
BURDEN ASSESSMENT AND QUALITY OF LIFE AMONG CAREGIVERS FOR ALZHEIMER'S PATIENTS

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ABSTRACT

Background The burden associated with caring for Alzheimer's patients not only affects the health of family caregivers and increases their mortality risk, but also reduces the quality of caregiving. **Aim:** To assess burden and quality of life of caregivers of Alzheimer's patients. **Design:** A cross-sectional descriptive research design was applied. **Setting:** This study was carried out at neurologic outpatient clinics of psychiatric hospital in Port Said city. **Subjects:** A Purposive sample of all family caregivers of Alzheimer's patients (110) were included. **Tools of data collection:** Family Caregivers' Socio-Demographic Information Questionnaire; Caregivers' Burden Scale; and Short Form Health-Related Quality of Scale were used. **Results:** Mean age of caregivers was 41.36 ± 12.74 and more than two-thirds of them were females. Also, physical burden was the most prevalent at 19.45 ± 3.47 among caregivers. Furthermore, the highest percentage 71.8% of caregivers reported having poor quality of life concerning limitations of activities. Additionally, there was a highly statistically significant positive correlation between the total quality of care of caregivers of Alzheimer's patients with caregiver's total burden assessment at $P < 0.05$. **Conclusion:** Total burden assessment among the caregivers of Alzheimer's patients was 51.43 ± 9.20 ; with a higher percentage of the caregivers of Alzheimer patients had the total average quality of life, while a lower percentage of the caregivers of Alzheimer patients had a total average good quality of life. **Recommendations:** Continuous health educations programs for caregivers of Alzheimer's patients are necessary needed and further studies using a large study sample size in different settings are highly recommended.

Keywords: Alzheimer's, Burden of care, Family Caregivers, Quality of life.

INTRODUCTION

The burden of care is a concept emerging in the literature that describes the physical, emotional, social, and financial problems that can be experienced by family caregivers. The burden associated with caring for Alzheimer's patients not only affects the health of family caregivers and increases their mortality risk, but also reduces the quality of caregiving (Monteiro, Santos, Kimura, Baptista&Dourado, 2018).

Alzheimer's disease (AD), the most common form of dementia, is the term that describes the loss of mental abilities in a variety of areas of cognition, such as memory, speech, executive functions, and visuospatial skills. This loss is so severe that it leads to the impairment of everyday, professional, and social activities of the individual. Approximately 26.6 million people worldwide are living with AD. This number is expected to quadruple to more than 100 million by 2050. In 2010 the worldwide cost of dementia was 604 billion dollars. In Europe alone, overall expenditures related to dementia exceeded 170 billion € by 2006(WHO, 2019).

Caregiving is by definition a very stressful task, especially when the patient faces a chronic, degenerative disease that presents several challenges such as AD. Although the loss of recent memory is one of the early symptoms of the disease, the gradual loss of decision-making, orientation, and finally communication requires increased levels of supervision and personal care. In the final stages of the disease, patients may be completely dependent on their caregivers, even for basic daily activities such as eating and bathing(Babarro, Barral, Ponce, Ruiz, & Pastor, 2019).

One option for the provision of this level of care consistently is to provide it in an organized facility like a nursing home through "formal" caregivers, such as nurses and doctors. More often, however, care is provided by relatives (usually spouses and adult children), in an "informal" unpaid fashion. These caregivers, without formal training, may end up both emotionally and physically exhausted due to the round-the-clock involvement with the patient. This is why they have often been called "the hidden victims" of AD(Smith and Graves, 2021).

The caregiver's "burden" is a term coined to describe the accumulation of problems ranging from the stress involved in caretaking for AD patients to social isolation and financial problems that eventually could damage a caretaker's own professional and social life, physical and mental health, and financial prosperity. Caregivers of

Alzheimer's patients report more burden compared to caregivers of people with other chronic diseases, it can be overwhelming to take care of a loved one with Alzheimer's, but too much stress can be harmful to both and can lead to caregiver burnout. Furthermore, caring for someone with Alzheimer's disease has been found to hurt the health, employment, income, and financial security of many caregivers (Monteiro, Santos, Kimura, Baptista&Dourado, 2018).

