

## **Caregivers' Needs and problems toward Care of patients with Dementia**

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**Abstract:** Caregivers of patient with dementia often called the invisible second patients. The effects of being a caregiver, though sometimes positive, are generally negative, with high rates of burden and psychological morbidity as well as social isolation. Purpose of the study: was to assess caregivers' needs and problems toward care of patients with dementia. Design: A descriptive research design was utilized. Setting: The present study conducted at out-patient clinic of Alkhanka Mental Health Hospital. Sampling: Simple random sample used in the study and total number of the sample was 150 caregivers who had patients ( $\geq 50$  yrs) having dementia. Instruments: Two instruments were used. 1 Structured interviewing questionnaire. It contained 5 parts (A. Socio-demographic characteristic of demented patient, B. Socio-demographic characteristic of caregivers, C. Caregivers' knowledge about dementia, D. Caregivers' needs and problems. E. Caregivers' reported practice). 2 An Attitude rating scale and Burden scale. Results: Female caregivers of demented patients were more than males, 49.3% of caregivers had average knowledge, 52.7% of them had satisfactory practice, 70.7% of caregivers had positive attitude and 50.7% had moderate burden. **Conclusion:** Caregivers of demented patients have financial, physical and psychological problems. Needs of caregivers of demented patients are financial, social, emotional, physical and personal needs. There was highly statistical significant positive relation between total knowledge of caregivers and their total needs. There was a highly statistical significant positive relation between total practices of caregivers and their total needs as well as problems. Also, there was a positive statistical significant relation between total attitude of caregivers and their total needs. Recommendation: Increase awareness of caregivers about community resources and how to gain access to them through mass-media, develop a health educational program for caregivers in neuro-psychiatric out-patient clinic to provide them with needed knowledge about disease process, therapeutic activities and positive behavior interaction.

**Key words:** *Patients with dementia, caregivers' needs and problems.*

### **Introduction**

Alzheimer's disease and related dementias are a major health problem as someone in the world develops dementia every 3 seconds. Currently, there are 46.8 million people worldwide living with dementia in 2015, this number is believed to be close to 50 million people in 2017 and this number will almost double every 20 years, reaching 75 million in 2030 and 131.5 million in 2050 (Alzheimer's disease International, 2017). In Egypt, the number of demented patients is about 300,000 cases, which is expected to become one million by the year 2030 (Ashour, 2013).

Dementia is a decline or loss of reasoning, memory, and other mental abilities (the cognitive functions such as judgment, thinking, behavior, and language) and is not a normal part of aging. This decline is progressive and eventually impairs the ability to carry out daily living activities such as household duties and personal care such as bathing, dressing and feeding (Beck et al., 2014).

Dementia is caused by gradual changes and damage in the brain. The most common causes of dementia include diseases in which the brain cells degenerate and die more quickly than they would as part of the normal aging process. The changes usually

happen because of a build-up of abnormal proteins in the brain. A variety of diseases and injuries that primarily or secondarily affect the brain, such as Alzheimer's disease or stroke cause dementia. The abnormal proteins are different in each type of dementia. In most cases, dementia is not inherited directly from family members. However, frontotemporal dementia can sometimes run in families (**Gelder & Harrison, 2016**). Caregivers face many obstacles as they balance caregiving with other demands, including child rearing, career, and relationships so the risk for burden, stress, depression, and a variety of other health complications increased. The effects on caregivers are diverse and complex, and there are many other factors that may exacerbate or ameliorate how caregivers react and feel as a result of their role. Caring for a person with dementia is more stressful than caring for a person with a physical disability (**Kim & Schulz, 2017**).

Caregivers may need someone to help them for caring the patient including help with transportation, daily living needs and home tasks. Caregivers are in need for financial and psychological support and adequate intervention schemes, especially within the home. These should be provided by trained personnel to manage patient's problems particularly behavioral disorders. This may alleviate caregivers' burden and allow patients to continue to be managed at home (**Schulz & Matire, 2012**).

