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## EFFECT OF COPING STRATEGIES PROGRAM ON QUALITY OF LIFE AND BURDEN OF CARE AMONG FAMILY CAREGIVERS OF ALZHEIMER PATIENTS

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### ABSTRACT

**Background:** Improving the effective coping strategies of caregivers of Alzheimer's patients lead to a decrease in care pressure and ultimately, promotion of their health. **Aim:** To evaluate the effect of coping strategies program on quality of life and burden of care among caregivers of Alzheimer patients at Port Said City. **Design:** A quasi-experimental design was applied. **Setting:** This study was carried out at neurologic outpatient clinics of the psychiatric hospital in Port Said city. **Subjects:** Purposive sample (110) of all family caregivers of the Alzheimer's patients were included in this study. **Tools of data collection:** The Family Caregivers' Socio-Demographic Information Questionnaire; Caregivers' Burden Scale; and Short Form Health-Related Quality of Life translated Scale were used. **Results:** Mean age of the caregivers was  $41.36 \pm 12.74$  years and 70.9% of them were females. There was a reduction in total caregivers' burden in post-test phase of the program compared to the pre and follow-up stages. In addition, there were highly statistically significant differences between total items of the caregiver burden assessment through all phases of the program. Also, there was an obvious improvement in the caregivers' quality of life levels during the program. **Conclusion:** After implementation of the program, those Caregivers who received the designed program reduced their care burden experienced and affected their quality of life positively. **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, Coping strategies, Family Caregivers, Quality of life.

## **INTRODUCTION**

Alzheimer's disease (AD) is a chronic neurological illness marked by a progressive loss of cognitive function, which typically begins with memory loss. Daily activities such as washing, dressing, eating, and going to the bathroom are frequently difficult for those with Alzheimer's disease. Alzheimer's patients are frequently reliant on their caregivers (WHO, 2019).

Alzheimer's disease is a complex illness that affects persons over 60. A rare form of familial Alzheimer's disease caused by genetic factors affects less than 0.5 percent of people with early symptoms, mainly between the ages of 30 and 50 (Bateman, et al., 2017). Furthermore, the incidence of Alzheimer's disease differs significantly between men and women. Women account for roughly two-thirds of those diagnosed with Alzheimer's disease (Alzheimer's Association, 2017). Every three seconds, a case of Alzheimer's disease (a neurological illness) is diagnosed worldwide. These disorders affected an estimated 50 million individuals globally in 2015, and the number is anticipated to double every 20 years, reaching 75 million by 2030 and 131.5 million by 2050 (WHO, 2019).

In addition, Alzheimer's disease will be diagnosed in over half a million new cases in the United States this year. Alzheimer's disease patients, on average, spend much more money on health care each year than their peers (Alzheimer's Association, 2019). Alzheimer's disease is recognized as a family disease because caregivers of persons with Alzheimer's disease are frequently concealed secondary patients who suffer from high stress, mood disorders, sadness, sleeplessness, anxiety, and a lower quality of life. Furthermore, anxiety and stress raise their chances of acquiring medical problems including headaches, back pain, and obesity, all of which may make them more likely to die than their non-dependent counterparts (Chiatti, et al., 2013).

Among cases of people with chronic conditions in general, caring for a person with Alzheimer's disease particularly is stressful, and these caregivers have been called the hidden victims of the disease. The burden of performing caregivers' tasks, coupled with emotional stress and a sense of being trapped in the caregiving role, is among the leading reasons caregivers cite for institutionalizing their loved ones (Hazzan, Ploeg, Shannon, Raina & Oremus, 2013).

The phrase "care burden" is used in the literature to characterize the physical, emotional, social, and economical difficulties that caregivers may face. Caring for people with Alzheimer's disease harms caregivers' health and increases their chance of death, as

well as lowers the quality of care. Alzheimer's disease caregivers reported a higher burden than caregivers of patients with other chronic conditions. Caring for a loved one with Alzheimer's disease can be stressful, but too much stress can be harmful to both parties and result in caregiver burnout. Additionally, caring for Alzheimer's patients has been shown to negatively impact the health, employment, income, and financial security of many caregivers (Monteiro, Santos, Kimura, Baptista, & Dourado, 2018).

Nursing is an important element of treating persons who have Alzheimer's disease; it entails supporting and monitoring the activities of those who have the disease. Personal care, domestic services, medication management, and other responsible activities where caregivers become an intrinsic part of their well-being are examples of help that might take the shape of routine medical, financial, emotional, or legal support (Gibbons, Ross, Bevins, & Year 2014).

Caregivers with Alzheimer's disease have a lower quality of life (QoL) than caregivers without the disease, according to studies. The ability to manage disease progression, symptoms, and other issues related to the caregiver experience are important determinants of quality of life for people with Alzheimer's disease and may reflect a person's deterioration or prolonged transfer to institutional settings- Alternatives to long-term care delays (Hamad, 2017).

It takes ability, attention, and organization to combine the arduous responsibility of caring for someone with Alzheimer's disease with the other responsibilities of a family caregiver. With so much attention focused on the needs of a loved one, it's easy to overlook the caregiver's health, endangering the Alzheimer's patient who is attempting to care for them. Family caregivers should develop coping methods to improve their quality of life by changing communication and behavior, maintaining routines, and seeking support when needed. Specific behavioral and psychological efforts to cope with or lessen stressful experiences are referred to as coping strategies. Coping can help to reduce the negative effects of stressful situations on one's quality of life (Monteiro, et al., 2018).

Caregivers from all sectors of the healthcare system are focused on assisting home caregivers. Community health nurses provide additional care at home and in the community for the sick and old, easing the pressure on caregivers. They teach caregivers how to offer high-quality care so that their loved ones can live longer at home and avoid costly long-term care facilities, as well as how to keep healthy themselves. Community health nurses also play a bigger role in care coordination, transition, health, and wellness

education, and support for all caregivers, all of which contribute to a better quality of life and care for people with Alzheimer's disease (Reinhard, Given, Petlick& Bemis, 2008).

