

Home Care: Nursing Intervention for Family Caregivers of Alzheimer Clients

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Abstract: The aim: of the study was to evaluate the effect of nursing intervention on daily living activities (DLAs) for family caregivers (FCGs) of Alzheimer clients. **Design:** This study is a quasi-experimental research design. **Setting:** This study was conducted at the Geriatric Outpatient Clinic and Alzheimer Outpatient Clinic at Ahmed Okasha Center in Ain-Shams University Hospitals **Sample:** A purposive sample of 60 Alzheimer clients and their family caregivers; 32 from Alzheimer Outpatient Clinic at Ahmed Okasha Center; and 28 from Geriatric Outpatient Clinic. **Tools:** Data were collected using two tools. **1):** An interviewing questionnaire, consisting of socio-demographic characteristics of FCGs of the Alzheimer clients, their needs for knowledge about Alzheimer disease (used pre/post program), their activities of daily living, toward their Alzheimer clients (used pre/post program), and their as physical, psychosocial, emotional and strain problems. **2):** An observational checklist for assessing the Alzheimer clients' home environment. **Results:** The main results revealed that most of FCGs had physical and psychosocial strain problems, followed by emotional strain, and more than half of them had safe environment. There was a highly statistically significant difference between family caregivers' total knowledge, and providing DLAs towards their Alzheimer clients pre / post implementation of the program. As well there was a positive correlation with highly statistically significant difference between FCGs according to home environment and providing DLAs towards their Alzheimer clients pre / post program. **Recommendations:** Counseling and nursing intervention for FCGs of Alzheimer clients about knowledge of Alzheimer disease, DLAs, as well as emotional support and relieving stress, and prevention of environmental hazards. [Naglaa M. Girgis, Hanan Ibrahim Ahmed and Hemat Abd Elmoneem Elsayied. **Home Care: Nursing Intervention for Family Caregivers of Alzheimer Clients.** Journal of American Science 2012; 8(2):584-595]. (ISSN: 1545-1003). <http://www.americanscience.org>.82

Key: Family care givers (FCGs), Alzheimer disease, Daily living activities (DLAs)

1. Introduction

Alzheimer's disease is a degenerative, and progressive neuropsychic disorder that results in cognitive impairment, emotional and behavioral changes, physical and functional decline, and ultimately death. This disease robs its victims of everything learning in life, so that they are unable to fall back on preserved intelligence (Boyd, 2005).

Currently, an estimated 4.5 million Americans have Alzheimer's disease and by year 2050 the number of people with Alzheimer's disease will range from 11.3 to 16 million. In Europe, North America, and Australia the Alzheimer's disease is more common. There is much less information about other parts of the world (Michel et al., 2002).

In Egypt, those above 60 years of age constitute nearly 8% of whole population, which is expected to increase over the next few decades. However, there are 200.000 cases of Alzheimer's disease which is expected to become one million cases by year 2030 ((Michel et al., 2002).

The National Institute of Health(NIH) (2004) reported that subtypes of Alzheimer's disease are defined by age of onset as, early onset Alzheimer's disease is in age 65 or under, late onset Alzheimer's disease for onset after age 65. The late onset Alzheimer's disease is much more common than early onset Alzheimer's disease, but

the early onset Alzheimer's disease has a more rapid progression.

Alzheimer's Association (2009) provides ten warning signs of Alzheimer's disease to allow early detection of the patients, it includes the following: Recent memory loss, difficulty performing familiar tasks problems with language, disorientation of time and place, poor or decreased Judgment, problems with abstract thinking, misplacing things, changes in mode or behavior, changes in personality and loss of initiative care giving has all the features of a chronic stress experiences; it creates physical and psychological strain over extended periods of time, is accompanied by high levels of unpredictability and uncontrollability, has the capacity to create secondary stress in multiple life domains such as work and family relationships, and frequently high levels of vigilance (Vitaliano, 2003).

In most cases of Alzheimer, at least two individuals are affected; the person with condition and the caregiver. Many problems can face the caregivers of people with Alzheimer, which include the effective loss companionship and support of a life partner, social isolation and complex financial, legal and social decision-making. The burden of caring is financially, emotionally and physically significant (Thompson et al., 2002).

It is also important for caregivers to maintain a daily routine, which serves as another type of memory aid. Activities such as eating, bathing, and dressing should be performed in the same order and at the same time every day to help the Alzheimer's disease client remember that each of them should be performed every day. Another method is the use of telephone reminders. For a person who can remain unsupervised at home, relatives or friends should be instructed to call throughout the day. These calls provide a way to check the person's safety while maintaining independence (Mace & Rabin, 2001).

Nurses can help family caregivers to identify their negative experience about care giving and can help them to find balance in their situation. Risk groups of caregivers may be identified, especially those with low perceived health and sense of coherence, for early intervention to reduce burden. The nurse should be providing emotional support and counseling and serving as a coordinator of available community resources, the nurse can significantly help to relieve the stress on the family caregivers (Signe & Solve, 2008).

Magnitude of the Problem:

In Egypt, a million clients are suffering from Alzheimer. This number will continue to increase unless new discoveries facilitate prevention of the disease. Most of those patients live in their homes and about 75 percent being cared for by family caregivers (Ashour, 2007).

The family caregiver is in need for educative support from the nurse on how to care for his/her loved one, who can no longer meet his / her own physical needs or daily living activities (DLAs). Family caregivers assume an exhausting, 24 hours, and 7/days a week job for someone who shows less and less appreciation for what they do and, with time, does not even recognize who they are (Ham, 2002).

The nurse must assess the family and the client to determine their needs for information and instructions about the illness, care of the clients, and support for the caregivers. The use of psycho-educational approaches has been demonstrated to be effective in enhancing family coping, and reducing caregiver depression and anger (Hepburn et al., 2003).

Aim of the study:

The aim of the study is to evaluate the effect of nursing intervention on daily living activities (DLAs) for family caregivers of Alzheimer clients through:

- 1- Assessing family caregiver's knowledge and practices about Alzheimer disease.
- 2- Assessing family caregiver' needs regarding DLAs, physical, emotional, and psychosocial problems.
- 3- Assessing Alzheimer client' home environmental hazards.
- 4- Designing and implementing a nursing intervention according to Alzheimer caregivers' client needs.

5-Evaluating the effect of the nursing intervention on knowledge, and practices of the DLAs of Alzheimer caregivers' clients.

Research hypothesis:

The implementation of nursing intervention will improve the Alzheimer caregiver's knowledge, practiceS, and DLAs.

