Emotional involvement and burden in caregivers of patients with Alzheimer's disease

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Background

There has been relatively little research on caregivers of patients with Alzheimer's disease and those with cognitive disorders for long durations.

Aim

To examine the psychological dimensions, defensive styles strategies, and distress in caregivers of Alzheimer's patients.

Methods

Caregivers of 40 patients with Alzheimer's disease were interviewed and compared with a group of caregivers of diabetic patients on the experience of caregiving, emotional stress, and burden. Caregivers of patients with Alzheimer's disease were assessed using the Defense-Style Questionnaire and the Involvement Evaluation Questionnaire.

Results

Caregivers of patients with Alzheimer's disease used mature, neurotic, and immature defensive strategies to cope with the patient's symptoms and difficult behavior, and experienced more worry about these problems and led to increased supervision. There were sex differences among caregivers; female caregivers were more prone to worry and overinvolvement than male caregivers.

Conclusion

Caregivers of patients with Alzheimer's disease have to cope with a wide range of problems and develop coping defensive strategies. Caregivers worried most about the difficult behavior and symptoms of patients with Alzheimer's disease. The increased levels of worry, tension, negative feelings, and overuse of mature defenses in caregivers are associated with personal and sociodemographic variables, rather than variables related to the illness itself.

Keywords:

Alzheimer's disease, behavioral and psychological symptoms, caregivers, psychological burden

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Introduction

It has been found that a patient's illness may have an impact on several aspects of family life (Georges *et al.*, 2008), but it is unclear why some family members are more adversely affected than others. Caring for a family member with Alzheimer's disease is extremely stressful and contributes toward the development of psychiatric and physical illnesses among caregivers (Belle *et al.*, 2006). Numerous potential factors have been examined, including sociodemographic characteristics of the patients and the caregivers, patients' clinical characteristics, and family setting and members. However, generally, the findings have been inconsistent, possibly reflecting differences in the conceptualization and measurement of caregivers' experiences (Thompson and Spilsbury, 2007). Provision of better ways to support family caregivers is a major public and psychiatric health challenge.

Most studies have found that the severity of symptoms of patients with Alzheimer's disease is strongly related to their caregivers' burden (Conde-Sala *et al.*, 2009), although a few have found no association; for example, Wilson *et al.* (2007).

Coresident caregivers, especially spouses, are of primary importance in situations in which patients with Alzheimer's disease are cared for in their own homes in their community rather than in institutional settings, which may be costly and may result in social stigma (Schneider *et al.*, 1999).

Negative attitudes are prevalent in the society toward individuals with any mental illness. Discrimination occurs across every aspect of social and economic existence. Research has documented stigma, with its negative impacts on individuals with mental, cognitive, or psychiatric illness (Boucharlat *et al.*, 2006).

Stigma not only affects individuals with psychiatric illness but also their families, a process by which an individual is stigmatized by virtue of association with another

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stigmatized individual (Gormley, 2000), that is, 'associative stigma'.

Families are more actively involved in the long-term care of their relatives who have severe cognitive and behavioral impairments. Caregivers' experiences encompass distress, stigma, worry, shame, and guilt, and positive emotions such as Care giver satisfaction to that effort (Huang *et al.*, 2009). Studies have consistently shown that approximately one-third of caring relatives have elevated levels of anxiety or depression linked to their role as caregivers (Yeung *et al.*, 2007), especially caregivers of patients with Alzheimer's disease, who are mainly elderly spouses (Aguglia *et al.*, 2004).

Methods

A consecutive sample of forty previously diagnosed patients with Alzheimer's disease and their caregivers attending Kasr El-Aini psychiatric outpatient clinics were included in the study. A group of 40 caregivers of diabetic patients were used as controls. Patients were recruited over a period of 6 months (September 2010–March 2011). Caregivers younger than 21 years of were excluded.

A psychiatrist assessed the patients using a semistructured interview and confirmed a previously assigned diagnosis according to the (DSM IV) criterion for Alzheimer's disease of a history of at least 2 years of illness. The psychiatrist interviewed the patient and sought consent to interview the caregiver. This study was designed as an outpatient cross-sectional study after receiving the approval of the ethical research committee, and conformed to the provisions of the World Medical Association's Declaration of Helsinki.