**Significance of the study:**

Alzheimer's disease is becoming a global health problem as its prevalence continues to climb. Alzheimer's disease affects roughly 29.8 million people around the world. Although few papers in Egypt discuss Alzheimer's disease prevalence estimates, the global rate of aging and the rising incidence of Alzheimer's disease make neurological illnesses a big public health challenge for developing countries. The number of Egyptians suffering from Alzheimer's disease is on the rise. In 2013, there were roughly 350,000 people with the condition and linked diseases, the majority of them being elderly. Alzheimer's disease has several negative economic effects in Egypt, in addition to affecting a person's quality of life (El-Masry, Elwasify&Khafagi, 2018).

This study offers family caregivers coping methods to assist them to deal with the significant expectations and problems that come with the rising demand for long-term home care. It can also lead to integrated care management, local protection for Alzheimer's patients, and improved home care by addressing concerns and priorities, hence improving quality of life and lowering caregiver stress. Furthermore, research shows that family carers experience anxiety and burden in their quality of life (Tallawy, et al., 2019). As a result, it's critical to evaluate the influence of coping strategies on carers' quality of life and care burden.

**AIM OF THE STUDY**

The aim of this study was to evaluate the effect of coping strategies program on quality of life and burden of care among familycaregivers of Alzheimer's patients in Port Said City through the following objectives:

- 1- Assess the quality of life among family caregivers of Alzheimer's patients.
- 2- Identifythe level of burden among family caregivers of Alzheimer's patients.

- 3- Design coping strategies program for family caregivers of Alzheimer's patients.
- 4- Implement coping strategies program for family caregivers of Alzheimer's patients.
- 5- Evaluate the effect of coping strategies program on family caregivers' quality of life.
- 6- Evaluate the effect of coping strategies program on family caregivers' burden of care.

**Study Hypotheses:**

- There is an improvement in caregivers' quality of life score after implementing a coping strategies program.
- The coping strategies program has a sufficient improvement in reducing the care burden score among family caregivers of Alzheimer's patients.

**SUBJECT AND METHOD****I. Technical Design****Study Design:**

A quasi-experimental design with one group (pre/post-testing) was employed to achieve the research aims.

**Study Settings:**

The research was carried out in the Neurology outpatient clinic at Port Said Psychiatric Health Hospital. The Port Said Psychiatric Health Hospital, which is located on December 23rd Street and the Suez Canal in front of Al Marwa Residences in Port Said's Alzhour area, has two outpatient neurology clinics. The hospital, which opened in 2006, has a total size of 19,000 square meters, with more than half of that area dedicated to green space for patients. Patients come from eight provinces, including Ismailia, Suez, Port Said, North Sinai, and South Sinai, as well as Dakahlia, Sharkia, and Damietta, bringing the hospital's occupancy to 100%.

All hospital staff, including doctors, nurses, and their support workers, are working hard to improve mental health rehabilitation and medical care. The hospital has roughly 30 beds and has been in operation since its establishment. Over the years, the number of beds has grown to 140, with a goal of 200 beds, 60 percent of which are free and 40 percent of which are affordable and capable. Furthermore, the hospital accepts emergencies after official working hours, taking all legal precautions into account. The hospital is open seven days a week, 24 hours a day.

**Study Subjects:**

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

**Inclusion criteria:**

- 1- Caregivers more than 18 years old.
- 2- Caregivers who have spent at least 4 hours per day in the last 6 months caring for and personally assisting the patient with activities of daily living.

**Study sample:**

A purposive sample of carers of Alzheimer's patients attending the above-mentioned settings, both male and female, who are available within 6 months of data collection and meet the inclusion criteria.

**Tools for Data Collection:**

Data was collected for this study by using the following tools in pre & post-test.

**Tool (I): A structured Questionnaire:-**

This tool consisted of two parts; Part (1): This part is about family caregivers' socio-demographic information which was developed by Hamad (2017). It included information on the demographics of patients and caregivers (age, sex, marital status, employment status, level of education, monthly income, genetic and present health problem, number of family members, 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 caregiving activities and the formal support services).

Part (2): Cognitive Assessment Questionnaire of Alzheimer's patients: This is a short, standardized Arabic questionnaire based on World Health Organization guidelines. Tallawy, et al (2019) and developed this questionnaire to assess cognitive impairment in Alzheimer's disease patients. The questionnaire began with 24 questions divided into six categories and ended with 17 questions after being translated into Arabic through an elite group specialized in the field of translation from professors at the Faculty of Arts, Port Said University. Memory, language, orientation, visuospatial memory, everyday activities, and behavioral changes are the six components.

**Scoring system**

The cognitive Assessment Questionnaire of the Alzheimer's patients was transformed into items answered on a 3-point Likert scale ranging from 1 (mild response), 2 (moderate response), and 3 (strong response /severe response). To get the average score for cognitive impairment in patients with Alzheimer's disease, the total score was divided by the number of questions. The mean and standard deviation were determined when the

entire score was translated into one percentile. A score of 70 or higher is considered good, 50-70 is considered average, and less than 50 is considered poor.

**Tool (II): Caregiver Burden Scale:-**

The original version of the Montgomery Borgatta Caregiver Burden Scale was developed by Kosloski, Montgomery, & Savundranayagam (2011). Hamad was the one who accepted and developed the tool (2017). This instrument was designed to assess three types of caregiver burdens:

- The first aspect was physical (Objective Burden), which comprised six items that disrupted a caregiver's life due to caregiving tasks (1:6).
- The second aspect, social and economic (Relationship Burden), is comprised of five items and was defined as relationships between caregiver and care receiver based on the demands of caregiving responsibilities (7:11).
- There were five measures in the third aspect: psychological and emotional (Stress Burden), which represented the emotional impact of caregiving (12:16).