2. Subjects and Methods:

I: Technical Design:

Research design:

A quasi-experimental study design

Setting:

This study was conducted at the Geriatric OutPatient Clinic and Alzheimer Out-Patient Clinic at Ahmed Okasha Center in Ain-Shams University Hospitals as those hospitals represented Cairo governorates as well as at Alzheimer clients homes. These settings were selected because they have the highest frequency of Alzheimer clients than any other hospitals

Sampling:

A purposive sample of all clients who attended within one year, from January to December, 2011. accounting for a total number of 60 Alzheimer clients and their family caregivers were included in this study these were 32 Alzheimer clients and their family caregivers from Alzheimer OuPatient Clinic at Ahmed Okasha Center and 28 Alzheimer clients and their family caregivers from the Geriatric Outpatient Clinic. They were chosen according to the inclusion criteria for Alzheimer clients, their age over 50/years accompanied with their main family caregivers and able to communicate, their family caregivers living with them for at least six months.

Tools:

Two main tools were used for data collection:

The First Tool: An interview questionnaire designed by the researchers to assess the following:

Part 1-

Socio-demographic characteristics of family caregivers of Alzheimer clients such as age, education, gender, monthly income, relation to Alzheimer client.

Part 2-

Family caregiver's needs regarding knowledge about Alzheimer disease such as meaning, causes, risk factors, stages of Alzheimer disease, general and common warning signs and symptoms, disease treatable, effect of medications, complications, age of occurrence and availability of community health care resources. This tool was used pre/post implementation of the program.

Scoring system:

For each of the knowledge items, a correct answer was scored 1 and the incorrect answer was scored zero. For each part, the scores of the items were summed-up and the total divided by the number of the items, giving a mean score for each part. These scores were converted into a percent score. The total score was 11 grades, for 11 items, and equal 100%. The caregiver's knowledge was considered correct answer if the percent score was 60% or more and incorrect answer if the score was less than 60%.

Part 3- Family caregivers according to their providing for:

- A-** Activities of daily living toward their Alzheimer clients that refer to six activities (feeding, bathing, dressing, transferring, and walking, and toileting).
- B-** Instrumental activities of daily living that refer to six daily tasks with modification (household, medical care, shopping for groceries and personal needs, preparing meals, and managing money as going to arrested pension, and payment of electricity, gas, phone bills, etc. to the Alzheimer client. It was designed by the researchers based on review of related literature and experts opinions. This tool was used pre/post implementation of the intervention.

Scoring system:

The scoring system ranged from one score for the done, and zero for not done. The total grades were 36 for 36 statements equal 100%. The caregiver's practices were categorized into done practices if percent score was 60% or more, and not done if less than 60%.

Part 4-

Family caregiver's strain problems as reported by them. The tool included the following:

Physical:

As fatigued from giving all daily living activities, feeling exhausted from giving daily living activities, and loss ability to provide proper care.

Psychosocial:

Psychological problems as more nervous excited, non-response from Alzheimer clients' side, feeling stress towards their occupation, feeling guilty and stress for not providing best care, and mood has totally changed. Social problems as loss of partner support, social decision making, social isolation, recreation facilities, and community awareness about the disease, lack of financial support to be able to provide care, unavailable home visits by health care team, and lack of health care resources.

Emotional:

As getting more close to God, feeling of high level of uncontrollability, feeling of high level of vigilance, and feeling less appreciation.

Scoring system: For each item of family caregiver's problem, the items present and not present were scored 1 and 0 respectively. Then, the scores of the items were summed-up and the total divided by the number of the items, giving a mean score for each part. These scores were converted into a percent score and categorized into. Present if percent score was 60% or more and not present if less than 60%.

The Second Tool:

An observation checklist to assess the environmental home of the Alzheimer client. It included items related to noise (inside & outside home), lighting (in rooms, night light, & corridors/bathroom), ventilation, housekeeping, water supply, sewage disposal, furniture state, floors, bathroom cleanliness, and stairs. It was adopted from **Guirguis (2000)** after making necessary modifications.

Scoring system:

For each observation in the checklist, the items were categorized into low level, moderate level, and high level and scored as 0, 1, and 2, respectively. For each part, the scores of the items were summed-up and the total scores were 68 grades 34 items, equal 100%. The home environment is considered safe if percent score was 60% or more and unsafe if percent less than 60%.

Validity of the tools was done by 5 experts from the community specialty of Faculties' Staff Nursing.

II. Operational Design:**Preparatory phase:****Pilot Study:**

A pilot study was carried out in order to test the applicability and clarity of the constructed tools, as well as to estimate the average time needed to complete all parts of the tools. Twenty Alzheimer clients and their family caregivers were equally distributed between the Geriatric Outpatient Clinic and Alzheimer Outpatient Clinic at Ahmed Okasha Center in Ain-Shams University Hospitals (September-December 2010), those subjects were excluded from the main study sample.

Ethical considerations:

All ethical considerations were considered as far as privacy and confidentiality during home visits. The family caregivers were informed about the nature of the study, and that they had the right to withdraw at any time, or choose not to answer specific questions. Caregivers' verbal agreement to participate was obtained, confidentiality of their names, addresses, and information were regarded.

Field Work:

- Official permissions were obtained from the Deans of Benha and Ain Shams Faculties of Nursing, also from administrators of the Geriatric Out-patient Clinic and Alzheimer Outpatient Clinic at Ahmed Okasha Center in Ain-Shams University Hospitals.
- Preparation of data collection tools was carried out over a period of four months from beginning of January 1, 2011 to end of April, 2011 after being revised by experts to test their validity.
- All items of the tools were covered in two interviews with clients and their family caregivers at the Geriatric Outpatient Clinic and Alzheimer Outpatient Clinic at Ahmed Okasha Center in Ain-Shams University Hospitals, One interview was conducted in the study outpatient clinics and the other one during home visits.
- A pilot study was carried out to test clarity and simplicity of questions.
- Data collection was done by the researchers, who prepared a time schedule to allow their presence on Sundays and Tuesdays in the selected out patient clinics from 8.30 a.m. - 12. 30 p.m. in order to complete data collection of the questionnaire tools of the demented persons and those of their caregivers, it took about 45 minutes to be filled in. Implementation of the program was carried out in the outpatient clinics, and at their homes.
- The nursing intervention was designed to evaluate the improvement of knowledge, practices, and daily living activities of the family caregivers of Alzheimer clients through simplified sessions presented in Arabic language.
- The application of the nursing intervention lasted for 8 months from the beginning of May 2011 till the end of December 2011. The intervention was applied in seven sessions ; (10) hours for total sessions (3 hours for theory and 7hours for practices), at the Geriatric Outpatient Clinic and Alzheimer Outpatient Clinic at Ahmed Okasha Center in Ain-Shams University Hospitals, and the other two sessions at elderly homes.