The quality of life (QoL) experienced by the family caregivers with Alzheimer's disease is lower than the QoL of family caregivers for persons who don't have Alzheimer's disease. The family caregiver's quality of life and ability to manage disease progression, symptoms, and other issues surrounding the caregiving experience are important factors for the quality of life of Alzheimer's patients and may delay the person's deterioration or time of relocation to institutional long-term care alternatives (Hamad, 2017).

Supporting the family caregivers is a major focus for nurses across the healthcare system. Community health nurses are providing more care for the sick and elderly in their homes and communities, which alleviates burdens on the caregivers. They are teaching family caregivers to provide skilled care so their loved ones can live longer in their homes and avoid expensive long-term care facilities and they are teaching family caregivers how to stay healthy and well. Community health nurses are also taking on bigger roles in care coordination, care transitions, and health and wellness education and promotion, all of which support family caregivers which is helpful to improving the quality of life and care for Alzheimer's patients (Reinhard, Given, Petlick & Bemis, 2008).

SIGNIFICANCE OF THE STUDY

The World Health Organization (WHO) reported that in 2015 there will be 46.8 million people living with AD worldwide and this figure will almost double every 20 years, reaching 74.7 million in 2030. In Egypt, a systematic review estimated that the prevalence of AD among individuals aged ≥ 50 years was 2.01%-5.07%. AD is one of the leading contributors to the burden of illness and disability as they have significant implications for individuals, their families, the health care system, and the economy. Therefore future research is about reducing the impact of AD on aged care facilities and home caregivers (WHO, 2019). So it is important to assess the burden and quality of life of caregivers of Alzheimer's patients.

AIM OF THE STUDY

To assess the burden and quality of life of caregivers of Alzheimer's patients.

Through the following objectives:

- 1- Assess the quality of life among family caregivers of Alzheimer's patients.
- 2- Determine the level of burden among family caregivers of Alzheimer's patients.
- 3- Identify the relationship between caregivers Alzheimer patients' total burden assessment and their total quality of life

SUBJECT AND METHOD

Study Design:

To meet the objective of the research, a cross-sectional descriptive design was used.

Study Settings:

The study was conducted at the outpatient neurologic clinics of the psychiatric hospital in Port Said City. There are two outpatient neurologic clinics presented in the psychiatric hospital, situated at 23 December Street and the Suez Canal in front of Al-Marwa Residences, Alzhour district, Port Said. The hospital was opened to receive patients in 2006, on an area of 19 thousand square meters, more than half of which are green areas; the hospital receives patients from 5 governorates: Ismailia, Suez, Port Said, North and South Sinai, as well as patients from Dakahlia, Sharkia, and Damietta, which resulted in an increase Occupancy ratio to 100%.

The hospital has been operating since its inception with about 30 beds, and over the years the number of its beds has reached 140 beds, and the target is being achieved to reach 200 beds, with 60% of free treatment and 40% economic treatment for those who are able. Besides the hospital receives emergency cases after the completion of the official work period in light of taking all legal measures. The hospital is open 7 days a week 24 hours/day.

Study Subjects:

The total number of the study subjects was 110 family caregivers of Alzheimer's patients.

Study sample:

Purposive sample of all family caregivers of the Alzheimer patients attending from the previously mentioned settings, who are available within 6 months of data collection and fulfilling the inclusion criteria.

Inclusion criteria:

- 1- Caregivers more than 18 years old.
- 2- Both male & female
- 3- Family caregivers who care for and directly support the patient with the activities of daily living for at least 4 hours per day within the last 6 months.

Tools for Data Collection:

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

Tool (I): Family Caregivers' Socio-Demographic Information Questionnaire

This tool was adopted and developed by *Hamad (2017)*. It included demographic characteristics of patients and caregivers related to (age, sex, marital status, employment status, level of education, monthly income, genetic and present health problem, number of family members, number of children in 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 caregiving activities and the formal support services).

