 26.86. Additionally, the highest percentage of the caregivers of Alzheimer patients reported having average and poor QoL, while only little percentage of the caregivers of Alzheimer patients had total average good QoL. Also, there was a highly statistical significant positive correlation between total QoL of the informal caregivers of Alzheimer patient with total informal caregivers' burden assessment at $p < 0.05$.

Recommendations

In the light of the results of the present study, the following recommendations are suggested:

1. In the Egyptian context, ongoing health education initiatives for those who care for Alzheimer patients are essential, and additional research employing large study sample sizes in varied contexts is strongly advised. These programs must to be created in accordance with advice based on scientific research. In addition, in order to provide adequate support, future initiatives should be formed through the partnership of other sectors.

2. Materials for informal caregivers of Alzheimer patients, such as booklets and brochures, should be created based on their level of education and include all information on caregiving, the burden, and QoL to help them during their work and serve as a reminder for them.

3. Promoting the attendance of national and international congresses, seminars, and workshops by Alzheimer patients' caregivers in order to increase their knowledge about caregiving, the burden it entails, and coping mechanisms.

4. It is strongly advised to conduct similar particular research in diverse environments and with larger probability samples.

Competing interests. None declared.

References

(2022) 2022 Alzheimer's disease facts and figures. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association* **18**(4), 700–789. doi:10.1002/alz.12638

Abdollahpour I, Noroozian M, Nedjat S, et al. (2012) Caregiver burden and its determinants among the family members of patients with dementia in Iran. *International Journal of Preventive Medicine* **3**(8), 544–551.

Adelman RD, Tmanova LL, Delgado D, Dion S and Lachs MS (2014) Caregiver burden: a clinical review. *JAMA* **311**(10), 1052–1060. doi:10.1001/jama.2014.304.

Al Abdulmohsin SA, Coons S, Draugalis JR, et al. (1997). Translation of the RAND 36-item health survey 1.0 (aka SF-36) into Arabic.

Andreakou MI, Papadopoulos AA, Panagiotakos DB, et al. (2016) Assessment of health-related quality of life for caregivers of Alzheimer's disease patients. *International Journal of Alzheimer's Disease* **2016**, 9213968. doi:10.1155/2016/9213968

Arvanitakis Z, Shah RC and Bennett DA (2019) Diagnosis and management of dementia: Review. *JAMA* **322**(16), 1589–1599. doi:10.1001/jama.2019.4782

Ashrafizadeh H, Gheibizadeh M, Rassouli M, et al. (2021) Explain the experience of family caregivers regarding care of Alzheimer's patients: A qualitative study. *Frontiers in Psychology* **12**, 699959. doi:10.3389/fpsyg.2021.699959

Babarro AA, Barral AG, Ponce AD, et al. (2019) Profile and burden of care in caregivers of patients with dementia included in the ALOIS Program. *Atencion primaria* **33**(2), 61–66. doi: 10.1016/s0212-6567(04)79352-x

Cengiz Z, Turan M, Olmaz D, et al. (2021) Care burden and quality of life in family caregivers of palliative care patients. *Journal of Social Work in End-of-Life & Palliative Care* **17**(1), 50–63.. doi:10.1080/15524256.2021.1888844

Dawood S (2016) Caregiver burden, quality of life and vulnerability towards psychopathology in caregivers of patients with dementia/Alzheimer's disease. *Journal of the College of Physicians and Surgeons Pakistan: JCPSP* **26**(11), 892–895.

Elshahidi MH, Elhadidi MA, Sharaqi AA, et al. (2017) Prevalence of dementia in Egypt: A systematic review. *Neuropsychiatric Disease and Treatment* **13**, 715–720. doi:10.2147/NDT.S127605

Froelich L, Lladó A, Khandker RK, et al. (2021) Quality of life and caregiver burden of Alzheimer's disease among community dwelling patients in Europe: Variation by disease severity and progression. *Journal of Alzheimer's Disease Reports* **5**(1), 791–804. doi:10.3233/ADR-210025

Ghezeljeh N, Rafii F, and Ladani F (2020) in the caregiver burden of Alzheimer's patients: An evolutionary concept analysis. *Revista Latinoamericana de Hipertensión* **15**(1), 37–43 doi:10.5281/zenodo.4074208

Hazzan AA, Dauenhauer J, Follansbee P, et al. (2022) Family caregiver quality of life and the care provided to older people living with dementia: Qualitative analyses of caregiver interviews. *BMC Geriatrics* **22**(1), 86. doi:10.1186/s12877-022-02787-0