Caregivers were sons, spouses, siblings, and others (distant relatives). For each participant recruited in the study, a main caregiver was identified as the individual who was most available (contact) and most supportive either emotionally or financially. To be eligible, caregivers were required to be 'responsible'; that is, older than 21 years of age and with reasonable contact with the patient face to face at least twice weekly. An informed consent was obtained for participation in the study.

Psychological and psychiatric assessment of the caregivers was performed and the following tools were used:

(1) Psychiatric sheet for the caregiver.
(2) Involvement Evaluation Questionnaire (IEQ) (Schene and Wijngaatchen, 1992): This questionnaire assesses the main aspects of burden such as worry, tension, and supervision, and assesses the negative and positive emotions associated with caregiving. The IEQ is one of the most valid and simple instruments used for the evaluation of caregivers (Reine *et al.*, 2003). The worrying part covers the painful interpersonal factors as concern about the patient safety, general health, and the help they receive. Tension involves a strained interpersonal atmosphere between the caregivers and the patient: quarrels, annoyance, and occasional threats. Supervision involves caring about the medications, sleep, and dangerous behavior. The questionnaire also measures the negative and positive aspects of caregiving. Negative aspects (caregiver distress) include negative symptoms, stigma, effect on the family, and the need to provide backup and dependency.
(3) Defensive Style Questionnaire (DSQ40) (Soliman, 1996, 1997): The Arabic version of the DSQ40 was applied for an assessment of ego defenses of the caregivers. Defenses include anticipation, suppression, humor, sublimation, pseudoaltruism, idealization, reaction formation, undoing, acting out, denial, devaluation, displacement, dissociation, autistic fantasy, isolation, passive aggression, projection, rationalization, somatization, and splitting. The DSQ40 can yield 20 individual scores and three higher order factor scores, namely, mature, immature, and neurotic.
(4) Clinical dementia rating scale (CDR) (Washington University, 1998): The CDR is a five-point scale used to characterize six domains of cognitive and functional performance applicable to Alzheimer's disease and related dementias. It assesses memory, orientation, judgment, problem solving, home and hobbies, and personal care, with scores of 0 = normal, 0.5 = very mild, 1 = mild, 2 = moderate, and 3 = severe. The research methodology was approved by the ethical committee of the psychiatric department of Cairo University (Kasr El-Aini).

Statistical analysis

Descriptive statistics were presented including frequency tables, means, SD, and range whenever appropriate.

The analytic tests used included an unpaired Student's *t*-test for comparing the means of the two groups, a paired *t*-test for comparing the values before and after analysis of variance (i.e. *t*-test) for comparison of the means of more than one group.

The χ^2-test was used for contingency table analysis correlation, and regression analysis was also carried out.

The threshold of significance was fixed at a 5% level (*P* value). A *P* value more than 0.05 was considered not significant. A *P* value less than 0.05 was considered significant.

Results

No statistically significant difference was found in terms of the sex of the caregivers of patients with Alzheimer's disease and diabetes. The relationship of the caregivers with the patients showed a statistically significant difference (spouses were the caregivers for 40% of the patients with Alzheimer's disease) (sons were the caregivers in 45% of the control group) ($P = 0.019$). Marital status of the caregivers showed a statistically

Table 1 Comparative data of caregivers of patients with Alzheimer's disease and control caregivers

	N (%)		
	Case	Control	*P*
Caregiver sex			0.6
Male	12 (30%)	15 (37.5%)	
Female	28 (70%)	25 (62.5%)	
	40 (100%)	40 (100%)	
Caregiver relation			0.019
Spouse	16 (40%)	4 (10%)	
Sibling	10 (25%)	13 (32.5%)	
Son	10 (25%)	18 (45%)	
Distant relative	4 (10%)	5 (12.5%)	
	40 (100%)	40 (100%)	
Marital status			0.000
Married	28 (70%)	14 (35%)	
Single	5 (12.5%)	18 (45%)	
Widow	3 (7.5%)	8 (20%)	
Divorced	4 (10%)	0 (0%)	
	40 (100%)	40 (100%)	