TOOL (II): Caregiver Burden Scale (Appendix II):-

Montgomery Borgatta Caregiver Burden Scale, the original version developed by *Montgomery, Goren, Wroblewski, Nakamura, and Ueda (2018)*. The tool was adopted and developed by *Hamad (2017)*. This tool aimed to measure aspects of caregiver burden that can be categorized into three aspects of caregiver burden:

- The first aspect: physical (Objective Burden), as disruption of a caregiver's life due to caregiving tasks consisted of 6 items (1:6).
- The second aspect: Social & economical (Relationship Burden), as relationships between caregiver and care receiver based on the demands of caregiving responsibilities, consisted of 5 items (7:11).
- The third aspect: Psychological & emotional (Stress Burden), as the emotional impact of caregiving, consisted of 5 items (12:16).

Scoring system

The scoring of the Caregiver Burden Scale for family caregivers was been answered on a 5-point Likert scale ranging from 1 (not at all) to 5 (a great deal). The burden scores in each subscale are summed, with higher scores indicating a greater burden. The score of items was summed up with the total score divided by the number of the item giving the mean score for aspects of caregiver burden. The total score is converted into a percent score, and means and standard deviations were computed. It is would be good if the percent score was ≥ 70 , while wouldbe average if the percent score is 50-70 and poor if the percent score is less than 50.

TOOL (III): Short Form Health-Related Quality Of Life translated Scale (HRQOL) (Appendix III):-

The scale was adopted and developed by *Al Abdulmohsin, Coons, Draugalis & Hays (1997)*, aimed to assess health-related quality of life. HRQOL, it included multi items scales that assess eight health concepts : physical functioning (items 1, 2), bodily pain(items 7, 8), role limitation due to physical health problems(items 3, 4), limitation due to emotional problems(item 6), emotional wellbeing(item 5), social functioning(item 10), energy/fatigue (item 9) and general health perceptions(item 11).

Scoring system

The scoring of the Short Form Health-Related Quality Of Life translated Scale (HRQOL) was been calibrated so that 50 is the average score or normal, a score of 100 corresponds to a high level of functioning, higher scores indicate a better HRQOL. The score of items was summed up with the total score divided by the number of the item giving the mean score for health-related quality of life. The total score is converted into a percent score, and means and standard deviations were computed. It is considered good if the percent score was ≥ 70 , while considered average if the percent score is 50-70, and poor if the percent score is less than 50.

II. Operational design:

The operational design included the preparatory phase, pilot study, validity & reliability of the tools, and data collection phase.

Preparatory phase:

It is based on reviewing related literature and theoretical knowledge of various aspects of the study using books, articles, internet periodicals, and magazines to develop the tool for data collection.

Content Validity

Validity was used for the modified tool (I) to determine whether the tool covered the aim of this study and to make sure that the measuring instrument looks as though it is measuring what purports to measure, this stage was developed by a jury of seven experts from faculty of nursing four experts in the field of family and community health nursing, two experts in the field of nursing administration and one expert in the field of psychiatric nursing. Then necessary modifications were done. This phase was carried out over one month, who reviewed the tool for clarity, relevance, comprehensiveness, understanding, and applicability. Their opinions were elicited regarding the tool format, layout, and consistency. The necessary modifications were done accordingly.

Reliability

The Cronbach's α was calculated to assess the reliability of the developed tools through their internal consistency, Montgomery Borgatta caregiver burden scale was Cronbach's α reliability showed 0.88 and short-form health-related quality of life translated scale (HRQOL) was Cronbach's $\alpha = 0.87$.

Pilot Study:

A pilot study was conducted on 10% (11) of the total sample of family caregivers of Alzheimer's patients, who were then included in the sample to test the reliability and applicability of the tools of the study and estimate the time required filling in them. Necessary modifications were carried out to develop the final form of the tools. It was conducted over one month before embarking on the fieldwork of the study (from the beginning to the end of March 2020).

Field Work

This study was conducted for burden assessment. Data were collected over 10 months throughout the period from the beginning of April 2020 to the end of Jan 2021; 1 month out them for obtaining the official permission, 1 month for the pilot study, the next 6 months for data collection, and the final 2 months for data entry and statistical analysis. Besides, official approval was obtained from the study set to carry out the study. A clear explanation was given about the nature and the expected outcomes of the study. The researcher started to collect data and explain the objectives of the study during the interview. The researcher started each phase with a summary of the previous one. The psychiatric hospital was visited one day/per week from the beginning to the end of the work at morning shift (Saturday and Tuesday).