#### **purpose**

The present study aimed at assessing needs and problems of caregivers of patients with dementia

#### **Research Question:**

- 1) What are the problems of caregivers of demented patients?

- 2) What are the needs of caregivers of demented patients?
- 3) Is there a relation between caregivers' knowledge, practices, attitude and needs or problems?

#### **Methods**

##### **Research design:**

A descriptive research design was utilized to conduct this study.

##### **Setting:**

The study was conducted at Out-Patients clinic of Alkhanka Mental Health Hospital.

##### **Sampling:**

Simple random sample was utilized in this study and data was collected within 6 month. The total number of the sample was 150 caregivers who caring for patients with dementia.

##### **Criteria of selection of the sample:**

- 1) Patients should be free from other chronic diseases.
- 2) Patients should be aged 50 years or more.
- 3) Caregivers should be living with demented patients in the same residence or nearby.
- 4) Caregivers should be providing care for demented patients.

##### **Instruments:**

Data were collected by using two instruments:

##### **1: Structured interviewing**

**questionnaire:** It was developed by the researcher and consisted of five parts:

##### **▪ Part 1: Socio-demographic characteristic of the demented patient:**

It consisted of 7 items closed ended questions related to Age, gender, marital status,

education, income, income source and patient's disease stage.

▪ **Part 11: Socio-demographic characteristic of the caregivers:** It consisted of 13 closed ended questions related to Age, education, gender marital status, family size, job status, residence, income, relation to patient, duration of caregiving , caregiving hours, other member assisting in caregiving and assistant personal.

▪ **Part 111: Caregivers' knowledge about dementia.**

caregiver's knowledge consisted of 9 items about meaning of dementia, cause of dementia, signs and symptoms of mild stage, signs and symptoms of moderate stage, signs and symptoms of late stage, effects of medication, age of dementia occurrence, common affected type and common affected sex.

▪ **Part IV: Caregiver's problems and needs.**

A. Caregivers' problems consisted of 2 items in the form of closed ended questions related to caregiver's problems and problems during daily living.

B. Caregivers' needs consisted of 7 items in the form of closed ended questions related to financial needs, information needs, social

needs, emotional needs, needs from relatives and friends, physical needs and personal needs.

▪ **Part V: Caregivers' practices as reported:** It was developed to assess caregivers' practices to help demented patients in performing activities. It was consisted of 9 items inform of closed ended questions (multiple choice type) covering areas such as feeding, bathing, transfer, moving, toileting, clothing, personal hygiene, household and medical care.

**2: An Attitude rating scale (Likert scale) and Burden scale**

A. **An Attitude rating scale (Likert scale):** It adopted from Yanni (1996) and modified by investigator.

The scale was divided in to three categories: Agree, some times and disagree. It measures 24 items.

B. **Burden scale:** It adopted from Zarit et al (1980) and modified by investigator. The scale was divided in to three categories: Always, some times and never. It measures 22 items.