The nursing intervention program construction included the following phases:

Phase 1:

A pre-program assessment tool using the previous interview questionnaire for data collection from family caregivers of Alzheimer clients.

Phase 2:

The nursing intervention was designed by the researchers based on results obtained from the pre-program assessment tool. It was revised and modified based on related literature, and socio-demographic aspects of the study sample to cover family caregivers of Alzheimer clients' knowledge and practices.

The general objective of the nursing intervention was to improve the Alzheimer caregiver's knowledge, practices, and DLAs.

Contents of the educational nursing intervention program:

Knowledge included meaning causes, risk factors, stages, general signs and symptoms, common warning signs and symptoms, complications of Alzheimer disease ,age of occurrence and effect of medications that can help in care, and availability of special centers for health care resources.

Practices dealing with daily living activities DLAs. as feeding, bathing, personal hygiene, transfer, walking, toileting, clothing and dressing , household, medical care, and other activities as shopping personal needs, arrested pension, and managing money as payment of "electricity, gas, phone bills, etc." to the Alzheimer clients.

Phase 3: Implementation was done in the Geriatric Outpatient Clinic and Alzheimer Outpatient Clinic at Ahmed Okasha Center in Ain-Shams University Hospitals in the waiting area after the Alzheimer clients being examined and diagnosed by physician.

Methods of teaching used: They include; discussions, role play, followed by demonstration and re-demonstration using simple Arabic language for family caregivers of Alzheimer clients. As well audio-visual aids were used such as posters, handouts, booklets,

Phase 4: Evaluation of the nursing intervention was done immediately after the program by using the same pre-program tools.

III. Administrative Design:

Approval was taken for carrying out this study in the selected areas from the administrators of the Geriatric Outpatient Clinic and Alzheimer Outpatient Clinic at Ahmed Okasha Center in Ain-Shams University Hospitals.

IV. Statistical Design

Data entry was done using Epi-info version 6.04 computer software package, while statistical analysis was done using the statistical package for social sciences (SPSS) version 11.0. Quality control was done at the stages of coding and data entry. Data were presented using descriptive statistics in the form of frequencies and percentages for qualitative variables, and means and standard deviations for quantitative variables. Qualitative variables were compared using Chi- square test (χ^2), significance of the results was considered as Not significant, if $P > 0.05$; Significant, if $P < 0.05$; and Highly significant, if $P < 0.001$.

3. Results:

Figure (1): Demonstrates that 63.3% of family caregivers aged 45+ years old, 71.7% were females, and 53.3% of caregivers were sons/daughters of family

caregivers. In relation to their income, 83.3% had insufficient monthly income meet their needs. As for education 41.7% and 38.3% had university, and secondary education respectively.

Table (1): Shows that 81.7% of family caregivers' physical strain problems were feeling exhausted from giving daily living activities and 70% were fatigued from giving all daily living activities. As regards psychosocial strain problems 93.3% of them were feeling stressed for not providing best care, 81.7% loss of community awareness about the disease, and 70.0% were more nervous excited. The same table shows 65% of caregivers' emotional strain problems, were getting more close to God and increasing faith while 63.3% have feeling of high level of vigilance.

Table (2): Represents that 55% of home environment was considered low level in floors. As regards 71.7% of moderate level was in furniture order/state, while 96.7% of high home environmental level was for water supply. The table also shows that 58.3% of family caregivers had safe environment.

Tables (3&6): States that before program 18.3% , 20%, 5%, 16.7%, 33.3%, 41.7%, 6.7%, 25%, 0.0, & 26.7% vs 81.7%, 80%, 95%,83%, 66.7%, 58.3%, 93.3%, 75%, 100%,& 73.3% post program of family caregivers had knowledge about the meaning of Alzheimer disease, the causes, the risk factors, stages, the general signs and symptoms of Alzheimer, treatable, the effects of medications, complication of Alzheimer disease, age of occurrence, and availability of community health care resources. The same table shows that there were highly statistically significant differences pre and post implementation of the program.

Tables (4&6): Shows that concerning bathing& personal hygiene before program 31.7%, 3.3%, 16.7%, 25%, 18.3% vs 68.3%, 96.7%, 83.3%, 75%, 81.7% post program helping Alzheimer's clients in complete bath, they were helping in moving to and from toilet, clean and comb hair to Alzheimer clients, shave head, chin and unwanted hair, and wash/dry face and hands every morning respectively. As regards clothing (dressing) before program 33.3%, vs 66.7% post program provide assistance to Alzheimer clients in clothing and wearing

shoes. Concerning transferring and walking before program 35%, 30%, and 13% vs 65%, 70%, & 86.7% post program were for help to get in and out of bed, help to use moving aids (e.g., crutch, walker, and wheelchair), and help during standing and sitting. As regards the toileting the same table shows that before the program 31.7% vs 68.3% post program help in cleaning and wearing clothes after toileting. There were highly statistically significant differences between pre and post implementation of the program.

Tables (5&6): Shows that before program as regards household, all family caregivers were not cleaning pots and dishes used in eating and cleaning floors, furniture and furnishings to Alzheimer clients vs all of them post program. Concerning medical care 8.3% vs 91.7% pre/post program were giving medication and observing prognosis of Alzheimer clients' case. All caregivers making shopping as buying supplies of groceries. As for meals preparing and cooking foods for them before and after program implementation they represented all of them. As regards managing money the same table shows that before program 11.7% and 26.7% vs 88.3% and 73.3% post program of family caregivers go to arrest pension and payment of electricity, gas, phone bills etc. of their Alzheimer clients. There was high statistical significance difference pre and post implementation of the program. p value < 0.001.

Table (6): Shows that there were highly statistically significant differences between total knowledge, and providing total activities of daily living towards their Alzheimer clients pre/post implementation of the program ($p < 0.001$).

Table (7): Shows that there were highly statistically significant differences between family caregivers according to their educational level, and total knowledge, and total providing activities of daily living towards their Alzheimer clients pre / post program ($p < 0.001$).

Figure (2): Shows that there was a positive correlation with highly statistically significant differences between family caregivers according to their environment and total providing activities of daily living towards their Alzheimer clients pre / post program ($p < 0.001$).