Administrative design

Official permission to carry out the study from the responsible authorities was obtained. Before conducting the study, an official letter explaining the aim of the study was submitted from the dean of the faculty of nursing, Port Said University to the director of the Psychiatric hospital in Port Said city to obtain their approval to carry out the study.

Ethical consideration

Ethical consideration approval was obtained from the scientific research ethics committee of the faculty of nursing (N 14), Port Said University. Additionally, written approval was taken from the director of the psychiatric hospital to conduct the study after an explanation of the study's aim and process. All family caregivers were informed before initiating the research. Next, verbal consent was obtained from the participants before the beginning of the study after explaining the purpose of the study. Ethical considerations were maintained through anonymity and confidentiality of the collected data. Also, voluntary participation and the right to withdraw from the study were emphasized to subjects.

IV. STATISTICAL DESIGN

The collected data were organized, tabulated, and statistically analyzed using SPSS software (Statistical Package for the Social Sciences, version 22, SPSS Inc. Chicago, IL, USA). For quantitative data, the mean, standard deviation, number, and percent frequency were calculated. For qualitative data, comparison between two groups and more was done using the Chi-square test (χ^2). For comparison between two means of parametric paired data, the p-value of the (t) test was calculated. For comparison between more than two means of non-parametric data, the (p) value of the Kruskal-Wallis test was calculated, while for the comparison between more than two means of parametric data, the (p) value of the (f) ANOVA test was used. Correlation between variables was evaluated using Pearson's correlation coefficient (r). Significance was adopted at $p < 0.05$ for statistically significant interpretation of results of tests of significance, while $p \leq 0.01$ was adopted for highly statistically significant interpretation of results.

RESULTS

Table (1): This shows that 36.4 % of the caregivers are aged 31-40 years with a total Mean \pm SD of 41.36 ± 12.74 years, 70.9% of the caregivers are females and 33.6% of the caregivers had a technical institute educational level. Besides, the table revealed that 61.8% of the caregivers were married and 47.3% of them were employed part-time. Eventually, the results demonstrated that 54.5 % of the caregivers reported having enough income.

Table (1)Cont, ...: The table denoted that 41.8% of the patients were the caregivers' sons, 50.9% had more than 5 members of the family and 60.0 % of the caregivers confirmed that they had 1-3 children living in their homes. Furthermore, 50% of the caregivers stated that they lived with their patients, with 38.2. % of the caregivers had 3-5 years with their patients as primary caregivers. Moreover, the results, adduced that 45.5 % of the caregivers' patients had been diagnosed with Alzheimer's disease and/or dementia for 3-5 years and 48.2 % of the caregivers said that they spent less than 4 hours with their patients daily. Besides, the table clarified that 39.1 % of the caregivers provided daily living assistance to the patients.

Table (2): shows that the physical burden was the most prevalent at 19.45 ± 3.47 among the caregivers of Alzheimer's patients. While the Psychological burden was the lowest (15.58 ± 3.76) among the caregivers of Alzheimer's patients. Besides, the table detected that the total burden assessment among the caregivers of Alzheimer's patients was 51.43 ± 9.20 .

Table (3): indicates that the highest percentage 71.8% of the caregivers of Alzheimer's patients reported having poor quality of life concerning limitations of activities. On the other hand, the highest percentage 20% of the caregivers of Alzheimer's patients said that they had a good quality of life relating to pain items. Furthermore, the findings, elaborated that, 53.6% of the caregivers of Alzheimer's patients had a total average quality of life, while only 5.5% of the caregivers of Alzheimer's patients had a total average good quality of life.

Table(4): Adduces the relation between socio-demographic Characteristics of the Caregiver and burden assessment for caregivers. As observed in the table, there were highly statistically significant differences between employment status and the annual income of the caregivers with their burden assessment. No other statistically significant differences could be detected in the table.