**Scoring system**

The caregiver burden scale was answered and rated on a 5-point Likert scale ranging from 1 (not at all) to 5 (very much). Each subscale's burden levels are added together, with higher scores indicating more stress. To get the average caregiver burden score, the item scores were added together and the total was divided by the number of items. The mean and standard deviation were determined when the entire score was translated into one percentile. A score of 70 or higher is considered good, 50-70 is considered ordinary, and less than 50 is considered poor.

**Tool (III): Short Form Health-Related Quality Of Life translated Scale (HRQOL):-**

To assess health-related quality of life, this scale was adapted from Al Abdulmohsin, Coons, Draugalis, & Hays (1997). HRQOL is a multi-item scale that evaluates eight health concepts: physical functioning (items 1, 2), role limitations due to physical health problems (items 3, 4), emotional health (item 5), emotional problems due to limitations (item 6), physical pain (items 7, 8), energy/fatigue (item 9), social functioning (item 10) and general perceptions of health (item 11).

**Scoring system**

The HRQOL assessment's Short Form Health-Related Quality of Life translated Scale (HRQOL) was calibrated so that a score of 50 indicates ordinary or normal functioning, a score of 100 indicates high functioning, and higher values indicate greater HRQOL.

## **II. Operational design:**

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

### **Preparatory phase:**

It used books, articles, internet journals, and magazines to develop data collection tools based on relevant literature reviews and theoretical knowledge of many aspects of research, and it creates a handout for Alzheimer's disease caregivers that contain all of the above covering points. The program had been completed.

### **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 reliability test Cronbach's  $\alpha$  was calculated to assess the reliability of the developed tools through their internal consistency. The cognitive assessment questionnaire of the Alzheimer patients was Cronbach's  $\alpha$  and split-half reliability showed a very high value of more than 0.9, Montgomery Borgatta caregiver burden scale was Cronbach's  $\alpha$  reliability showed 0.88 and short-form health-related quality of life translated scale (HRQOL) was Cronbach's  $\alpha = 0.87$ ). The reliability of all tools reveals good reliability.

### **Pilot Study:**

A pilot study was done with 10% (11) of Alzheimer's patient caregivers, who were then excluded from the sample to assess the clarity and applicability of research tools as well as estimate the time required to complete them. To develop the tool's final form, necessary changes were made. One month before the start of the research fieldwork, it was conducted (early to late March 2020).



**Field Work**

This study was conducted through four successive phases: assessment, planning, implementation, and evaluation. Data were collected over 12 months throughout the period from the beginning of April 2020 to April 2021; 1 month out of them for obtaining the official permission, pilot study, modification of the tools next 6 months for data collection and implement the program next 3 months for follow up the family caregivers of the Alzheimer patients and 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 researcher used different teaching strategies (lectures, group discussion). The psychiatric hospital was visited three days/a week from the beginning to the end of the work at morning shift (Saturday, Tuesday, and Thursday).

**Phase I: Assessment (Pre-test phase):**

This phase involved the preparation of the tools and assessment of the Cognitive capabilities of Alzheimer's Patients, in addition, to measuring aspects of caregiver burden and their health-related quality of life. The researcher visited the study setting, met with the eligible studied family caregivers of the Alzheimer's patients, introduced herself, and explained the aim of the study and maneuvers. After obtaining informed consent from the Psychiatric hospital director and oral consent from the studied family caregivers of the Alzheimer's patients, the researcher started to interview them. This was conducted individually and privately. The questionnaire sheet was filled by interviewing the studied family caregivers of the Alzheimer's patients. It took approximately (30-40) minutes to be filled. The data collected constituted a pre-test for baseline comparisons. It also served in preparing the health education program based on identified needs.

**Phase II: Planning**

The researchers developed a health education program on coping strategies, caregivers of patients with Alzheimer's disease, and related healthy quality of life based on information acquired during the initial evaluation, with the help of caregivers. To aid in the learning process and boost comprehension, the researchers created a simple flyer with Arabic handouts and a range of illustrated color photos. Includes Alzheimer's disease definitions, pathophysiology, risk factors, signs and symptoms, brucellosis history, Alzheimer's disease diagnosis and prevention, historical background of nursing,

professional qualifications of nurses, roles and responsibilities of nursing staff of Alzheimer's patients, the burden of nursing staff, coping strategies, and nursing staff quality of life.

### **Phase (III): Health educational program Implementation**

In outpatient neurology clinics at Port Said Psychiatric Health Hospital, the developed health education program is both theoretical and practical. The caregivers of Alzheimer's patients who were caring for them were separated into ten groups, each with eleven caregivers. Each group received a health education program three days a week for ten weeks; each group received the program 10 times in total, and each group received it three times a day for around half an hour each time. Over 11 weeks, the total time allotted to all groups to achieve the policy goals is 35 hours (10 groups×3.5 hours).

The goals of the study and the health education program, as well as the phases of the planning session, were explained to caregivers of the Alzheimer's patients who were assessed (time, duration, location, and content).

**Sections 1 and 2** are introductory sessions that focus on the relationship between groups and researchers and explain why techniques and sequences are used. The necessity of continuous attendance and active participation was stressed by the researchers. Each session begins with a summary of the previous session and goals for the new session, written in simple language appropriate for the level of the health education program being studied, while including motivating and reinforcement approaches. Direct reinforcement is provided as a bonus to each health education session in the form of a copy of the educational manual for future reference.

**Section 3** focuses on Alzheimer's disease (definition, causes, symptoms, and treatment).

**Section 4** examines the role of caregivers for Alzheimer's patients.

The importance and characteristics of caregiver load are discussed in **Section 5**.

The topic of quality of life and its dimensions will be explored in **Section 6**.

Teach caregivers different strategies to manage a load of care in **Sections 7 and 8**.

**Section 9** focuses on educating caregivers on how to improve their quality of life.

**In Section 10**, all program aspects are summarized and revised.

The health education program is delivered simply and concisely, serves as a reminder, and concentrates on key learning areas. During the conference, a variety of teaching approaches were employed, including interactive lectures, group discussions, and instructional media such as PowerPoint slides, photographs, and printed handouts.