## Results

**Table (1): Distribution of studied caregivers regarding their socio-demographic characteristics (N=150).**

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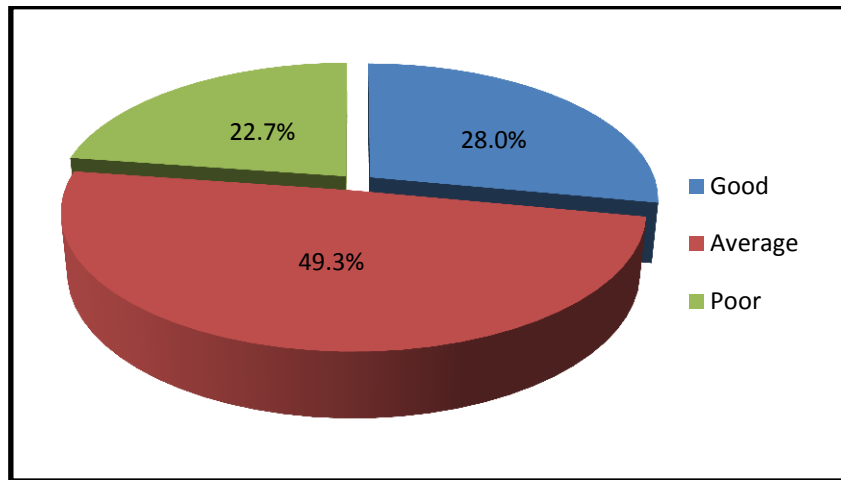
<b>Socio-demographic of caregivers</b>	<b>No</b>	<b>%</b>
<b>Age/Years</b>		
< 30	7	4.7
30 –	61	40.7
40 –	65	43.3
50+	17	11.3
Mean & SD	<b>41.5±7.6</b>	
<b>Education</b>		
Not read & write	19	12.7
Read & write	52	34.7
Secondary	8	5.3
University	71	47.3
<b>Gender</b>		
Male	73	48.7
Female	77	51.3
<b>Marital status</b>		
Single	14	9.3
Married	136	90.7
<b>Family size/Members</b>		
Single	14	9.3
< 5	106	70.7
> 5	30	20.0
<b>Job status</b>		
Employed	100	66.7
Not employed	50	33.3
<b>Residence</b>		
Urban	88	58.7
Rural	62	41.3
<b>Income</b>		
Enough	27	18.0
Not enough	123	82.0
<b>Relation to patient</b>		
Spouse / wife	36	24.0
Son / Daughter	70	46.7
Friends/Neighbors	44	29.3

**Table (1):** demonstrates that 43.3% of studied sample aged from 40-50 years with mean age 41.5±7.6years, 47.3% of them had university education, while 51.3% were

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females, 90.7% were married, and 70.7% had less than 5 members of family size, 66.7% were employed, 58.7% were living

in urban areas, 82.0% of them had not enough income and 46.7% of caregivers were son / daughter.



**Figure (1):** Distribution of studied caregivers regarding their total knowledge score (N=150).

**Figure (1):** represents that 49.3% of studied sample had average knowledge about dementia, while 28.0% had good knowledge, and 22.7% had poor knowledge.

**Table (2):** Distribution of studied caregivers regarding their problems (N=150).

Caregiver's problems	No	%
<b>Caregiver's Problems</b>		
Financial problem	80	53.3
Understanding \ dealing with caregiver demented patient behavior	88	58.7
Physical fatigue	79	52.7
Psychological burden due to society look	75	50.0
<b>Problems during daily living</b>		
Personal hygiene	86	57.3
Cooking and feeding	72	48.0
Giving medications	83	55.3
Elimination function	75	50.0

**Table (2):** states that 58.7% of caregiver's problems were related to understanding/dealing with demented patients, while 52.7% for physical fatigue and 53.3% for financial ones. In addition to caregiver's problems during daily living, it was found that 57.3% were related to personal hygiene and 55.3% for giving medications.

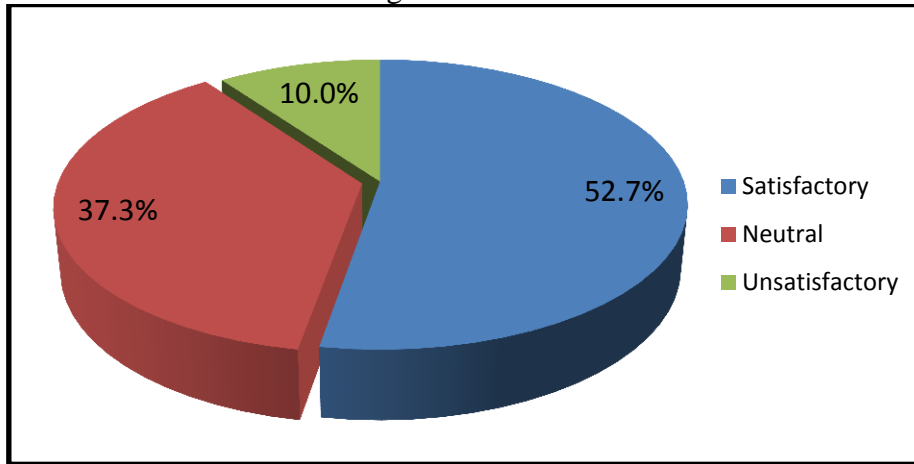
**Table (3):** Distribution of studied caregivers regarding their needs (N=150).