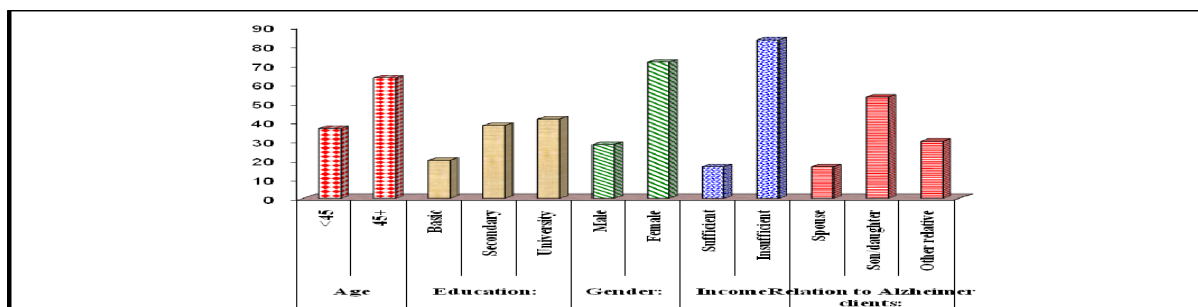


Figure (1): Distribution of family caregivers according to their socio-demographic characteristics (n=60).

Table (1): Distribution of family caregivers according to their strain problems as reported by them (n=60).

Items	No.	%
Physical[@]:		
Fatigued from giving all daily living activities	42	70.0
Feeling exhausted from giving daily living activities	49	81.7
Loss ability to provide proper care.	21	35.0
Psychosocial[@]:		
More nervous excited	42	70.0
Non-response from Alzheimer clients' side	24	40.0
Feeling stress towards their occupation	38	63.3
Feeling guilty for not providing best care	23	38.3
Feeling stress for not providing best care	56	93.3
Mood has totally changed	49	81.7
Loss of partner support	38	63.3
Loss of social decision making	14	23.3
Social isolation	24	40.0
Loss of recreation facilities	39	65.0
Loss of community awareness about the disease	49	81.7
Lack of financial support to be able to provide care	38	63.3
Unavailable home visits by health care team	14	23.3
Lack of health care resources	39	65.0
Emotional[@]:		
Getting more close to God and increasing faith	39	65.0
Feeling of high level of uncontrollability	31	51.7
Feeling of high level of vigilance	38	63.3
Feeling less appreciation	23	38.3

@ Not mutually exclusive

Table (2): Alzheimer clients' home environmental score level as stated by caregiver (n=60)

Items	Low level <50%		Moderate level 50 – 75 %		High level >75%	
	No.	%	No.	%	No.	%
Noise						
Outside	6	10.0	33	55.0	21	35.5
Inside	12	20.0	32	53.3	16	26.7
Lighting						
Room light	1	1.7	35	58.3	24	40.0
Night light	21	35.0	0	0.0	39	65.0
Corridors/WC	4	6.7	0	0.0	56	93.3
Ventilation	20	33.3	0	0.0	40	66.7
Housekeeping	0	0.0	21	35.0	39	65.0
Water supply	2	3.3	0	0.0	58	96.7
Sewage disposal	0	0.0	16	26.7	44	73.3
Furniture order/state	1	1.7	43	71.7	16	26.7
Floors	33	55.0	0	0.0	27	45.0
WC cleanliness/order/equipment	5	8.3	33	55.0	22	36.7
Stairways/corridors Layout/equipment/lighting	2	3.3	19	31.7	39	65.0
Total environmental score	Safe (60%+)			Unsafe (<60%)		
	No.	%	No.	%	No.	%
	35	58.3	25	41.7		

According to the research hypothesis:

The implementation of nursing intervention will improve the Alzheimer caregiver's knowledge, practice, and DLAs, (tables 3, 4, 5 & 6).

Table (3): Distribution of family caregivers according to their knowledge about Alzheimer disease pre- / post-program (n=60).

Items	Pre- program		Post-program		Chi-square	
	No.	%	No.	%	X ²	P-value
Meaning of Alzheimer disease	11	18.3	49	81.7	48.133	<0.001*
Causes of Alzheimer disease	12	20.0	48	80.0	43.200	<0.001*
Risk factors contributed to Alzheimer disease	3	5.0	57	95.0	97.200	<0.001*
Stages of Alzheimer disease	10	16.7	50	83.0	53.333	<0.001*
General signs and symptoms of Alzheimer disease	20	33.3	40	66.7	13.333	<0.001*
Common warning signs and symptoms of Alzheimer disease	27	45.0	33	55.0	1.200	>0.273
Alzheimer disease treatable	25	41.7	35	58.3	3.333	>0.068
Effects of medications	4	6.7	56	93.3	90.133	<0.001*
Complications of Alzheimer disease	15	25.0	45	75.0	30.000	<0.001*
Age of occurrence of Alzheimer	0	0.0	60	100.0	120.000	<0.001*
Availability of community health care resources	16	26.7	44	73.3	26.133	<0.001*

Table (4): Distribution of family caregivers' according to their providing activities of daily living towards their Alzheimer clients pre / post program (n=60).