Table (5): Reveals the relation between socio-demographic characteristics of the caregiver and quality of life for caregivers. As shown in the table, there was a highly statistically significant difference between the age of the caregivers and their quality of life. No other statistically significant associations could be detected in the table.

Table (6): Puzzles out the correlation between caregiver's quality of life and burden assessment. As exhibited in the table, there was a highly statistically significant positive correlation between the total quality of care of caregivers of Alzheimer's patients with the caregiver's total burden assessment at $r = 0.169$ and $P < 0.05$.

Table (1): Distribution of caregivers according to socio-demographic characteristics (n=110).

Variable	No	%
Age		
20 -	9	8.2
30 -	23	20.9
40 -	40	36.4
50 -	23	20.9
60 -	11	10.0
70+	4	3.6
Mean \pm SD	41.36 \pm 12.74	
Gender		
Male	32	29.1
Female	78	70.9
Educational level		
Primary school	10	9.1
preparatory school	21	19.1
Secondary school	23	20.9
Technical institute	37	33.6
College graduate	17	15.5
Postgraduate	2	1.8
Marital status		
Single	2	1.8
Married	68	61.8
Divorced	6	5.5
Widowed	34	30.9
Employment status		
Employed full time	9	8.2
Employed part time	52	47.3
Self-commerce	17	15.5
Retired	8	7.3
Housewife	18	16.4
occupational work	6	5.3
Monthly income		
Enough	60	54.5
Enough and more	29	26.4
Not-Enough	21	19.1

Table (1): Distribution of caregivers according to socio-demographic characteristics (n=110). (Continued)

Variable	No	%
Relationship to the Patient		
Spouse	30	27.3
Son	46	41.8
Daughter in law	3	2.7
Grandchild	31	28.2
Number of family members		
1-3	14	12.7
4-5	40	36.4
More than 5	56	50.9
Children living in your home		
1-3	66	60.0
4-5	37	33.6
More than 5	7	6.4
Live with the patient		
Yes	55	50.0
No	55	50.0
Number of years provide care for the patient		
Less than 1 year	11	10.0
1-3 years	25	22.7
3-5 years	42	38.2
More than 5 years	32	29.1
The patient has been diagnosed with Alzheimer's disease and/or dementia		
Less than 1 year	18	16.4
1-3 years	27	24.5
3-5 years	50	45.5
More than 5 years	15	13.6
Hours do you spend caring for the patient daily		
Less than 4 hours	53	48.2
5 to 8 hours	49	44.5
More than 8 hours	8	7.3
Type of assistance do you provide to the patient		
daily living activity	43	39.1
Instrumental activates	38	34.5
Both	29	26.4

Table (2): Distribution of caregiver according to their total of BurdenAssessment (no=110).

Items	Scores
Physical (Objective Burden)	19.45±3.47
Social (Relationship Burden)	16.39±4.04
Psychological (Stress Burden)	15.58±3.76
Total	51.43±9.20

Table (3):Distribution of caregivers according to their total quality of life(no=110).

Items	No	%
Physical health		
Poor	26	23.6
Average	75	68.2
Good	9	8.2
Limitation of activities		
Poor	79	71.8
Average	26	23.6
Good	5	4.5
Emotional health		
Poor	39	35.5
Average	54	49.1
Good	17	15.5
Social activities		
Poor	58	52.7
Average	47	42.7
Good	5	4.6
Pain		
Poor	47	42.7
Average	41	37.3
Good	22	20.0
Energy and emotions		
Poor	41	37.3
Average	52	47.3
Good	17	15.5
General health		
Poor	54	49.1
Average	54	49.1
Good	2	1.8
Total quality of life		
Poor	45	40.9
Average	59	53.6
Good	6	5.5

Table (4): Relation between socio-demographic characteristics of the Caregiver and their total burden assessment (n=110).