Caregivers of Alzheimer's patients can ask for an explanation, elaboration, or clarification of any of the meeting's points.

#### **Phase IV: Evaluation**

Until the end of the session, participants were given the same questionnaire using the same tool (post-test). To analyze the impact of coping planning on caregiver burden and quality of life in caregivers with Alzheimer's disease, the results were compared to pre-test results. This occurs right after the plan is put into action

#### **III. Administrative design**

Formal approval to conduct this study has been obtained from the relevant authorities. Before conducting the study, the Dean of the Faculty of Nursing at the University of Port Said sent an official letter explaining the purpose of the study to the Directors of the above-mentioned settings seeking their approval to conduct the study.

#### **Ethical consideration**

The Scientific Research Ethics Committee (N14) of the Faculty of Nursing, University of Port Said, gave its approval for ethical considerations. In addition, after discussing the study's goal and protocols, the director of the mental clinic gave his written clearance to perform the study. Before the start of the trial, all nursing personnel was informed. Before the study began, the participants' verbal consent was gained after they were informed of the study's purpose. The anonymity and secrecy of the data obtained preserve ethical considerations. Subjects also underlined their right to choose whether or not to participate in the study.

#### **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 ( $\chi^2$ ). For comparison between two means of parametric paired data, a 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  $41.36 \pm 12.74$  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.

**Figure (1):** Shows distribution of cognitive scores in patients with Alzheimer's disease is shown in the figure, 22.7% of patients with Alzheimer's disease have mild impairments in orientation and behavioral changes, and the overall mild impairment score is 17.3 %. Meanwhile, 46.4% of Alzheimer's patients had moderate language impairment, including 31% with moderate overall impairment. In addition, the results showed that 51.8% of Alzheimer's patients had severe disorientation out of 54.5% of the total severity.

**Table (2):** Shows the total score of caregiver burden assessment at the different stages of program implementation. As shown in the table, there was a highly statistically significant difference between all burden assessment items in the three phases of the program (pre, post, and follow-up) with a p-value  $< 0.05$ .

**Table(3):** Shows the assessment of caregivers' quality of life at different stages of program intervention. As shown in the table, the quality of life of caregivers improved

significantly during the program intervention phase. The most significant improvement was the good quality of life score related to emotional health, which reached 78.2% post-program. The percentage of improvement in the follow-up was increased compared to the post-program. Nonetheless, both tests showed greater improvements compared to the preprogram tests. There was a highly statistically significant difference in the overall quality of life of caregivers across the three phases of the program,  $P < 0.05$ .

**Table (4):** Shows the relation between the socio-demographic characteristics of the caregivers and the quality of life of the caregivers at different stages of the program intervention. As shown in the table, there was a high statistical difference between the age of the caregivers and their quality of life before and during follow-up. In the same context, the results showed that in the post-program phase, there were highly statistically significant differences between caregivers' marital status and quality of life, and between caregivers' employment status and their quality of life. In late and subsequent phases of the project. No further statistically significant correlations were found in the table.

**Table(5):** Explains the relationship between caregivers' socio-demographic characteristics and caregivers' burden assessments at different stages of program intervention. As can be seen from the table, there was a statistically highly significant difference between the employment status and annual income of caring relatives in the pre-program assessment. In addition, there were highly statistically significant associations between caregivers' employment status, gender, and their post-program assessments. No other statistically significant differences were found in the table.

**Table (6):** Puzzles out the correlation between cognitive assessment of Alzheimer's patient with caregiver's quality of life and burden assessment during stages of program intervention. As exhibited in the table, there was a highly statistically significant positive correlation between cognitive assessment of Alzheimer's patients with caregiver's assessment during the two stages (post and follow-up) of program intervention at  $P < 0.05$ .

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

<b>Socio-demographic Characteristics</b>	<b>No</b>	<b>%</b>
<b>Age</b>		
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	
<b>Gender</b>		
Male	32	29.1
Female	78	70.9
<b>Educational level</b>		
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
<b>Marital status</b>		
Single	2	1.8
Married	68	61.8
Divorced	6	5.5
Widowed	34	30.9
<b>Employment status</b>		
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
<b>Monthly income</b>		
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). ( Cont, ...)

<b>Socio-demographic Characteristics</b>	<b>No</b>	<b>%</b>
<b>Relationship to the Patient</b>		
Spouse	30	27.3
Son	46	41.8
Daughter in law	3	2.7
Grand child	31	28.2
<b>Number of family members</b>		
1-3	14	12.7
4-5	40	36.4
More than 5	56	50.9
<b>Children living in your home</b>		
1-3	66	60.0
4-5	37	33.6
More than 5	7	6.4
<b>Live with the patient</b>		
Yes	55	50.0
No	55	50.0
<b>Number of years provide care for the patient</b>		
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
<b>The patient has been diagnosed with Alzheimer's disease and/or dementia</b>		
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
<b>Hours do you spend caring for the patient daily</b>		
Less than 4 hours	53	48.2
5 to 8 hours	49	44.5
More than 8 hours	8	7.3
<b>Type of assistance do you provide to the patient</b>		
Daily living activity	43	39.1
Instrumental activates	38	34.5
Both	29	26.4