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<b>Caregiver's needs</b>	<b>No</b>	<b>%</b>
<b>Financial needs</b>		
Medications	103	68.7
Diapers	40	26.6
Wheel chair	35	23.3
Periodic visits to physician	87	58.0
Shopping \ buying demented patient's needs	64	42.7
<b>Information needs</b>		
Nature of disease and its progress	55	36.6
Medication and its effect	88	58.7
How to face daily problems with demented patient	102	68.0
Specialized center that can help in care	96	64.0
<b>Social needs</b>		
An assistant to help in care giving	50	33.3
A counselor to advise about care giving	56	37.3
Suitable recreation facilities for these demented patient	84	56.0
Increasing community awareness about the disease	88	58.7
Home visits by health care team	90	60.0
<b>Emotional needs</b>		
Interaction with similar caregivers	91	60.7
Seminars and meetings to increase awareness	69	46.0
Hotline service	68	45.3
Group therapy	75	50.0
<b>Needs from relatives/friends</b>		
Sharing in care giving	48	32.0
Keeping in away from demented patient's affairs	39	26.0
Understanding caregiver's situations	83	55.3
Cannot ask for help	29	19.3
<b>Physical needs</b>		
Specialized center to host demented patient for a few days	80	53.3
Help in shopping and cooking	46	30.7
Equipment as wheel chair and special beds	57	38.0
<b>Personal needs</b>		
Recognition from patient's family	41	27.3
Financial support to be able to provide care	93	62.0
Social life with friends/ exchange visits	58	38.7
One day off per week	40	26.7

**Table (3):** shows that 68.7% of caregivers' financial needs were to buy medication, and 68.0% of them were in need information about how to face daily problems with demented patients, while 60.0% of caregivers' social needs were home visits by health care team. In addition to 60.7% of caregivers' emotional needs were interaction with similar caregivers

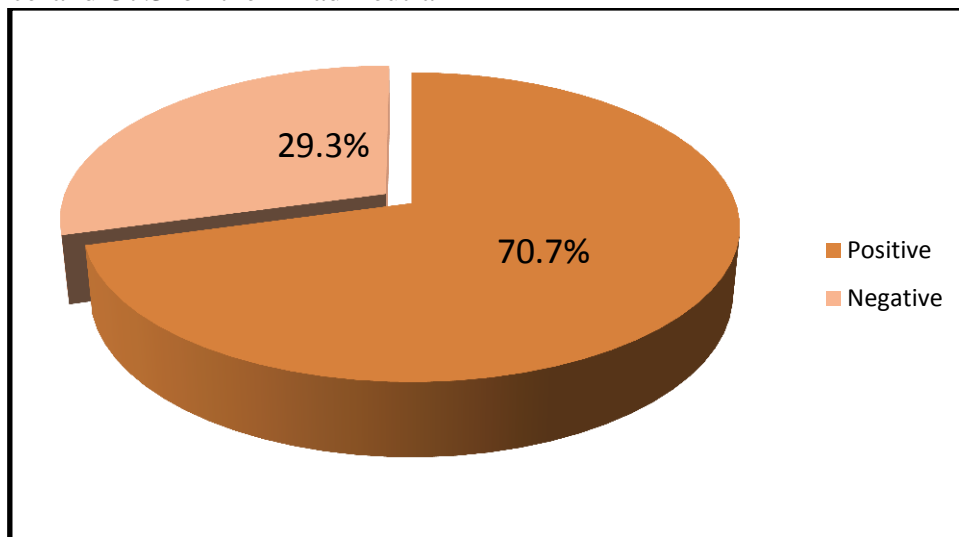
and 55.3% of their needs from relatives/friends were understanding caregiver's situation, while 53.3% of caregivers' physical needs were specialized center to host demented patient for a few days and 62.0% of their personal needs were financial support to be able to provide care.