Items	Pre-program		Post- program		Chi-square	
	No.	%	No.	%	X ²	P-value
Feeding (eating):						
Help in taking his food.	30	50.0	38	63.3	2.172	>0.141
Help in feeding by Ryle or intravenous.	3	3.3	3	3.3	0.209	>0.648
Bathing & personal hygiene:						
Prepare the bathroom (suitability of water temperature, soap, shampoo, chair to sit on it, towel and clothes) .	60	100.0	60	100.0	-	-
Help in cleaning and washing part of body (back, legs, abdomen, dressing and taking off cloth, drying body).	39	65.0	42	70.0	0.342	>0.559
Help in complete bath.	19	31.7	41	68.3	16.133	<0.001*
Help in moving to and from toilet.	2	3.3	58	96.7	104.533	<0.001*
Clean and comb hair to Alzheimer clients	10	16.7	50	83.3	53.333	<0.001*
Shave head, chin and unwanted hair.	15	25.0	45	75.0	30.000	<0.001*
Wash hands and mouth after eating.	23	38.3	37	61.7	6.533	0.011*
Wash/dry face and hands every morning.	11	18.3	49	81.7	48.133	<0.001*
Clothing (dressing):						
Provide assistance in clothing (e.g., wearing shoes).	20	33.3	40	66.7	13.333	<0.001*
Help in arranging and repairing clothes.	29	48.3	31	51.7	0.133	>0.715
Make complete dressed and taking off his/her clothes.	30	50.0	38	63.3	2.172	>0.141
Transferring & walking :						
Help to get in and out of bed.	21	35.0	39	65.0	10.800	<0.001*
Help to use moving aids (e.g., crutch, walker, and wheelchair).	18	30.0	42	70.0	19.200	<0.001*
Help during the sit-down and stand up.	37	61.7	52	86.7	9.786	<0.002*
Help in moving to and from a lying position.	27	45.0	33	55.0	1.200	>0.273
Help in continuously changing position in bed.	30	50.0	33	55.0	0.301	>0.583
Make massage and range of motion as physiotherapy.	38	63.3	52	86.7	8.711	>0.003*
Help during standing and sitting.	8	13.0	52	86.7	64.533	<0.001*
Make complete dressed and taking off his/her clothes.	30	50.0	38	63.3	2.172	>0.141
Toileting:						
Help during toileting (e.g., help in sitting and standing on toilet, provide bedpan or urinal).	23	38.3	37	61.7	6.533	<0.011*
Help in cleaning and wearing clothes after toileting.	19	31.7	41	68.3	16.133	<0.001*
Make diaper care if needed	3.0	5.0	3	5.0	0.000	<1.000
Make catheter care if needed	3.0	5.0	3	5.0	0.000	<1.000

Table (5): Distribution of family caregivers' according to their providing instrumental activities of daily living towards their Alzheimer clients pre / post program (n=60).

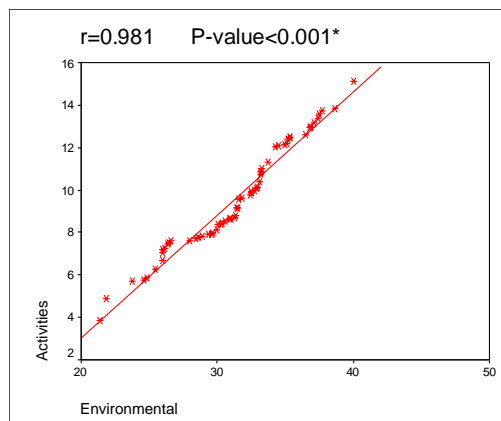
Items	Pre-program		Post-program		Chi-square	
	No.	%	No.	%	X ²	P-value
Household work:						
Clean pots and dishes used after eating.	0	0.0	60	100.0	120.000	<0.001*
Clean floors, furniture, and furnishings.	0	0.0	60	100.0	120.000	<0.001*
Arrange the bed.	10	16.7	50	83.3	53.333	<0.001*
Make laundry to unclean clothes	15	25.0	45	75.0	30.000	<0.001*
Medical care:						
Accompany to the doctor and care setting.	26	43.3	34	56.7	2.133	>0.144
Give the medication and observe prognosis	5	8.3	55	91.7	83.333	<0.001*
Shopping for groceries and personal needs						
Buy supplies of groceries or clothes	60	100.0	60	100.0	-	-
Preparing meals:						
Prepare and cook food	60	100.0	60	100.0	-	-
Managing money:						
Defray the costs of transmission, checkup, and investigation and buy treatment needed from own budgets.	15	25.0	45	75.0	30.000	<0.001*
Go to with clients for arrested pension	7	11.7	53	88.3	70.533	<0.001*
Go to payment of electricity, gas, phone bills ,etc.	16	26.7	44	73.3	26.133	<0.001*

Table (6): Family caregivers' total knowledge, and providing activities of daily living towards their Alzheimer clients pre / post program (n=60).

Items	Pre			Post			Paired t-test	
	Mean	±	SD	Mean	±	SD	t-test	P-value
Total knowledge	2.751	±	1.030	9.512	±	3.490	25.310	<0.001*
Total activities	9.330	±	2.671	34.125	±	2.811	30.544	<0.001*

Table(7): Relation between level of education and total knowledge, and providing activities of daily living of family caregivers' towards their Alzheimer pre / post program (n=60).

Items	Basic			Secondary			University			ANOVA	
	Mean	±	SD	Mean	±	SD	Mean	±	SD	F-test	P-value
Total knowledge	1.995	±	0.255	2.607	±	0.192	3.372	±	0.283	36.982	<0.001*
Total activities	6.293	±	1.125	8.529	±	0.714	12.063	±	1.401	19.958	<0.001*

**Figure (2): Correlation between environment and total providing activities of daily living of family caregivers towards their Alzheimer clients' pre / post program (n=60).**

4. Discussion:

Concerning the socio-demographic characteristics the finding of the present study revealed that less than two thirds of family caregivers aged 45+ years (*figure*,

I). This finding is in agreement with *Papastavrou, (2007)*, who emphasized that most of FCGs' age ranged between 50 to 75 years. However this finding contradicted with *Pandy and Coleman, (2004)*, who reported that the majority of FCGs' aged 30-45 years.

Regarding the educational level of FCGs, the results clarified that less than two fifths and more than two fifths had secondary and university education respectively (*figure, I*). This finding is on line with *Abo Elyazeed (2011)*, who find out in his study that the educational level of FCGs was around one-third having secondary school education. On the other hand this finding is incongruent with *Scazuza (2002)*, who stated in his study in US that FCGs had high educational level. This could be attributed to that the caregivers in this study had low socioeconomic class and most of families didn't consider education as an important issue.

Concerning gender of the FCGs the finding of the present study revealed that less than three quarters of them were females (*figure, I*). The main cause that the majority of family caregivers are females' could be attributed to the Egyptian cultures where feeling of sympathy is in the prevailing Egyptian's society, these feelings emerge from strong religious beliefs and

positive culture since early childhood and also, could be due to the nature of Egyptians who can accept additional duties for their family members besides their own social burden.

As regards FCGs' income, the finding of the present study clarified that most of them mentioned that they had monthly income insufficient for their needs (*figure, 1*). This finding is in agreement with *Ali (2009)*, who stated that almost all families in Egypt had insufficient income, while *Novaie et al, (2006)* mentioned that all families were financially supported by adequate monthly pension and social support services. This could be attributed to the unclear individual income per/month, as well as common financial problems in the Egyptian society which led to raising poverty level, where around one-third of the total Egyptian families are living under the poverty line.