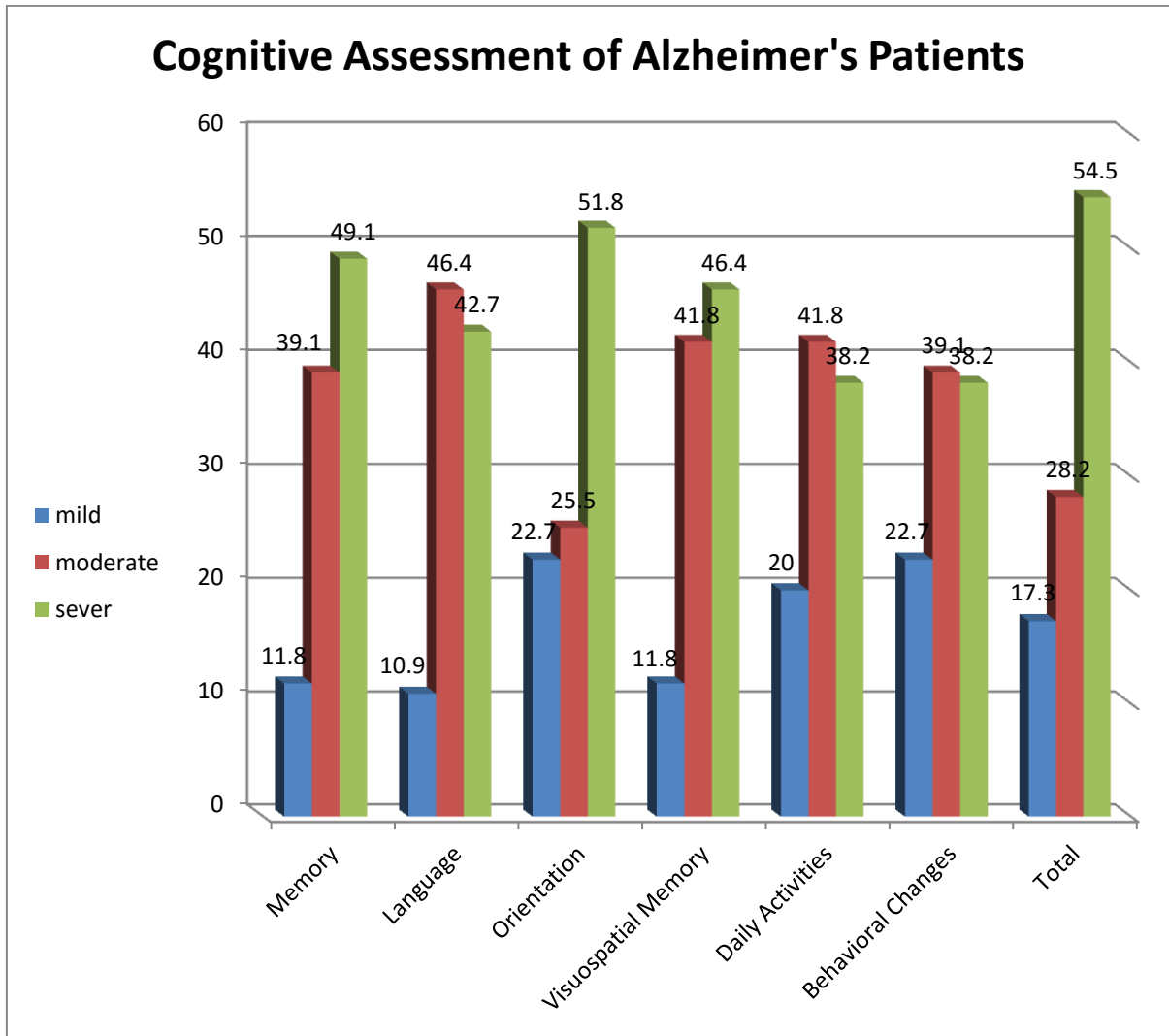


Figure (1): Cognitive Assessment of Alzheimer's Patients (no=110).

Table (2): Total Score of caregiver burden assessment at the different stages of program implementation (no=110).

Items	Pre-program	Post program	Follow-up	(f)	P value
Physical (Objective Burden)	19.45±3.47	11.21±2.88	12.61±2.58	85.08	0.001*
Social (Relationship Burden )	16.39±4.04	10.05±2.74	10.80±2.81	70.91	0.001*
Psychological (Stress Burden)	15.58±3.76	10.14±2.84	10.30±2.49	61.17	0.001*
<b>Total</b>	51.43±9.20	31.39±5.76	32.79±4.96	79.85	0.001*

(f)= ANOVA test

\*Significant (P<0.05).



**Table (3):** Distribution of caregiver quality of life assessment at different stages of program intervention (no=110).

Items	Pre-program		Post-program		Follow-up		(H)	P value
	No	%	No	%	No	%		
<b>Physical health</b>								
Poor	26	23.6	4	3.6	9	8.2	39.263	0.000*
Average	75	68.2	36	32.7	30	27.3		
Good	9	8.2	70	63.6	71	64.5		
<b>Limitation of activities</b>								
Poor	79	71.8	23	20.9	13	11.8	56.084	0.000*
Average	26	23.6	17	15.5	20	18.2		
Good	5	4.5	70	63.6	77	70.0		
<b>Emotional health</b>								
Poor	39	35.5	4	3.6	12	10.9	61.332	0.000*
Average	54	49.1	20	18.2	5	4.6		
Good	17	15.5	86	78.2	93	84.5		
<b>Social activities</b>								
Poor	58	52.7	37	33.6	23	20.9	18.262	0.001*
Average	47	42.7	36	32.7	49	44.6		
Good	5	4.6	37	33.6	38	34.5		
<b>Pain</b>								
Poor	47	42.7	17	15.5	32	29.2	4.332	0.096
Average	41	37.3	35	31.8	32	29.2		
Good	22	20.0	58	52.7	46	41.6		
<b>Energy and emotions</b>								
Poor	41	37.3	6	5.5	9	8.2	5.228	0.073
Average	52	47.3	58	61.8	77	70.0		
Good	17	15.5	36	32.7	24	21.8		
<b>General health</b>								
Poor	54	49.1	17	15.5	28	25.5	19.148	0.001*
Average	54	49.1	61	55.5	70	63.6		
Good	2	1.8	32	29.0	12	10.9		
<b>Total quality of life</b>								
Poor	45	40.9	17	15.5	19	17.3	18.917	0.001*
Average	59	53.6	43	39.0	48	43.6		
Good	6	5.5	50	45.5	43	39.1		

(H)= Kruskal Wallis Test\*Significant (P&lt;0.05)

**Table (4):** Relation between socio-demographic characteristics of the caregiver and quality of life for caregivers at different stages of program intervention (n=110).