**Figure (2) Distribution of studied caregivers regarding their total practices score (N=150).**

**Figure (2):** shows that 52.7% of studied sample had satisfactory practice and 37.3 of them had neutral

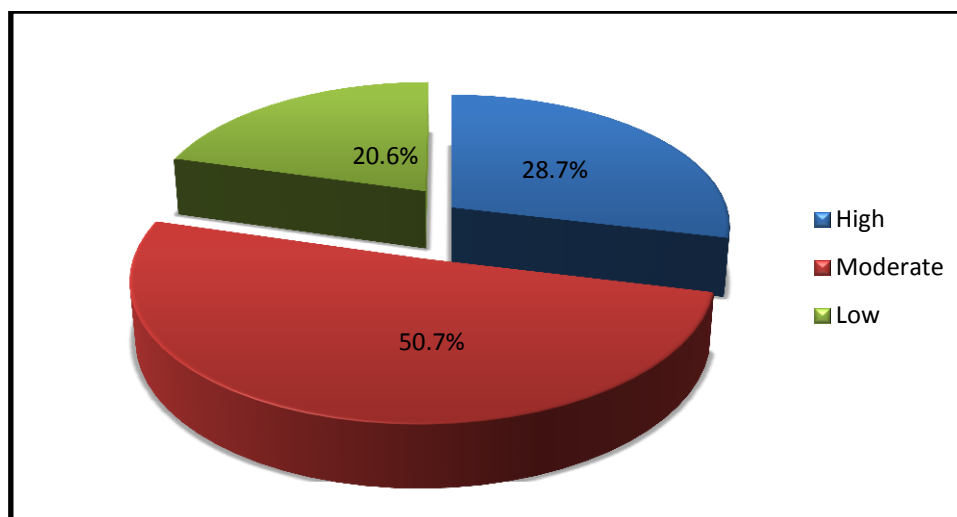
practice, while 10.0 of them had unsatisfactory practice.



**Figure (3): Distribution of studied caregivers regarding their total attitude score (N=150).**

**Figure (3):** Illustrates that, 70.7% of caregivers had positive attitude toward their patient's care, while 29.3% of

them had negative attitude toward their patient's care



**Figure (4): Distribution of studied caregivers regarding their total burden score (N=150).**

**Figure (4):** Demonstrates that, 50.7% of caregivers had moderate burden as a result of patient's care, while 28.7% of

**Discussion**

Concerning socio – demographic characteristics of demented patients' caregivers, results of the current study indicated that, more than two fifths of studied sample aged from 40-50 years with mean age (41.5±7.6) years, less than half had university education, while females were represented more than half, more than three quarters of studied sample were married, more than three fifths were employed, more than half were living in urban areas, more than three quarters of them had not enough income and less than half of caregivers were son / daughter (Table 1).

These results are on line with El-Bosaty, (2009), who studied problems and needs of family caregivers dealing with demented persons in Dakahlia and Cairo governorates Ain shams University, Egypt, who said that, the majority of family caregivers were married, workers, educated, females, with insufficient income, more than three fifths of the caregivers were aged 45+ years, and more than half were sons / daughters of demented persons

them had high burden and 20.6% of them had low burden.

.Also the results was in contrast with Pinto et al., (2013), who claimed that the majority of caregivers were females, married, and more than half had low levels of income.