Jones RW, Romeo R, Trigg R, et al. (2015) Dependence in Alzheimer's disease and service use costs, quality of life, and caregiver burden: The DADE study. *Alzheimer's & Dementia* **11**(3), 280–290.. doi:10.1016/j.jalz.2014.03.001

Khalil A, Aladwani N and Aljehani S (2020) Relationship between knowledge, attitude, and burden among Alzheimer's family care givers in Jeddah, Saudi Arabia. *Saudi Journal of Nursing and Health Care* **3**(6), 167–174. doi:10.36348/sjnhc.2020.v03i06.002

Kuzu F. and Tel Aydin H. (2022) Effects of Education on Care Burden and Quality of Life to Caregivers of Patients with COPD. *Turkish Thoracic Journal*, **23**(2), 155–122. doi:10.5152/TurkThoracJ.2022.21002.

Maldonado G, Bedmar G, Casares F, *et al.* (2017) Health-related quality of life in caregivers of patients with Alzheimer disease. *Neurología* **32**(8), 508–515 doi:10.1016/j.nrleng.2016.02.011

Margelaki A and Katharaki M (2021) Assessing the burden of family caregivers of people with dementia living in the community of a Greek Island. *International Journal of Nursing and Health Care Research* **4**, 1227. doi:10.29011/2688-9501.101227

Mas M, Aribau A, Souza D, *et al.* (2021) Improving the quality of life of family caregivers of people with Alzheimer's disease through virtual communities of practice: A quasi-experimental study. *International Journal of Alzheimer's Disease* **2021**(1), 8817491. doi:10.1155/2021/8817491

Monteiro AMF, Santos RL, Kimura N, *et al.* (2018) Coping strategies among caregivers of people with Alzheimer disease: A systematic review. *Trends in Psychiatry and Psychotherapy* **40**(3), 258–268 doi:10.1590/2237-6089-2017-0065

Montgomery W, Goren A, Wrobleski K, *et al.* (2018) Alzheimer's disease severity and its association with patient and caregiver quality of life in Japan. *BMC Geriatrics* **18**, 141. doi:10.1186/s12877-018-0831-2

Ohno S, Chen Y, Sakamaki H, *et al.* (2021) Humanistic burden among caregivers of patients with Alzheimer's disease or dementia in Japan: A large-scale cross-sectional survey. *Journal of Medical Economics* **24**(1), 181–192. doi:10.1080/13696998.2021.1877149

Queiroz R, Camacho A and Gurgel J (2018) Socio-demographic profile and quality of life of caregivers of elderly people with dementia. *Revista Brasileira de Geriatria e Gerontologia* **21**(2), 205–214. doi:10.1590/1981-22562018021.170170

Seidel D and Thyrian J (2019) Burden of caring for people with dementia – Comparing family caregivers and professional caregivers. A descriptive study. *Journal of Multidisciplinary Healthcare* **12**, 655–663. doi:10.2147/JMDH.S209106

Srivastava G, Tripathi RK, Tiwari SC, *et al.* (2016) Caregiver burden and quality of life of key caregivers of patients with dementia. *Indian Journal of Psychological Medicine* **38**(2), 133–136. doi:10.4103/0253-7176.178779

Toledano-Toledano F, Rodríguez-Rey R, Moral de la Rubia J, *et al.* (2019) A sociodemographic variables questionnaire (Q-SV) for research on family caregivers of children with chronic disease. *BMC Psychology* **7**(1), 1–11. doi:10.1186/s40359-019-0350-8

Tsai CF, Hwang WS, Lee JJ, *et al.* (2020) Predictors of caregiver burden in aged caregivers of demented older patients. *BMC Geriatrics* **21**(59), 2–9. doi:10.1186/s12877-021-02007-1

Villars H, Cantet C, de Peretti E, *et al.* (2021) Impact of an educational programme on Alzheimer's disease patients' quality of life: Results of the randomized controlled trial THERAD. *Alzheimer's Research & Therapy* **13**(1), 152. doi:10.1186/s13195-021-00896-3

Wimo A, Ali G, Guerchet M, *et al.* (2015) World Alzheimer Report 2015: The global impact of dementia: An analysis of prevalence, incidence, cost and trends. London: Alzheimer's Disease International, 87. https://www.alzint.org/u/WorldAlzheimerReport2015.pdf (accessed 12 May 2022).

World Health Organization (2019) Risk reduction of cognitive decline and dementia: WHO guidelines. In *Risk Reduction of Cognitive Decline and Dementia: WHO Guidelines* Geneva: World Health Organization, 401–401.