Concerning the FCGs' relation to Alzheimer clients, the finding of the present study revealed that more than half were sons /daughters (*figure, 1*). This finding is congruent with *Wallsten (2000)*, who stated that sons/daughters become caregivers in case of one or both parents' sickness. While, the study finding was contradicting with *Hassan (2003)*, who emphasized that wives and/or husbands were caregivers in their families. This could be attributed to the strong family bounding between kids and their parents as well; also, sons/daughters in the family most properly take responsibilities of care giving.

As regards family caregivers' physical strain problems, the present study proved that the majority of family caregivers were fatigued, feeling exhausted, and more than one third loss ability to provide proper care in dealing with Alzheimer clients (*table, 1*). These findings agreed with *Cheffings (2005)*, who reported that most of caregivers believed that their health was adversely affected by their caring role. Also this finding is in accordance with *Youssef, (2002) and Grunfeld (2004)*, who reported that half of FCGs feel that caring of Alzheimer clients need great effort to provide all kind of care.

Regarding psychosocial strain problems almost two thirds of them mentioned that they were, feeling stressed for not providing best care, and loss of community awareness about the disease, and become more nervous excited and lack of health care resources. The majority reported that mood has totally changed, (*table, 1*). These findings were in agreement with *Victor (2004)*, who asserted that almost half of FCGs were suffering from frustration by lack of experiences, resources, and skills to effectively plan, manage and organize their one's care. Furthermore, many FCGs cannot recognize when they are suffering burnout and eventually get the point where they cannot function effectively. Also, this result agreed with *Shaji et al. (2003)*, who reported that there is absence of supportive health and welfare services in the developing countries. In a similar study, *Nijboer (2001)*,

also found that the main effects of social and psychologic resources on caregiver experiences were found to be small to absent. In this respect, **Shulman and Cohen (2003)** recorded that care giving stress can be reduced when community support programs are available.

As identified by *Yoo et al. (2007)*, caregivers also are often unaware of the availability of support services. One in three caregivers were using no services, only 9% used respite services and only 11% participated in support groups as reported by *Scharlach et al. (2003)*. As well this finding is in agreement with *Abo Elyazeed (2011)*, who found that only one-tenth of FCGs never suffer from shortage of personal responsibilities, and *Montgomery and Kosloski (2006)* stated that less than one-third of FCGs express social burden feeling resulting from caring of Alzheimer clients, social burden caused by many factors which include role confusion, and lack of control, in addition, to be unrealistic expectations (i.e., many FCGs expect their involvement to have a positive effect on the health and happiness of the patient) and unreasonable Alzheimer.

Concerning emotional strain problems, less than two thirds of them reported that they were, getting more close to God and increasing faith, and have feeling of high level of vigilance (*table 1*). This finding is in agreement with *Rennard (2008)*, who assured that the family needs support through closer to God. In another study, *Abdel Moneim (2000)* clarified that God is the most support among all systems. The whole family tends to accept their own disabilities as fate due to God's will, and this is usually associated with less emotional burden, reduced personal distress, more positive outlook, and enhanced feeling of being able to cope with the situation. Most of all caregivers need time to lead their own lives. This makes them more vigilance as possible to provide care as house managers and coordinate services.

The current study revealed that, approximately three fifths of Alzheimer clients were living in safe home environment, and there was positive correlation between the environment and total providing ADLs of FCGs towards their Alzheimer clients pre / post program (*table, 2& figure 2*). These results agreed with *Horvath et al. (2005)*, who reported that home safety is a major concern for persons with Alzheimer clients, because much direct care is provided in home. In their study, **Lach and Chang (2007)** showed that home safety is a significant problem for caregivers of people with Alzheimer. In a study, carried out by *Huang (2008)*, he highlighted that creating a safe and supportive environment can be remarkably helpful. For example, when the light is dim, people with Alzheimer are even more likely to misinterpret what they see, so lighting should be relatively bright. Leaving a night-light on can also help. Such changes can help prevent accidents (particularly falls) and help people function better.

The previous findings are contradicting with *that of Hassan (2003)*, who stated that around two-thirds of Alzheimer clients live with unprotected electricity wires, and, almost all of them had bedside light. This could be attributed to that light is provided in a way to prevent risk for falling especially during night in unsafe environment.

According to FCGs' knowledge about Alzheimer disease, the finding of the pre-intervention program showed that all of them had incorrect knowledge (*tables, 3&6*). These findings are in agreement with *Kneebone and Martin (2003)*, who highlighted that the level of FCGs' knowledge was poor in all items related to Alzheimer disease. However, these findings are incongruent with *Evan et al. (2009)*, who reported that, most of FCGs had correct knowledge about the Alzheimer disease. In a similar study, *Chung (2000)* stressed that the highest percentage of correct knowledge of caregivers was related to the type and nature of the Alzheimer. In this respect, *Steeman et al. (2007)* mentioned that having accurate knowledge of what one experiences when living with Alzheimer is important for developing proactive care for individuals with Alzheimer and their families.

The previous findings contradicted with *Werner (2003)*, who has noted that the low levels of knowledge were found in caregivers, especially in items related to the cause and symptoms of the disease. As well, these findings disagreed with *Paton et al. (2004)*, who asserted that providing facts about the illness to caregivers is not enough as caregivers may not understand that the symptoms they observe are related to the diagnosis. However, after implementation of the nursing intervention, the present study showed that there was improvements in all items with statistically significant differences pre/post tests except for common warning signs and symptoms of Alzheimer disease, and Alzheimer disease treatable items, that were statistically insignificant (*tables, 3&6*).

The fact that more than three quarters of caregivers had knowledge and total provided ADLs activities of daily living towards their Alzheimer clients improved post program in relation to their level of education (*figure, 1, & table, 7*). This may be because the majority of them were either university or secondary levels education, which helped them to gain information from different sources, e.g., books, journals, and internet. Moreover, education helps them increase their abilities to access community resources, and interact effectively with the health care team.

Regarding family caregivers according to their providing ADLs and instrumental activities of daily living towards their Alzheimer clients, before the program intervention they had helped in providing some items such as help in feeding by Ryle or intravenous, prepare the bathroom, shopping for groceries and personal needs, and prepare and cook food. On the other

hand they had not helped in providing some items related to personal hygiene such as help in cleaning and washing part of body, help in complete bath, help in moving to and from toilet, clean and comb hair to Alzheimer clients, shave head, chin and unwanted hair, and wash/dry face and hands every morning, also all items related to clothing, transferring and walking, toileting, household work, medical care, and managing money (*tables 4, 5 & 6*). The previous findings agreed with *Hassan (1999)*, who reported that the majority of caregivers suffer from exhaustion because of Alzheimer personal hygiene. As well, these results are on the same line with *Cutler and Sramek (2002)*, who explained that as Alzheimer progresses, mistakes are made in dressing and every day life, appearance deteriorates, and personal hygiene is neglected. This study is in contrast with, *Evan et al. (2009)*, who reported that majority of Alzheimer clients need complete supervision during bathing.