Table 2 Involvement Evaluation Questionnaire for the case and the control group

	N (%)		
Involvement Evaluation Questionnaire	Case	Control	*P*
Perceived stigma			0.000
Absent	19 (47.5%)	38 (95%)	
Present	21 (52.5%)	2 (5%)	
	40 (100%)	40 (100%)	
Worries			0.005
Absent	9 (22.5%)	22 (55%)	
Present	31 (77.5%)	18 (45%)	
	40 (100%)	40 (100%)	
Fears			0.000
Absent	13 (32.5%)	35 (87.5%)	
Present	27 (67.5%)	5 (12.5%)	
	40 (100%)	40 (100%)	
Loss and grief			0.000
Absent	7 (17.5%)	40 (100%)	
Present	33 (82.5%)	0 (0%)	
	40 (100%)	40 (100%)	
Negative feelings			0.002
Absent	18 (45%)	32 (80%)	
Present	22 (55%)	8 (20%)	
	40 (100%)	40 (100%)	

Table 3 Characteristics of the patients with Alzheimer's disease

Patients' characteristics	*N* (%)
Sex	
Male	25 (62.5%)
Female	15 (37.5%)
Marital status	
Married	21 (52.5%)
Unmarried	19 (47.5%)
Residence	
Urban	24 (60%)
Rural	16 (40%)

Table 4 Characteristics of caregivers of patients with Alzheimer's disease

Caregivers' data	*N* (%)
Sex	
Males	12 (30%)
Females	28 (70%)
Relation to the patient	
Son	10 (25%)
Spouse	16 (40%)
Sibling	10 (25%)
Others	4 (10%)
Marital status	
Single	5 (12.5%)
Married	28 (70%)
Divorced	4 (10%)
Widowed	3 (7.5%)
Employment	
Working	15 (37.5%)
Unemployed	25 (62.5%)
Residence with patient	
Living with patient	28 (70%)
Not living with patient	12 (30%)

significant difference between the two groups (70% of the caregivers in the Alzheimer group were married and 35% of the controls were married) ($P = 0.000$) (Table 1).

Alzheimer caregivers' perceived stigma to the illness was statistically significant than the diabetic caregivers (52.5% while it was only 5% in the diabetic caregivers; $P = 0.000$). Caregivers of patients with Alzheimer's disease expressed significantly more worry than diabetic caregivers (77.5 vs. 45%; $P = 0.005$). Fears were expressed significantly more by the caregivers of patients with Alzheimer's disease than diabetic caregivers (67.5 vs. 12.5%; $P = 0.000$). Loss and grief were expressed significantly more by the caregivers of patients with Alzheimer's disease than diabetic caregivers (82.5 vs. 0%; $P = 0.000$). Negative feelings were expressed significantly more by the caregivers of patients with Alzheimer's disease than diabetic caregivers (55 vs. 20%; $P = 0.002$) (Table 2).

Baseline data showed that patients with Alzheimer's disease were predominantly men (62.5%); only 52.5% were married. In terms of area of residence, 60% mainly lived in urban areas and 40% lived in rural areas. For most patients, the duration of illness was long. The mean duration of illness was 3 years (Table 3).

A total of 70% of the caregivers were women and 30% were men. The mean age of the caregivers was 49 years. A total of 40% were partners (spouse), 25% were sons, 25% were siblings, and 10% had another relationship (relative, neighbor) with the patient. Of the caregivers 37.5% were working, of whom 20% were skilled manual workers, 12% were semiskilled manual workers, and 38% were unskilled manual workers. 62.5% were not working. 70% of the caregivers were living with the patient in the same household. Of the caregivers of patients with Alzheimer's disease, 70% were married, 12.5% were single, 10% were divorced, and 7.5% were widowed (Table 4).

There was no statistically significant difference ($P = 0.1$) in terms of sex in the types of defenses used by caregivers. Psychological defenses for coping used by the caregivers were mainly mature (67.5%), neurotic (17.5%), and immature (15%). Female caregivers showed defenses that were mature (45%), neurotic (15%), and immature (10%), with no significant difference compared with male caregivers ($P = 0.1$) (Table 5).

Statistically significant differences were found in the defensive styles of caregivers according to their employment ($P = 0.001$).

Nonworking caregivers showed a higher frequency of mature defenses than those who were working (50%). The difference was statistically significant ($P = 0.001$) (Table 6).