Variables	Scores	(F) (P) value
Age		
20 -	50.89± 11.61	0.198 0.963
30 -	50.48± 8.35	
40 -	51.25± 10.03	
50 -	53.04± 6.52	
60 -	51.00± 9.81	
70 +	51.75± 12.79	
Marital status		
Single	49.00± 11.97	0.100
Married	51.51± 8.45	0.964
Widowed	51.65± 10.47	
Divorced	50.00± 10.01	
Educational level		
Primary school	52.30± 10.04	1.644
Middle school	51.57± 9.59	0.155
High school	49.35± 9.58	
Technical institute	52.38± 9.05	
College graduate	53.29± 7.15	
Postgraduate	36.00± 9.20	
Employment status		
Working fulltime	42.33± 10.32	2.571
Working part-time	50.90± 9.06	0.023*
Self-commerce	56.06± 6.62	
Retired	52.63± 8.31	
Housewife	53.11± 9.91	
Occupational work	50.33± 6.42	
Gender		
Male	53.63± 6.29	2.611(t)
Female	50.53± 10.05	0.109
Annual income		
Enough	52.23± 8.81	5.011
Enough and more	53.66± 8.19	0.008*
Not-Enough	46.05± 9.94	

Table (5):Relation between socio-demographic characteristics of the caregiver and their total quality of life(n=110).

Variables	Scores	(F) (P) value
Age		
20 -	79.56± 5.79	2.960 0.015*
30 -	76.83± 6.26	
40 -	75.73± 5.32	
50 -	72.52± 5.42	
60 -	73.73± 2.86	
70 +	74.25± 4.92	
Marital status		
Single	80.50± 10.61	0.635 0.594
Married	75.43± 5.59	
Widowed	75.03± 5.83	
Divorced	74.50± 3.88	
Educational level		
Primary school	78.20± 7.39	0.641 0.669
Middle school	75.05± 5.52	
High school	75.35± 7.04	
Technical institute	75.19± 4.96	
College graduate	74.29± 4.19	
Postgraduate	76.00± 2.82	
Employment status		
Working fulltime	77.22± 4.84	0.992 0.435
Working part-time	76.02± 5.80	
Self- commerce	74.47± 4.75	
Retired	73.00± 8.26	
Housewife	73.78± 4.89	
Occupational work	75.33± 4.61	
Gender		
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	
Not-Enough	75.29± 6.76	

(F)= ANOVAsTest (t)=t- test

*Significant (P<0.05).

Table (6): Correlation between quality of life and Burden assessment for Caregivers (no=110).

Items	r	p
Quality of life vs Caregiver Burden assessment	0.169-	0.039*

(r)= Pearson correlation Test*Significant (P<0.05).

DISCUSSION

Alzheimer affects patients' personal, social, and occupational life along with significant impairment in their activities of daily living (ADL). Patient with Alzheimer becomes more and more dependent on their caregivers for their ADL as the disease progresses. In the course of this constant caregiving, the key caregiver makes lots of sacrifices. Many times key caregiver experiences a lot of strain and burden resulting from this rigorous activity of caregiving, which harms their physical, psychological, and social Quality of Life (QOL). Thus, they become more prone to developing a psychiatric disorder. About one-third of family caregivers of Alzheimer reported depressive symptoms (Srivastava, Tripathi, Tiwari, Singh, & Tripathi, 2016).

Caregiver distress and burden indicate prolonged consequences of poor physical and emotional health which in turn leads to negative effects on their quality of life and the standard of care delivered (WHO, 2019). Thus the study was conducted to assess the burden and quality of life of caregivers of Alzheimer's patients.

The findings of the current study elaborated that the physical burden was the most prevalent among the caregivers of Alzheimer's patients. While the Psychological burden was the lowest among the caregivers of Alzheimer's patients. Besides, the results detected that in total burden assessment among the caregivers of Alzheimer's patients the mean was 51.43 ± 9.20 . From the researcher's point of view, the largest percentage of the caregivers are subjected to physical burden, as the Alzheimer's patient needs help in all aspects of life, including eating, drinking, entering the toilet, and lifting from one place to another. After some time, the Alzheimer's patient becomes completely dependent on

caregivers, which results in physical exhaustion for caregivers especially since most of them are females. Psychological stress may be less prevalent among them, as the caregivers, most of whom are the sons of the patients and their families, and most of them are females, who have a sympathetic heart toward their parents. This is all thanks to the tolerant teachings of the Islamic religion, which is conscious of the love of parents and compassion for them in old age and sickness.