However, these findings are contradicting with Lach & Chang (2014), who reported that the number of male caregivers increase and will continue due to variety of social demographic factors. The cause of the majority of female caregivers may be due to their feeling of sympathy and in our society, these feeling emerge from our strong religious beliefs and positive culture since early childhood and also, due to the nature of Egyptians that they can accept additional duties for their family members besides their own social burden.

In relation to caregivers' knowledge about dementia the present study showed that, slightly less than half of studied sample had average knowledge about dementia (Figure 1). These results were in agreement with Chung, (2015), who stressed that the highest percentage of correct knowledge of



caregivers was related to the type and nature of the dementia. According to Arai et al., (2014), there was a gap in knowledge on dementia among the general public, which may prevent caregivers from planning upcoming social and financial challenges. In this respect Steeman et al., (2013), mentioned that having accurate knowledge of what one experiences when living with dementia is important for developing proactive care for individuals with dementia and their families.

This finding contradicted with Werner, (2013), 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., (2014), who asserted that the provision of facts about the illness to caregivers is not enough as caregivers may not understand that the symptoms they observe are related to the diagnosis. The fact that slightly less than half of studied sample had average knowledge about dementia may be because the majority of them were university level educated which helped them to gain information from different sources e.g., books, journals, internet.

Concerning caregivers' problems, the present study proved that more than half of caregivers have problems related to understanding/dealing with demented patients, physical fatigue and financial ones (Table 2). These findings were in accordance with Houser, (2017), who reported that, dementia caregivers have a significant higher mortality risk than non – caregivers. Nearly half of female caregivers also reported high level of physical strain or emotional stress as a result of care giving.

Also these findings were in agreement with Chow et al., (2013), who reported that most of caregivers believed that

their health was adversely affected by their caring role. According to Dwyer and Writer (2016), sleep deprivation and fatigue are common denominators as a result of caregiving. Fatigue contributes to increased vulnerability to illness, robbing the energy of family caregivers. It can produce anxiety, anger, and irritability, can affect concentration and consequently task performance, impaired judgment to the point of danger when driving, using machinery and administering medication, and so has impact on job performance. Sleep deprivation can lead to mental distress, memory loss, and depression.

Furthermore, Chow et al., (2013), asserted that caregivers of demented patients are at a greater risk of developing poor financial, physical, and emotional health. Moreover, Lango et al., (2011), reported that median incomes of caregiver were 15% lower than those of non caregivers and the poverty rate is higher among families with disabled members than among families without. However, the previous findings are to some extent in contradiction with Thomas et al., (2012), who have noted that the caregivers' problems concerned mainly with the absence of relief and impossibility of having any time to themselves.

The finding of current study demonstrated that the most common demented persons physical care problems faced by caregivers was personal hygiene (Table 2). This result is on the same line with Cutler & Sramek (2012), who explained that as dementia progresses, mistakes are made in dressing, appearance deteriorates, and personal hygiene is neglected. Also this finding agreed with Hassan (2003), who studied effective nursing intervention for formal and informal caregivers caring for dementia patient Ain shams

University, Egypt, who reported that the majority of caregivers suffer from exhaustion because of demented person's personal hygiene and sleep disturbance.

As regards caregivers' needs, the present study proved that, more than three fifths of caregivers' financial needs were to buy medication (Table 3). This result was in contrast with **Soute et al., (2010)**, who said that, although the financial burden associated with the disease has been shown to be significant cost of hospitalization, medical consultation, paramedical services, laboratory and diagnostic tests and medications were other indirect costs.

The present study also revealed that, less slightly than two thirds of caregivers were in need for information about how to face daily problems with demented patients (Table 3). This result was in accordance with **Davis & Maglivi, (2010)**, who clarified that most caregivers of older adults received no instructions about how to perform the activities of care for their ill family members.