Table 5 Sex and defenses

	N (%)		
Types of defenses	Males	Females	Total
Neurotic	1 (2.5%)	6 (15%)	7 (17.5%)
Mature	9 (22.5%)	18 (45%)	27 (67.5%)
Immature	2 (5%)	4 (10%)	6 (15%)

Table 6 Work and defenses

	N (%)		
Types of defenses	Working	Not working	Total
Mature	7 (17.5%)	20 (50%)	27 (67.5%)
Neurotic	3 (7.5%)	4 (10%)	7 (17.5%)
Immature	5 (12.5%)	1 (2.5%)	6 (15%)
Total	21 (100%)	9 (100%)	40 (100%)

Table 7 Relationship and defenses

	N (%)				
Types of defenses	Sons	Spouses	Siblings	Others	Total
Mature	6 (15%)	16 (40%)	5 (12.5%)	0 (0%)	27 (67.5%)
Neurotic	1 (2.5%)	0 (0%)	4 (10%)	2 (5%)	7 (17.5%)
Immature	3 (7.5%)	0 (0%)	1 (2.5%)	2 (5%)	6 (15%)

Table 8 Defensive styles in relation to the marital status of caregivers

	N (%)			
Defenses styles	Widowed	Married	Single	Divorced
Immature	0 (0%)	3 (50%)	1 (16.6%)	2 (33.3%)
Mature	3 (11.1%)	22 (81.5%)	0 (0%)	2 (7.4%)
Neurotic	0 (0%)	3 (42.8%)	4 (57.2%)	0 (0%)

There were statistically significant differences in caregiver defenses according to their relationship with the patient ($P = 0.001$). Spouses showed significantly higher mature defenses (40%), followed by sons (15%) (Table 7).

Married caregivers showed significantly more mature defenses ($P = 0.008$) (Table 8).

Fears were expressed significantly more by married caregivers ($P = 0.000$). Loss and grief was expressed significantly more by married caregivers ($P = 0.000$). Negative feelings were expressed significantly more by married caregivers (86.4%), followed by divorced caregivers (13.6%) ($P = 0.006$). The perception of stigma was significantly higher among widowed caregivers (42.9%), followed by married caregivers (33.3%), and to a lesser extent by single caregivers (23.8%) ($P = 0.014$) (Table 9).

Caregivers of patients with Alzheimer's disease of a severe degree on CDR expressed significantly greater perception of stigma (85.7%; $P = 0.003$), fears (81.5%; $P = 0.001$), and negative feelings and depression (100%), compared with caregivers of patients with Alzheimer's disease of a moderate degree ($P = 0.000$) (Table 10).

Trapped feelings were expressed significantly more by employed caregivers compared with those who were not working (68.2 and 31.8%; $P = 0.000$). Worries were expressed significantly more by nonworking than by working caregivers (51.6%; $P = 0.008$) (Table 11). Females expressed significantly higher trapped emotion ($P = 0.09$) (Table 12).

Worries were expressed the most by caregivers who were spouses (45.2%), followed by sons (32.3%), and finally siblings (9.7%). The difference was statistically significant ($P = 0.000$). Perception of stigma was reported by the most by caregivers who were sons (42.9%), followed by spouses (33.3%), and siblings (23.8%); the difference was statistically significant ($P = 0.014$) (Table 13).

Loss and grief were expressed the most by caregivers who were spouses, followed by sons, and siblings ($P = 0.000$). Trapped emotions were highest among the sons followed by siblings followed by others ($P = 0.000$). Depression

Table 9 Results of the Involvement Evaluation Questionnaire according to marital status

	N (%)					
	Married	Single	Widow	Divorced	Total	P
Fears						0.000
Absent	3 (23.1%)	5 (38.5%)	3 (23.1%)	2 (15.4%)	13 (100%)	
Present	25 (92.6%)	0 (0%)	0 (0%)	2 (7.4%)	27 (100%)	
Loss and grief						0.000
Absent	1 (14.3%)	4 (57.1%)	0 (0%)	2 (28.6%)	7 (100%)	
Present	27 (81.8%)	1 (3%)	3 (9.1%)	2 (6.1%)	33 (100%)	
Negative feelings						0.006
Absent	9 (50%)	5 (27.8%)	3 (16.7%)	1 (5.6%)	18 (100%)	
Present	19 (86.4%)	0 (0%)	0 (0%)	3 (13.6%)	22 (100%)	
Stigma						0.014
Absent	9 (47.4%)	5 (26.3%)	1 (5.3%)	4 (21.1%)	19 (100%)	
Present	7 (33.3%)	5 (23.8%)	9 (42.9%)	0 (0%)	21 (100%)	

was highest among caregivers who were spouses, followed by sons ($P = 0.000$) (Table 14).