These results are in agreement with *McKee et al. (2007)*, who concluded that FCGs perform all aspects of care such as meal preparation, cleaning and housekeeping activities. As well, around one-third of FCGs are providing shopping of goods for Alzheimer clients. These findings were in accordance with *Evan et al. (2009)*, who revealed that half of FCGs practices extended to outside as well as, inside the home such as shopping. Moreover, *Schulz, (2005)* reported that the caregivers are involved in giving medication and injection to their Alzheimer persons, in addition to the household, shopping, transportation, and personal care. This could be due to that Alzheimer clients loss their ability in choices of goods in advanced stages of the disease. The present finding is supported *Arno (2006)* who emphasized that majority of FCGs take responsibilities of care such as changing Alzheimer clients position either from standing to sitting or vice versa as well as, housekeeping activities. While, these findings are in disagreement with *Brauner et al. (2000)*, who asserted that majority of FCGs might neglected some responsibility toward their Alzheimer clients such as their mobility, and house activities.

Regarding medication administration, performing shopping and pension receiving, *Ali (2009)*, and *Croog et al. (2010)*, stated that all FCGs administrated medication to Alzheimer clients, making shopping and receiving pension.

Regarding managing bill payment the finding of the present study indicated statistically significant improvements after the program intervention that most of FCGs take care responsibility of paying bills. This Finding is congruent with *Lawton and Brody (2006)*, who stated that FCGs provided outside support to Alzheimer clients such as bills payment. This could be due to that the FCGs are responsible about financial support, additionally majority of Alzheimer clients depend on FCGs in managing their financial issues as a

result of decline in their ability to think, judge and/ or recognize the life issues.

After the intervention program there was improvement in all items, and there were statistically significant differences in both providing activities of daily living and instrumental activities of daily living towards their Alzheimer clients (*tables 4, 5 & 6*). This is could be due to current social situation in Egyptian society, have strong kin-relationship between Alzheimer clients and FCGs, and also feeling of responsibility toward them.

Conclusion

Based on results of the current study, and the research hypothesis the following can be concluded that:

As regards family caregivers most of them had physical, psychosocial, and emotional strain problems. There was a highly statistically significant difference between family caregivers' total knowledge, and providing activities of daily living towards their Alzheimer clients pre / post implementation of the program, as well as their educational level, and total knowledge, and providing activities of daily living towards their Alzheimer clients pre / post program. Moreover, there was a positive correlation with highly statistically significant difference between family caregivers according to home environment and providing activities of daily living towards their Alzheimer clients pre / post program.

Recommendations

Based on the results of the present study, and research hypothesis, it is recommended:

-Counseling and nursing intervention for FCGs of Alzheimer clients in all settings to provide care for the clients about:

*Knowledge about Alzheimer disease, and preventing environmental hazards.

*Daily living activities especially personal hygiene

*Emotional support and relieving stress.

-Providing postures, booklets, and leaflets for FCGs, which describe care practices of Alzheimer clients in combined with basic knowledge.

-Providing community awareness about early detection, signs and symptoms of Alzheimer disease.

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References

Abdel Moneim R. (2000): Stress of geriatric patient caregivers. Unpublished Master Thesis, Faculty of Nursing, Ain Shams University, Egypt, pp.13 -15

Abo Elyazeed, O. M.(2011): Coping patterns of family members caring of their Alzheimer patient. Unpublished

Master Thesis, Faculty of Nursing, Ain Shams University., Egypt. pp.92-108.

Ali, A.L. (2009): Problem and need of family caregivers dealing with demented persons in Dakahlia and Cairo Governorates Unpublished Master Thesis. Faculty of Nursing, Ain Shams University., Egypt.

Alzheimer's Association (2009): Alzheimer's disease: Facts and figures. To be published in Alzheimer's & Dementia., 5, 3.

Arno, P.S. (2006): Economic value of informal caregiving. Presented at the Care Coordination and the Caregiving Forum, Department. of Veterans Affairs, NIH, Bethesda, MD, pp. 25-27

Ashour, A. (2007): Increase number of Alzheimer patients to million. Egypt, J. El-Akhbar; 56: 17318.

Boyd, A. M., (2005): Psychiatric nursing contemporary practice, 3rd ed., Hong Kong: Mosby, chapter 29, pp. 671-705.

Brauner, D.J., Muir, J.C., & Sachs, G.A. (2000): Treating non dementia illnesses in patients with dementia. Journal of Geriatrics; 5, 3, 283- 3230.

Cheffings, J.(2005): Report of the Princess Royal Trust for Carers. Princess Royal Trust for Carers : London.

Croog, J.A., Burleson, A. & Sudilovsky, R.M. (2010): Spouse caregivers of Alzheimer patients: Problem responses to caregiver burden. Aging & Mental Health, March, 10(2): 87-100.

Chung, G.J. (2000): Lay interpretation of dementia. International Psycho-Geriatric, 12(3), 369 – 377.

Cutler, N.R., & Sramek, J.J. (2002): Understanding Alzheimer's Disease. University Press of Mississippi.

Evan, D.A., Scherr, P.A. & Cook, N.R. (2009): Estimated prevalence of Alzheimer's disease in the United States. Milbank Q, 68, 267-289.

Grunfeld, E. (2004): Family caregiver burden: Result from a longitudinal study of breast cancer patients and their principle caregivers. Canadian Medical Association Journal, 170(12), 1795:1801.

Guirguis, S.R. (2000): Health maintenance/promotion program for caregivers of ischemic heart diseased at home. Unpublished Doctorate Thesis, Faculty of Nursing, Ain Shams University, Egypt, pp. 8-11. 159-185.

Ham, R.J. (2002): Dementias and delirium. In: R.J. Ham, P.D. Sloane, and G.A. Warshaw [Eds]. Primary care geriatrics: A case based approach, (4th ed.); St. Louis ,Mosby, pp. 245 – 308.

Hassan, M. (1999): Assessment of psychosocial stress facing family caregiver of elderly patient with dementia, Unpublished Master Thesis, Faculty of Nursing, Ain Shams University, Egypt ,pp.64-87.