Moreover, **Huang, (2016)**, emphasized that the home based caregiver training program is helpful for decreasing problematic behaviors of elderly people with dementia and it improves the caregiver's self – efficacy for managing problematic behavior. **Similarly Hassan, (2003)**, who reported that the majority of caregivers need information regarding to care and the nature of the disease of their relatives.

This study emphasized that more than half of caregiver's physical needs was to presence of specialized center that can host demented persons for a few days (Table 3). This result was in agreement with **Flint, (2015)**, who mentioned that formal respite care has a significant effect on caregivers' burden, psychiatric status, and physical health, or on patients' cognition,

function, physical health, or rate of institutionalization. Caregivers need specialized center to host demented persons for a few days may be due to reduce of burden and physical strain of caregiving.

Concerning total practice of caregivers toward their demented patients, the present study revealed that, more than half of studied sample had satisfactory practice (Figure 2). This result is in agreement with **Huang et al., (2016)**, who have asserted that the caregivers had good practices toward their demented patients. However, the previous results disagreed with **Kasuya et al., (2011)** who reported that the caregivers had poor practices toward their patients.

Concerning total attitude of caregivers the present study illustrated that, two third of caregivers had positive attitude toward their patient's care (Figure 3). This result was supported by **Mohamed, (2017)**, who studied factors affecting caregivers burden in a sample of Egyptian dementia patients Ain shams University, Egypt, who found that, the majority of caregivers' attitude was positive to ward demented person. In their study, **Keefe et al., (2016)**, emphasized that although most caregivers believed their health wasn't at a good level, they were satisfied by caregiving. **Earlier, Yamamoto et al., (2010)**, suggested that care would better when given by caregivers who are blood relatives to the people they care for, in order to facilitate attitudes of acceptance among them.

Having a positive attitude towards helping others may be an important determinant of positive emotional functioning among dementia caregivers and may help to offset the negative consequence of caregiving as mentioned by **Dulin & Dominy (2017)**. According to **Adams, (2008)**, the development of a positive attitude is important in maintaining emotional

balance during the course of a chronic illness and assisting patients with interpersonal relationships.

The positive attitude of caregivers could be explained on religious ground, which gains a major importance in the Egyptian culture. To the great majority of people, taking care of their relatives, especially the parents and older ones, in an obligation ordered by the religion. Thus, the process would provide satisfaction on the person both psychologically and spiritually.

Concerning total burden of caregivers, the present study showed that, more than half of studied sample had moderate burden as a result of patient's care (Figure 4). This result was contradicted with **Gemaey, (2004)**, study coping strategies for family caregivers of dementia patient Ain shams, who reported that most caregivers experience sever burden may be because of being close to severely ill persons with dementia imposing a high level of burden. Also this result not supported by **Serrano et al.,(2016)**, who reported that, majority of caregivers have high levels of burden as a result of patients' care.

### **Conclusion**

More than two fifths of the caregivers had average knowledge score about dementia disease. More than half of studied sample had satisfactory practices score regarding to care of their demented patients. More than two thirds of caregivers had positive attitude toward patient's care. More than half of studied sample had moderate burden due to patient's care. More than four fifths of studied sample were affected by the problems that facing them during providing care to demented patients. More than half of studied sample had high needs toward care of patients with dementia. There was highly statistically significant relation between total knowledge of caregivers and their total needs and

problems. Also there was highly statistically significant relation between total practices of caregivers and their total needs and problems. There was statistically significant relation between total attitude of caregivers and their total needs and there was statistical differentiation between total attitude of them and their total problems.

### **Recommendations**

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

- Encourage regular home visits by health care team to assess and meet the needs and solve problems of demented patients and their caregivers.
- Increase awareness of caregivers about community resources and how to gain access to them through mass media.
- Develop a health educational program for caregivers in neuro-psychiatric out-patient clinic to provide them with needed knowledge about disease process, therapeutic activities and positive behavior interaction.
- Further researches are needed to study different aspects of dementia, caregiving and design effective coping strategies for demented patients' caregivers.

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