Discussion

Strong evidence from previous research indicates that the caregiving role is very demanding, frequently distressing, and may adversely affect the health and quality of life of the caregivers (Schulz *et al.*, 2004). This study aimed to assess the distress levels, defensive styles, and variables of involvement among caregivers of patients with Alzheimer's disease, in relation to certain disease parameters such as the degree of severity of illness and caregivers' personal factors.

Table 10 Results of the Involvement Evaluation Questionnaire in relation to the severity of clinical dementia rating scale

	N (%)			
	Moderate CDR	Severe CDR	Total	*P*
Stigma				0.003
Absent	12 (63.2%)	7 (36.8%)	19 (100%)	
Present	3 (14.3%)	18 (85.7%)	21 (100%)	
Fears				0.001
Absent	10 (76.9%)	3 (23.1%)	13 (100%)	
Present	5 (18.5%)	22 (81.5%)	27 (100%)	
Negative feelings				0.000
Absent	15 (83.3%)	3 (16.7%)	18 (100%)	
Present	0 (0%)	22 (100%)	22 (100%)	
Depression				0.000
Absent	15 (88.2%)	2 (11.8%)	17 (100%)	
Present	0 (0%)	23 (100%)	23 (100%)	

CDR, clinical dementia rating scale.

Table 11 Trapping and worries in relation to caregivers' work

	N (%)			
	Working	Nonworking	Total	*P*
Feeling trapped				0.000
Absent	0 (0%)	18 (100%)	18 (100%)	
Present	15 (68.2%)	7 (31.8%)	22 (100%)	
Worries				0.008
Absent	0 (0%)	9 (100%)	9 (100%)	
Present	15 (48.4%)	16 (51.6%)	31 (100%)	

Table 12 Caregivers' fears, worries, and feelings of being trapped in relation to sex

	N (%)			
	Male	Female	Total	*P*
Trapped				0.09
Present	9 (40.9%)	13 (59.1%)	22 (100%)	
Absent	3 (16.7%)	15 (83.3%)	18 (100%)	
Worries				0.8
Present	9 (29%)	22 (71%)	31 (100%)	
Absent	3 (33.3%)	6 (66.7%)	9 (100%)	
Fears				0.9
Present	8 (29.6%)	19 (70.4%)	27 (100%)	
Absent	4 (30.8%)	9 (69.2%)	13 (100%)	

Unsurprisingly, the severity of Alzheimer's disease was correlated with the multiple effects suffered by the caregivers, especially when the mean duration of the illness was long (>2 years).

Earlier research has reported on the factors affecting caregivers' burden, including the severity of symptoms and duration of illness (Donaldson *et al.*, 1997). However, more recent research found these factors to be less effective. Elliottt *et al.* (2010) suggested that caregivers' burden is not directly linked to the severity of psychopathological symptoms, but rather a deficit in a patient's sphere of functioning (Burns, 1993). This might not only be linked to problems related to the illness but also a number of nonspecific factors related to the family such as poor living conditions, difficulties at work, the responsibility of physical caring, and financial responsibility (Benbow, 2001).

In order to investigate the effect of Alzheimer's disease on caregivers, it was necessary to compare caregivers of Alzheimer's disease with a control group. Caregivers of patients with diabetes mellitus were chosen, as it is a lifelong illness and in the long term, requires a degree of continuous supervision by the caregiver to prevent life-threatening complications such as hypoglycemic or hyperglycemic coma. On comparing caregivers of patients with Alzheimer's with the caregivers of patients with diabetes mellitus, it was found that the caregivers of patients with Alzheimer's disease showed higher levels of burden, especially caregivers of patients with more severe behavioral and cognitive impairments. This is in agreement with the results of Donaldson *et al.* (1998), who compared caregivers of patients with Alzheimer's disease and those with chronic medical conditions.