This study was agreed by Ghezaljah, Rafii, and Ladani (2020) in their study which is known as the caregiver burden of Alzheimer's patients: an evolutionary concept analysis concluded that most caregivers are exposed to physical exhaustion and burden while caring for Alzheimer's patients with little of them were prone to emotional, social and psychological distress. In addition, Tsai et al (2020) in the study entitled "Predictors of caregiver burden in aged caregivers of demented older patients", stated that the majority of older caregivers of older demented patients experience a higher physical care burden when patients had greater impaired functional autonomy and the presenting symptoms of apathy and irritability. Besides, around half of the sample suffered from total burden while caring for Alzheimer's patients.

Furthermore, Ohno et al (2021) who conducted a study in Japan entitled "Humanistic burden among caregivers of patients with Alzheimer's disease or dementia a large-scale cross-sectional survey concluded that Caregivers of AD/dementia patients in Japan reportedly experienced significant physical and humanistic burden which is associated with patients' living arrangements and the presence of an additional chronic condition. Therefore, the provision of effective care/support is essential to relieve the burden experienced by the caregivers.

The findings of the present study showed that the highest percentage of the caregivers of Alzheimer's patients reported having poor quality of life concerning limitations of activities. On the other hand, one-fifth of the caregivers of Alzheimer's patients said that they had a good quality of life relating to pain items. Furthermore, the findings, elaborated that, few percentages of the caregivers of Alzheimer's patients had a total good quality of life. From the researcher's point of view, the high percentage of caregivers have a limitation of activities, and this is a logical result because of their constant stay with their families of Alzheimer's patients, where the total dependence of the patients on the

caregivers in all their daily activities, and this all reflects on their overall quality of life, as a small percentage of them have a good quality of life.

This finding was supported by Andreakou, Papadopoulos, Panagiotakos and Niakas, (2016), in their study which labeled "Assessment of Health-Related Quality of Life for Caregivers of Alzheimer's Disease", which reported that AD patients' caregivers have a lower HRQoL almost in all dimensions compared to the Greek urban general population. The caregivers' social role, the existence of emotional problems, and their mental health status led to this result. In the same vein, Maldonado et al (2016) who conducted a study entitled "Health-related quality of life in caregivers of patients with Alzheimer's disease", revealed that health-related quality of life in caregivers of patients with AD deteriorates over time and is poorer than that of the age- and the sex-matched general population.

The findings of the current study puzzled out that there were highly statistically significant differences between employment status and annual income of the caregivers with their total burden assessment. From the researcher's point of view, employment status and annual income, and gender play an important role in the occurrence and reduction of the total burden especially among the caregivers of Alzheimer's patients, whereas, no employment, and female gender, the more the burden acquired. Unfortunately, these results disagreed with Babarro, Barral, Ponce, Ruiz and Pastor (2014) in the study entitled "Profile and Burden of Care in Caregivers of Patients With Dementia Included in the ALOIS Program", which indicated that no differences were detected in caregiver relation to the patient, marital status, sex or employment status of the caregiver.

Results of the concurrent study showed that there was a highly statistically significant difference between the age of the caregivers and their quality of life. From the researcher's point of view, these findings donate the effectiveness of personal characteristics of the caregivers particularly age which is the basics of life and affect strongly on their quality of life. This result came in the same line with, Villars, et al (2021), who concluded that age, marital status, educational level, and occupational status are highly associated and related to the total quality of life of the caregivers of Alzheimer's patients.

Findings of the present study revealed that there was a highly statistically significant positive correlation between the total quality of life and burden assessment for the caregiver. From the researchers point of view, this finding means that when the burden is reduced, the total quality of life of the caregivers increases. This result was contradicted by Aydin, et al (2020), who concluded that there was a significant and negative correlation between care burden and quality of life. As care burden decreased, quality of life increased ($p < 0.05$). Another study that assessed the quality of life of caregivers of patients diagnosed with AD during hospitalization and 12 months following hospitalization and conducted by Adelman, Tmanova, Delgado, Dion, and Lanchs (2014) suggested that caregivers' quality of life scores decreased significantly at 12 months after hospitalization.