Variables	Pre-program	(F) (P) value	Post program	(F) (P) value	Follow-up	(F) (P) value
<b>Age</b>						
20 -	79.56±5.79	2.960 0.015*	89.00±2.50	0.560 0.730	88.01±3.24	2.431 0.040*
30 -	76.83±6.26		90.00±5.22		93.65±4.98	
40 -	75.73±5.32		90.98±4.27		91.63±4.72	
50 -	72.52±5.42		90.04±3.56		91.13±4.15	
60 -	73.73±2.86		89.45±3.58		93.09±5.33	
70 +	74.25±4.92		91.27±3.09		96.50±4.51	
<b>Marital status</b>						
Single	80.50±10.61	0.635 0.594	91.50±4.95	3.007 0.034*	87.50±4.95	1.350 0.277
Married	75.43±5.59		89.78±4.12		91.94±4.66	
Widowed	75.03±5.83		90.38±3.79		92.06±4.91	
Divorced	74.50±3.88		94.83±3.54		94.83±4.87	
<b>Educational level</b>						
Primary school	78.20±7.39	0.641 0.669	92.70±3.16	1.635 0.157	91.70±5.43	0.817 0.540
Middle school	75.05±5.52		89.52±4.13		91.33±4.81	
High school	75.35±7.04		90.35±3.84		91.13±4.28	
Technical institut	75.19±4.96		89.68±4.46		92.27±5.12	
College graduate	74.29±4.19		91.41±3.74		93.94±4.38	
Post graduate	76.00±2.82		86.50±3.56		92.05±2.82	
<b>Employment status</b>						
Working fulltime	77.22±4.84	0.992 0.435	89.44±5.42	3.161 0.009*	90.44±3.97	0.455 0.480
Working part time	76.02±5.80		90.50±4.38		92.06±4.68	
Self- commerce	74.47±4.75		89.71±3.75		93.12±5.64	
Retired	73.00±8.26		88.88±4.76		93.25±5.36	
Housewife	73.78±4.89		90.72±3.21		91.44±4.63	
Occupational work	75.33±4.61		91.33±2.88		92.33±5.50	
<b>Gender</b>						
Male	74.31±6.61	1.518 (t) 0.221	90.34±3.51	0.113(t) 0.908	92.84±4.73	1.233(t) 0.269
Female	75.77±5.18		90.24±4.36		91.73±4.79	
<b>Annual income</b>						
Enough	74.97±5.34	0.443 0.643	90.13±4.13	0.083 0.921	92.75±4.66	1.444 0.241
Enough and more	76.17±5.55		90.38±3.75		91.07±4.69	
Not-Enough	75.29±6.76		90.52±4.68		91.43±5.14	

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

\*Significant (P<0.05).

**Table (5):** Relation between socio-demographic characteristics of the caregiver and burden assessment for caregivers at different stages of program intervention (n=110).

Variables	Pre-program	(F) (P) value	Post program	(F) (P) value	Follow-up	(F) (P) value
<b>Age</b>						
20 -	50.89± <b>11.61</b>	0.198	27.67± <b>4.41</b>	1.776	32.78± <b>6.11</b>	1.703
30 -	50.48± <b>8.35</b>	0.963	30.91± <b>5.49</b>	0.124	31.91± <b>5.06</b>	0.140
40 -	51.25± <b>10.03</b>		31.15± <b>5.36</b>		32.93± <b>4.96</b>	
50 -	53.04± <b>6.52</b>		33.96± <b>4.94</b>		31.48± <b>4.35</b>	
60 -	51.00± <b>9.81</b>		31.09± <b>7.63</b>		35.36± <b>4.45</b>	
70 +	51.75± <b>12.79</b>		31.00± <b>9.66</b>		37.00± <b>3.36</b>	
<b>Marital status</b>						
Single	49.00± <b>11.97</b>	0.100	29.00± <b>4.23</b>	1.916	32.00± <b>9.89</b>	0.257
Married	51.51± <b>8.45</b>	0.964	32.28± <b>6.08</b>	0.131	32.50± <b>5.039</b>	0.856
Widowed	51.65± <b>10.47</b>		29.56± <b>4.65</b>		33.26± <b>4.77</b>	
Divorced	50.00± <b>10.01</b>		32.50± <b>6.47</b>		33.67± <b>4.36</b>	
<b>Educational level</b>						
Primary school	52.30± <b>10.04</b>	1.644	27.10± <b>3.47</b>	2.020	33.20± <b>4.75</b>	0.608
Middle school	51.57± <b>9.59</b>	0.155	30.33± <b>5.65</b>	0.070	33.05± <b>5.11</b>	0.694
High school	49.35± <b>9.58</b>		32.78± <b>6.02</b>		33.57± <b>5.78</b>	
Technical institute	52.38± <b>9.05</b>		31.43± <b>6.72</b>		32.08± <b>4.68</b>	
College graduate	53.29± <b>7.15</b>		33.24± <b>5.03</b>		33.24± <b>4.57</b>	
Post graduate	36.00± <b>9.20</b>		31.50± <b>6.36</b>		28.05± <b>2.12</b>	
<b>Employment status</b>						
Working fulltime	42.33± <b>10.32</b>	2.571	28.67± <b>3.57</b>	3.944	31.67± <b>5.87</b>	2.274
Working part time	50.90± <b>9.06</b>	0.023*	31.21± <b>5.67</b>	0.013*	32.88± <b>5.06</b>	0.051
Self-commerce	56.06± <b>6.62</b>		30.94± <b>6.77</b>		31.56± <b>4.80</b>	
Retired	52.63± <b>8.31</b>		34.25± <b>6.94</b>		30.00± <b>4.72</b>	
Housewife	53.11± <b>9.91</b>		33.22± <b>4.42</b>		33.44± <b>2.95</b>	
Occupational work	50.33± <b>6.42</b>		34.00± <b>6.92</b>		39.00± <b>2.00</b>	
<b>Gender</b>						
Male	53.63± <b>6.29</b>	2.611(t)	33.22± <b>5.86</b>	4.683	33.09± <b>4.76</b>	0.168
Female	50.53± <b>10.05</b>	0.109	30.64± <b>5.58</b>	0.033*	32.67± <b>5.04</b>	0.683
<b>Annual income</b>						
Enough	52.23± <b>8.81</b>	5.011	31.72± <b>5.03</b>	0.306	32.58± <b>4.69</b>	0.114
Enough and more	53.66± <b>8.19</b>	0.008*	30.69± <b>6.70</b>	0.737	33.03± <b>5.87</b>	0.892
Not-Enough	46.05± <b>9.94</b>		31.43± <b>6.53</b>		33.05± <b>4.44</b>	