In this study, most caregivers perceived their patient's illness to be severe in the preceding two years. This provides an explanation for the relationship of severity of illness to caregivers' burden. Conde-Sala *et al.* (2009), studying spouses of patients with Alzheimer's disease, found that stable partnerships seem to be achievable when the partner's impairment is perceived as moderate

Table 13 Caregivers' relation to the patient and perception of stigma and worries

	N (%)					
	Spouse	Son	Sibling	Other	Total	*P*
Stigma						0.014
Negative	9 (47.4%)	1 (5.3%)	5 (26.3%)	4 (21.1%)	19 (100%)	
Present	7 (33.3%)	9 (42.9%)	5 (23.8%)	0 (0%)	21 (100%)	
Worries						0.000
Negative	2 (22.2%)	0 (0%)	7 (77.8%)	0 (0%)	9 (100%)	
Present	14 (45.2%)	10 (32.3%)	3 (9.7%)	4 (12.9%)	31 (100%)	

Table 14 Caregivers' relationship with the patient and feelings of loss, grief, trapping and depression

	N (%)					
	Spouse	Sibling	Son	Others	Total	P
Loss and grief						0.000
Absent	0 (0%)	3 (42.9%)	0 (0%)	4 (57.1%)	7 (100%)	
Present	16 (48.5%)	7 (21.2%)	10 (30.3%)	0 (0%)	33 (100%)	
Trapped						0.000
Absent	15 (83.3%)	3 (16.7%)	0 (0%)	0 (0%)	10 (100%)	
Present	1 (4.5%)	7 (31.8%)	10 (45.5%)	4 (18.2%)	22 (100%)	
Depression						0.000
Absent	5 (29.4%)	9 (52.9%)	0 (0%)	3 (17.6%)	17 (100%)	
Present	11 (47.8%)	1 (4.3%)	10 (43.5%)	1 (4.3%)	23 (100%)	

or moderately severe. Moraes and Silva (2009) reported that the most important factor affecting caregivers' burden was the change in the relationship occurring in 'severe' illness that could be accompanied with persecution or infidelity delusions and behavioral changes are the most important factors that affect negatively the care giver relationship with the patient. Especially when there are delusions of persecution and infidelity related to the care giver.

The high rate of unemployment among the caregivers of patients with Alzheimer's disease in this study, with its impact on the financial situation of the family, correlated with both the use of more mature defenses and more worry and stress among the caregivers. Different findings have been obtained in other studies. Coen *et al.* (1997) reported that most of the spouses and children of the patients experience the disadvantages of caring even if it did not cause them serious problems in their lives. Alison *et al.* (2000) found that financial burdens are usually compounded by other problems, such as dealing with aggressive episodes and worry about the future. This difference could be attributed to differences in the community support system and medical insurance of these patients, which covered the expenses of medications and did not place additional financial constraints on the caregivers; in contrast, in this study, the family covered all the medical expenses of the patient, which imposed additional burden financially and emotionally.

The caregivers interviewed in this study faced emotional and practical challenges as a result of caring for a patient with Alzheimer's disease. In terms of the demographic characteristics, the findings of this study showed that the majority of caregivers (72%) lived in the same house with the patient. Among them, unemployed (62.5%), there were more female caregivers; thus, they had closer and more frequent contact with the patient, which resulted in more direct exposure to day to day caring issues.

It can be argued that this finding may simply reflect the living circumstances of the general population (Office for National Statistics, 1998), and thus may be representative of the socioeconomic and cultural context. This contrasts with some western studies; for example, Coen *et al.* (1999), who found that less than half of the patients (40%) lived with their families.

In this study, with the use of the IEQ, female caregivers were found to experience nonsignificantly higher levels of distress than their male counterparts. Women expressed more worry (71%), especially among those who were unemployed; this was not significant. They also expressed more fears (70.4%), feelings of being trapped (59.1%), and significantly more loss and feelings of grief than male caregivers. Female caregivers were also more involved in the supervision of the patient, and thus felt trapped. This can be attributed to cultural factors. In Egypt, daughters and wives are more involved than husbands and sons in the care of chronically ill patients.

Whether the degree of exposure and involvement with the patient can explain this sex difference is difficult to assess. Some studies have emphasized the role of continuous involvement in increasing the caregivers' burden (Mittelman *et al.*, 2004). By being exposed to their relative's illness on a daily basis, they are exposed to many burdens, which has a negative impact on their own well-being (Burns *et al.*, 2005). In contrast, Alison *et al.* (2000) found that the stress levels and burden of caregivers living apart were similar to those who were living with the patients.

The sex differences in worries, fears, loss, and grief may be related to sex-specific factors. Moraes and Silva (2009) suggested that male caregivers avoid contact because they find the situation distressing; Aguglia *et al.* (2004), however, reported that female caregivers experience greater strain than male caregivers and have more behavioral and emotional problems, whereas Tarrier *et al.* (2002) found that male caregivers of psychiatric patients experienced more anxiety than female caregivers. Belle *et al.* (2006) have reported that men may respond to the challenges of providing care in a more task-oriented manner and with less emotional involvement.