CONCLUSION

Based on the findings of the present study, it can be concluded that the physical burden was the most prevalent among the caregivers of Alzheimer's patients. While the Psychological burden was the lowest among the caregivers of Alzheimer's patients. Additionally, the highest percentage of the caregivers of Alzheimer's patients reported having poor quality of life concerning limitation of activities while a lower percentage of the caregivers of Alzheimer's patients had a total average good quality of life. Also, there was a highly statistically significant positive correlation between the total quality of care for caregivers of Alzheimer's patients with caregiver's total burden assessment at $P < 0.05$.

RECOMMENDATIONS

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

- 1- The development of interventions in caregivers of dependent AD relatives to search for social support. Among these interventions, we have problem-solving interventions.
- 2- Educational materials such as booklets and pamphlets should be developed for caregivers according to their educational level, including all information about caregiving, burdens and quality of life to guide them during work and act as a reminder for them.
3. Encouraging caregivers to attend national and international congresses, seminars, and workshops to be aware of caregiving, burdens and coping strategies.

4- Replication of similar specific studies using large probability samples and different settings is highly recommended.

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تقييم العبء و جودة الحياة لدي مقدمي الرعاية الأسرية لمرضى الزهايمر

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الخلاصة

الخلفية: إن العبء المرتبط برعاية مرضى الزهايمر لا يؤثر فقط على صحة مقدمي الرعاية الأسرية وفرصه زياده مخاطر الوفاة لديهم ، بل يقلل أيضاً من جودة تقديم الرعاية ، هذا وكان الهدف من الدراسه هو تقييم عبء وجودة حياة مقدمي الرعاية لمرضى الزهايمر، هذا وتم استخدام تصميم البحث الوصفي المقطعي. تم اجراء هذه الدراسة في عيادات الأمراض العصبية الخارجية بمستشفى الأمراض النفسية في مدينة بورسعيد وقد اشتملت عينة الدراسه علي جميع مقدمي الرعاية الأسرية لمرضى الزهايمر (110). تم جمع البيانات من خلال: استبيان المعلومات الاجتماعية والديموغرافية لمقدمي الرعاية الأسرية ؛ مقياس عبء مقدمي الرعاية ؛ مقياس جودة الرعاية الصحية هذا وقد أسفرت نتائج رساله علي أن: كان متوسط عمر مقدمي الرعاية 41.36 ± 12.74 وأكثر من ثلثهم من الإناث. أيضاً ، كان العبء الجسدي هو الأكثر انتشاراً عند 19.45 ± 3.47 بين مقدمي الرعاية. علاوة على ذلك ، أفادت النتائج أن أعلى نسبة 71.8% من مقدمي الرعاية يعانون من رداءة جودة الحياة فيما يتعلق بقيود الأنشطة. بالإضافة إلى ذلك ، كان هناك ارتباط إيجابي ذو دلالة إحصائية عالية بين الجودة الإجمالية للرعاية لمقدمي الرعاية لمرضى الزهايمر مع تقييم العبء الكلي لمقدم الرعاية عند $P < 0.05$. وقد خلصت الدراسه الي أن: إجمالي تقييم العبء بين مقدمي الرعاية لمرضى الزهايمر كان 51.43 ± 9.20 ؛ مع وجود نسبة مئوية أعلى من مقدمي الرعاية لمرضى الزهايمر كان لديهم متوسط جودة الحياة الإجمالية ، في حين أن نسبة أقل من مقدمي الرعاية لمرضى الزهايمر كان لديهم متوسط جودة حياة جيدة. وقد أوصت الدراسه بأنه هناك حاجة لبرامج التنقيف الصحي المستمر لمقدمي الرعاية لمرضى الزهايمر ، وكذلك التوصيه بإجراء مزيد من الدراسات باستخدام حجم عينة دراسة كبير في أماكن مختلفة.

الكلمات المرشدة : الزهايمر ، عبء الرعاية، مقدم الرعاية و جودة الحياة