(F)= anovatest (t)=t- test

\*Significant (P&lt;0.05).

**Table (6):** Correlation between cognitive assessment of Alzheimer's patient with caregiver's quality of life and burden assessment during stages of program intervention (no=110).

Variables	cognitive assessment of Alzheimer's patient
<b>Quality of life</b>	
Pre-program	r= -0.106- p=0.136
Post-program	r= 0.161 p= 0.047*
After 3 months	r= 0.231 p= 0.018*
<b>Burden assessment</b>	
Pre-program	r= 0.350 p=0.037*
Post-program	r= -0.372- p= 0.001*
After 3 months	r= -0.157- p= 0.047*

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

## DISCUSSION

Caregivers for Alzheimer's patients and their families face a significant burden. caregivers express a variety of concerns about their health, and because the burden of caregivers ' sickness is assumed and necessarily hidden, both patients and caregivers suffer. Caregivers are in severe need of social assistance and education. According to WHO(2019), over 70% of caregivers confront two major challenges: treating patients and adapting to nursing-related obligations.

Because caregivers spend time and energy caring for patients, family members, especially caregivers, might easily lose their quality of life. Caregivers are more likely than the general population to suffer from mental disorders as a result of their caregivers ' responsibilities. This harms their quality of life and care. Persons who care for sick people at home are more likely to suffer from sadness and anxiety, and their life expectancy is 10 years lower than that of the general population (**Capistrant,2016**).

Improved coping strategies can help caregivers cope with stress and enhance their physical and emotional health. To properly engage in a patient's treatment plan, families face challenges. Mental health practitioners can help decrease family stress

and offer patients a more functional support system by giving broader training and more support to families (**Hawken, Turner-Cobb, & Barnett, 2018**). Impact of a coping strategy plan on caregivers of Alzheimer's disease patients in Port Said quality of life and care load.

Results of the current study showed that elaborated that there was a remarkable reduction in total caregivers' burden in the post-test phase of the program compared to pre and follow-up stages. In addition, there were highly statistically significant differences between total items of the caregiver burden assessment through the pre, post, and follow-up phases of the program with  $P < 0.05$ . From the researcher's point of view, this obvious change in total burden scores through the three phases of the applied program proves the significant effect of the educational program in improving the general status of the caregivers and reducing their feeling of burden and annoyance.

This study was agreed upon and endorsed by Aydin, Tel, Guler, Kocatas, and Gundogdu (2020) for their study titled "Effect of Educational Programs on Care Burden and Quality of Life in Patients Diagnosed with Alzheimer's Disease", concluded that education in the program reduced the burden of care for caregivers of Alzheimer's patients and had a positive impact on their quality of life. This finding contradicts Villars, et al., (2021), who highlight the impact of educational programs on Alzheimer's patients' quality of life, although the results of randomized controlled studies do not support this claim. After two months, therapeutic patient education had a substantial effect on nurse-reported patient QOL, but not on self-reported patient QOL. There were no other substantial effects on patient or caregiver outcomes.

The findings of the present study showed that there was an obvious improvement in the caregivers' quality of life levels during stages of program intervention. The most prominent improvement was in the score of good quality of life about emotional health in the immediate post-test. The percentage of improvement has been increased in the follow-up test compared with an immediate test. Nonetheless, the two tests had shown a higher improvement compared to the pre-program test. There were highly statistically significant differences between the caregivers' total quality of life through the three phases of the program. From the researcher's point of view, this result donates the successfulness of the educational program in attaining its objectives by improving the total good quality of life of the caregivers of Alzheimer's patients following its implementation.

This result was in the same line as Mas, Aribau, Souza, Cox, and Zúñiga, (2021) who concluded that the total quality of life of the caregivers before and after the intervention changed for the better significantly. Additionally, Aydin, Tel, Guler, Kocatas, and Gundogdu, (2020) agree with this finding, as they found that the overall quality of life for caregivers improved after an implementation program and is positively affected. In addition, Hsu, et al. (2017) who conducted a study in Taiwan titled "Sustained Benefits of Psychoeducational Training Programs for Caregivers of Dementia and Alzheimer's Disease" found that under the intervention of an intensive psychoeducational training program, dementia and Alzheimer's disease Caregivers with the mutated disease can consistently reap sustained benefits from improved quality of life, less suffering, less mental illness, and improved mental health.

Similarly, Smith and Graves (2021) reported that stress inventory data exhibited considerable high risk/low-risk fluctuation and low quality shown in their study named "Implementation and Evaluation of Self-Care Toolkits for Family Caregivers with Dementia and Alzheimer's Disease." From pre-test through post-test, high-quality categorization. Pre-tests identified 31 caregivers as having high-risk, low-quality harmful stress levels, whereas post-tests revealed that just nine were. In the posttest, around 70% of people who had high risk and low quality in the pretest were classified as low risk. As a result, this study found that evidence-based educational interventions can help caregivers enhance their knowledge and self-care. Ongoing support can be encouraged by providing training and resource manuals to caregivers during primary care visits.