Actually, all the previously mentioned factors are believed to play a role in the sex differences observed in this study, and cannot be considered without an understanding of cultural influences specific to our society. The role of a woman as the main domestic caregiver, with men playing a greater role outside the home, may be attributed to the higher degree of involvement and thus stress. It should also be kept in mind that men in our society tend to underplay the strain they are under and may be less expressive in terms of their feelings of distress.

The defensive styles reported in this study represent a cross-section of the caregivers' coping styles. Most caregivers used mature defenses (67.5%), mainly suppression, followed by neurotic defenses (17.5%), mainly pseudoaltruism and reaction formation, and immature defenses (15%). This is in agreement with the findings of the use of mature practical coping mechanisms as the main strategy among caregivers in a European study carried out by Aguglia *et al.* (2004). It is hard to relate our results to other studies results. There are cultural and community services in the European societies that help the care givers to cope better.

Again, sex differences were found, which were nonsignificant, with 45% of female caregivers using mature defenses and only 22% of male caregivers using mature defenses, followed by neurotic defenses, which can be considered as an attempt by the male caregivers to develop 'mastery' over the situation, a finding also reported by Moraes and Silva (2009).

Several studies have suggested that factors related to illness and the personal characteristics of caregivers have a significant influence on how they cope with caring for patients with Alzheimer's disease (Belle *et al.*, 2006). It seems, however, that sociodemographic factors may play a minor role, whereas the coping methods used to deal with problems may play the most significant role (Jönsson *et al.*, 2006). Most of the studies available have reported results that are in agreement with the findings of this study on the use of mature defenses and coping mechanisms by caregivers of patients with Alzheimer's disease; Scneider *et al.* (1999) have reported that caregivers of patients with chronic psychiatric illnesses frequently use nonpassive methods of coping.

The somatization defense, which was high in this study (17%), was also found by Connell *et al.* (2001) who found that those who were living with chronic psychiatric patients had more frequent general practioners visits. Campbell (2009) suggested that the severity of the patient's disease is a significant predictor of psychosomatic symptoms. In our culture the somatization defense is known to be high, particularly among females.

A reason given by Tarrier *et al.* (2002), might apply to the results of this study of increased mature defenses. They suggested that the family caregivers' knowledge had an indirect impact on the burden through active coping, and adapting, indicating that the less caregivers' knowledge, the more caregivers use of negative coping strategies.

Mature defenses were found to be used significantly more by caregivers who were unemployed, and stress and worry were also expressed significantly more by this group. However, trapped emotions were significantly higher among the employed group. Although employment can play a role as a buffer for feelings of helplessness and help care giver in distracting his negative feelings. Yet it also acts as extra efforts that make the care giver feel trapped all the time. Other mature defensive styles and coping strategies that were not explored in this study might have also been used by working caregivers. Schneider *et al.* (1999) suggested that denial, problem solving, and religious beliefs play an important role in helping to cope with the stress of caring for mentally ill patients.

Caregivers' distress

Seventeen percent of the caregivers in this study had psychiatric morbidity. The results showed that a relatively higher proportion of caregivers considered that the patients' illness had affected their relationship with others and had also led to mental health problems in them.

Previous research seems to support this finding. Aguglia *et al.* (2004) found, in a study carried out in Italy, that despite the advancements in hospital and community services, there are still many caregivers who are not only under stress but also have psychiatric and physical illnesses that go unnoticed. Caregivers of patients with Alzheimer's disease had a considerably higher prevalence of depressive disorders compared with that in the general population (Tarrier *et al.*, 2002). The figures for psychiatric morbidity range from 25% (Belle *et al.*, 2006), one-third (Alison *et al.*, 2000), up to 41% (Schneider, 1999). The relatively lower level of psychiatric morbidity in this study can be attributed to the methodology: the use of a semistructured interview rather than a diagnostic instrument.

Married caregivers had significantly greater negative feelings toward the patient than divorced and single caregivers, especially when the patients had a severe degree of impairment. Married caregivers not only face illness-specific burdens but also burdens resulting from their partnership and family roles. The burdens of everyday living can markedly affect the quality of life, and satisfaction with the relationship with the patient (Aguglia *et al.*, 2004).