Hassan, M. (2003): Effective nursing intervention for formal and informal caregivers of caring for dementia. Unpublished Doctorate Thesis, Faculty of Nursing, Ain Shams University; Egypt; pp. 191-193, 213.

Hepburn, K.W, Lewis, M., & Sherman, C.W. (2003): The savvy caregiver program: Developing and testing a transportable dementia family caregiver training program. Gerontologist; 43(6), 908-915.

- Horvath, K.J., Hurley, A.C., & Duffy, M.E., (2005):** Caregiver competence to prevent home injury to the care recipient with dementia. *Rehabil Nurse*: 30(5), 189-96.
- Huang, K. (2008):** Informal female caregivers of older adults with dementia in Taiwan, *California Journal of Health Promotion*, 2(3), 53-66.
- Kneebone, I.I. & Martin, P.R. (2003):** Coping and caregivers of people with dementia. *British Journal of Health Psychology*, 8(Pt. 1), 1-17.
- Lach, H.W., & Chang, Y.P. (2007):** Caregiver perspectives on safety in home dementia care. *West J Nursing Research*; Jul 13(7), 231-236.
- Lawton, M. & Brody, E. (2006):** Assessment of older people: Self-maintaining and instrumental activities of daily living. *Gerontologist*, 9, 179-186.
- Mace, N.L., & Rabin P.V. (2001) :** *The 36-hours day*. (3rd ed). Baltimore John Hopkins University Press.
- McKee, K.J., Whitlack, J.E., Ballinger, B.B., Gillhooly M.M., Gordon, D.S., Mutch, W.J., & Philip, I. (2007):** Coping in family supporters of elderly people with dementia. *British Journal of Clinical Psychology*, 36, 323-340.
- Michel, J.P., Pautex, S., & Zekry, D., (2002) :** End-of-life care of persons with dementia. *J Gerontol A Bio Sci Med Sci*, 57(10), 640-644.
- Montgomery, R. & Kosloski, K. (2006):** Change, continuity and diversity among caregivers. Washington, DC: Administration on Aging. Retrieved May 18, 2001.
- National Institute of Health (NIH) (2004):** Progress report on Alzheimer's: Research advanced at NIH (NIH pub. no. 04-5570). Washington, DC: US. Government Printing Office.
- Novae, W. M., Feldman, R., Gould, D.A., Levine, C.; Kuerbis, S. &**
- Donelan. K. (2006):** The experiences and challenges of informal caregivers: Common themes and differences among whites, blacks, and hispanics. *Gerontologist*. 41(6):733-41. [PubMed] <http://www.pub med central.mib.gov/rectirect3.cgi> [PubMed].
- Nijboer, C. (2001):** The role of social and psychologic resources in care giving of cancer patients. *Cancer Cytopathology CA. A Cancer Journal for Clinicians*, 91(5), 1029 - 1039.
- Papastavrou, R.E. (2007):** Alzheimer's disease: clinical features and differential diagnosis. *Neurology*, 43:45-51.
- Pandy, S.M. & Coleman, B. (2004):** Caregiver and long-term Care. Retrieved April t3, (2004), from <http://research.aarp.org/health/fs82-caregiving.html>.
- Paton, J., Johnston, K., Katona, C. (2004):** What causes problems in Alzheimer's disease: Attributions by Miller, M. (2000): Parkinson's disease. In R.J. Ham, P.D. Sloane, & G.A. Warshaw (Eds.), *Primary care geriatric: A case based approach*; (4th ed). London, Mosby, pp.605- 614.
- Renard, N. (2008):** The health status of elderly veteran enrollees in the veteran's health administration. *Journal of the American Geriatrics Society*, 52 (8), 1271 - 1276.
- Sczufa, M. (2002):** Brazilian version of burden interview scale for the assessment of burden of careers of people with mental illness. *Rev. Bras. Psiquiatr*; 24, (1). 25-30.
- Scharlach, A.E., Kellam, R., & Ong, N., (2003):** Cultural attitudes and caregiver service use lessons from focus groups with racially and ethnically diverse family caregivers. *Journal of Gerontological Social Work*, 47(12), 133 - 156.
- Schulz, R., (2005):** Care giving as a risk for mortality: The caregiver health effects study. *JAMA*, 282, 2215 - 2219.
- Shaji, K.S., Smitha, K., & Lalk, P., (2003):** Caregivers of people with AD: A qualitative study from the Indian 10/66 dementia research network. *Int J Geriatr Psychiatry*, 18(1), 1 - 6.
- Shulman, K.I. & Cohen, C.A. (2003):** Psychiatric issues in retrospective challenges of testamentary capacity.
- Signe, A., & Sölve, E. (2008):** The relationship between caregiver burdens, caregivers perceived health and their sense of coherence in caring for elder with dementia. *British Journal of Clinical Psychology* 17(6), 13 - 15.
- Steeman, E., Godderis, J., & Grypdonck, M. (2007):** Living with dementia from the perspective of older people: Is it a positive story? *Aging Ment Health*, 11(2), 119 - 30.
- Thompson, B. Rand, A., & Brigg, B., (2002):** Are there relations between coping and environment safety with Alzheimer's disease? *Experimental Research for Nursing*, 5(4), 319-330.
- Lawton, M., and Brody, E. (2006):** Assessment of older people: Self-maintaining and instrumental activities of daily living. *Gerontologist*, 9, 179-186.
- Victor, L.B. (2004):** Alzheimer's Association and National Alliance for Care giving. *Families care: Care giving in the United States*. Accessible @ www.alz.org.
- Vitaliano, P.P. (2003):** Is care giving hazardous to one's physical health? A meta-analysis. *Psycho Bull*, 129(6), 946 - 72.
- Wallsten, S.S. (2000):** Effects of care giving, gender and race on the health, mutuality and social supports of older couples. *Journal of Ageing and Health*, 12, 90-111.
- Werner, P. (2003):** Correlates of family caregiver's knowledge about Alzheimer's disease. *International Journal of Geriatric Psychiatry*, 16(1), 32 - 38.
- Yoo, H.J., Park, S., & Yun, Y.H. (2007):** Depression in family caregivers of cancer patients: The feeling of burden as a predictor of depression. *Journal of Clinical Oncology*, 26 (36), 5890-5895.
- Youssef, F.K. (2002):** Assessment of attitude and practice of family caregiver towards abuse and neglects of adults. Unpublished Master Thesis, Faculty of Nursing, Ain Shams University, Egypt, pp. 131-132.