A highly statistically significant difference in caregivers' age and their quality of life before and after the program was observed in the concurrent study. During the post-program period, the data revealed a highly statistically significant difference between marital status and caregivers' quality of life. Furthermore, there were statistically significant differences between caregivers' employment status and post-program and follow-up quality of life. These findings support the validity of family caregivers' characteristics, such as age, marital status, and employment status, which serve as the foundation of life and have a significant impact on their quality of life.

This result is in the same line as, 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. Furthermore, the findings were confusing in that there was a statistically highly significant difference in the stress evaluation between caring relatives' work status and annual income in the pre-program period. Furthermore, there were statistically significant links between caregivers' work positions, gender, and post-program stress ratings. According to researchers, employment status, annual income, and gender all play crucial roles in the occurrence and decrease of overall burden, particularly for caregivers of Alzheimer's patients who are unemployed and have little or no money. Work and women assume a larger role in society.

Unfortunately, these findings contradict those of Babarro, Barral, Ponce, Ruiz, and Pastor (2019), who found no differences between caregivers of persons with dementia in a program in a study titled "Profiles and care burden of caregivers of individuals with dementia in ALOIS program." Relationship between caregiver and patient, marital status, gender, or caregiver employment position.

During the three phases of program intervention, the results of this study revealed a highly statistically significant positive link between overall caregivers' quality of life and burden rating (before, after, and after). According to the researchers, this data indicates that reducing the burden enhances the overall quality of life of caring relatives.

Aydin et al. (2020) confirmed this finding, concluding that there is a strong negative relationship between nursing work and quality of life. Reduced care burden increased quality of life ( $p < 0.05$ ). Another study by Adelman, Tmanova, Delgado, Dion, and Lanchs (2014) looked at the quality of life of paramedics diagnosed with AD during and after hospitalization and found that after 12 months, paramedics had a considerably better quality of life. Increase the number of people admitted to the hospital.

## **CONCLUSION**

Based on the findings of the present study, it can be concluded that the caregivers had a total high burden in the pre-test phase than in the post and follow-up phases. There was an obvious improvement in the caregivers' quality of life levels during stages of program intervention. The most prominent improvement was in the score of good quality of life about emotional health, which reached 78.2% for each in the immediate post-test.

The percentage of improvement has been increased in the follow-up test compared with an immediate test. Nonetheless, the two tests had shown a higher improvement compared to the pre-program test. There were highly statistically significant differences between the caregivers' total quality of life through the three phases of the program where  $P < 0.05$ . Therefore, the educational program was successful in attaining its aim of positively reducing total caregivers' burden and improving their total quality of life.

## RECOMMENDATIONS

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

- 1- The development of interventions in caregivers of AD relatives to reduce avoidance-type coping and favor acceptance of their situation and the search for social support. Among these interventions, we have problem-solving interventions, benefit-finding, and positive reappraisal interventions, acceptance, and control of dysfunctional thoughts, and interventions aimed to strengthen social support.
- 2- Educational materials such as booklets and pamphlets should be developed for caregivers according to their educational level, including all information about caregiving, burden, 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, burden, and coping strategies.
- 4- Replication of similar specific studies using large probability samples and different settings is highly recommended.

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## تأثير برنامج استراتيجيات التكيف علي جودة الحياة وعبء الرعاية لدي مقدمي الرعاية الأسرية لمرضى الزهايمر

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صحة الاسرة والمجتمع -ماجستير تمريض صحة الاسرة والمجتمع- كلية التمريض - جامعة بورسعيد

### الخلاصة

**الخلفية:** ان تحسين استراتيجيات المواجهة الفعالة لمقدمي الرعاية لمرضى الزهايمر يؤدي إلى انخفاض في ضغط الرعاية وبالتالي تعزيز صحتهم في نهاية المطاف. هذا وكان الهدف من الدراسة هو تقييم تأثير برنامج استراتيجيات المواجهة على جودة الحياة وعبء الرعاية بين مقدمي الرعاية لمرضى الزهايمر في مدينة بورسعيد. وقد تم استخدام تصميم شبه تجريبي. هذا وقد أجريت هذه الدراسة في العيادات الخارجية للأمراض العصبية بمستشفى الأمراض النفسية في مدينة بورسعيد. وقد اشتملت عينه الدراسة علي (110) من جميع مقدمي الرعاية الأسرية لمرضى الزهايمر . هذا وقد تم جمع البيانات باستخدام: استبيان المعلومات الاجتماعية والديموغرافية لمقدمي الرعاية الأسرية ؛ مقياس عبء مقدمي الرعاية ؛ و مقياس جودة الحياة المترجم المتعلق بالصحة والنموذج القصير. وقد أسفرت نتائج الدراسة علي أن متوسط عمر مقدمي الرعاية كان  $41.36 \pm 12.74$  سنة و 70.9% منهم إناث. وكذلك كان هناك انخفاض في العبء الإجمالي لمقدمي الرعاية في مرحلة ما بعد الاختبار للبرنامج مقارنة بمرحلتي ما قبل والمتابعة. بالإضافة إلى ذلك ، كانت هناك فروق ذات دلالة إحصائية عالية بين العناصر الإجمالية لتقييم عبء مقدمي الرعاية خلال جميع مراحل البرنامج. أيضًا ، كان هناك تحسن واضح في نوعية حياة مقدمي الرعاية خلال البرنامج. وقد خلصت الدراسة الي أنه: بعد تنفيذ البرنامج ، قام مقدمو الرعاية الذين تلقوا البرنامج المصمم بتخفيض عبء الرعاية الملقى عليهم وأثروا على نوعية حياتهم بشكل إيجابي. وقد اوصت الدراسة بأن هناك حاجة لبرامج التنقيف الصحي المستمر لمقدمي الرعاية لمرضى الزهايمر وكذلك التوصيه بضروره إجراء مزيد من الدراسات باستخدام حجم عينة دراسة كبير في أماكن مختلفة.

**الكلمات المرشدة:** الزهايمر ، عبء الرعاية، استراتيجيات التكيف، مقدم الرعاية الاسرية و جودة الحياه