In everyday life with the patient, spouses and sons experience a major burden that can affect their living situation and well-being (Burns *et al.*, 2005).

Spouses expressed significantly greater worries and feelings of loss and grief in relation to the patient. They also used mature defenses more often. These findings are understandable because spouses have a longer binding relation and more exposure to the patient than sons, and are more directly responsible than siblings who have other aspects of their lives to worry about. Moraes and Silva (2009) reported that Alzheimer's spouses are overburdened because of their long-term caring role. The long duration of exposure to the patient could also explain their greater feelings of loss and grief. Coen *et al.* (1999) suggested that levels of grief increased over time, especially when there is infidelity or persecutory delusions.

Spouses of Alzheimer's patients in this study expressed significantly greater worry and used mature defenses significantly more. This could be attributed to the spouse effort to deal with behavioral and cognitive changes due to the illness (Moraes and Silva, 2009). Difference in caregivers' responses in this study are related to sex and personal differences in the coping mechanisms used, which is in accordance with Alison (2000).

Stigma

The literature suggests that burden could arise because of the stigma associated with individuals with mental or behavioral illness (Georges *et al.*, 2008). Alzheimer's disease, because of its distinctive symptoms of cognitive impairment, disruptive or disinhibited behavioral symptoms, emotional instability, and perceived dangerousness, that could result out of delusions of persecution or infidelity (Donaldson *et al.*, 1997), is particularly a target for stigma and discrimination.

Cognitive dysfunction worsens progressively over time in patients with Alzheimer's disease and could be followed by many behavioral changes. As a consequence, the family may prefer social isolation, and may develop feelings of frustration, anxiety, low self-esteem, and helplessness (Etters *et al.*, 2008). Evidence exists indicating that stigma and worry may be associated with lower levels of self-reported physical well-being among caregivers of patients with Alzheimer's disease (Burns *et al.*, 2005).

The present study found that several factors were independently related to the perceived magnitude of the effect of stigma on both the patient and the family. The perceived effect of stigma was greater if the patient had more severe behavioral symptoms, if the caregiver had a relatively low education level, and if the family lived in an urban area.

Stigma is more observed in urban areas where the patients' behavior is more supervised by people around (Kaufer *et al.*, 2005).

Daughters and wives were more vulnerable to the negative effects of stigma emotionally and socially than sons and husbands. Georges *et al.* (2008) noted that stigma as a negative societal attitude acts as a stress and augments negative emotions, worries, tension, loss and grief, and negative feelings of the caregiver toward the patient. Campbell (2009) found that family members who are not over anxious in response to the patients' illness perceive stigma in less threatening way.

Limitation

This study has some limitations.

- The sample of the present study may not be representative of the larger population of caregivers of patients with dementia, as they were recruited from a single center and included those from a certain socioeconomic class and with certain educational levels.
- The sample size of 40 patients is relatively modest and if solely used on cross-sectional basis limited the power of the study.
- The study did not include a comparison group who were cared for in care homes and assess the burden and the direct involvement of their relatives.
- There were great problem to assess the financial costs of therapy of the patient that could have an impact in the caring style of the patient.
- This study was cross sectional and focused only on the primary caregiver; therefore, the results cannot be generalized to the family of Alzheimer's patients as a whole.
- Not all the disease-related factors were correlated in depth with the stress and defenses of the caregivers.

Implications

Interventions might be planned on the basis of existing defensive coping strategies among caregivers as well as focusing on improving patients' cognitive symptoms and associated behavioral problems, which might help to reduce caregivers' burden.

Empowering the role of old age psychiatry services in hospitals that could be reached in all areas for better quality of life of the patient and the care giver.

Family education and mutual support groups for caregivers may be a useful approach as it was found that many caregivers believed that the negative symptoms are under the patient's control.

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Conflicts of interest

There are no conflicts of interest.

References

Aguglia E, Onor ML, Trevisiol M, Negro C, Saina M, Maso E (2004). Stress in the caregivers of Alzheimer's patients: an experimental investigation in Italy. Am J Alzheimers Dis Other Demen 19:248–252.

Alison N, Winslow B, Carter P (2000). Agitation in patients with dementia. Psychiatric services 50:1074-1079.

Belle SH, Burgio L, Burns R, Coon D, Czaja SJ, Gallagher-Thompson D, *et al.* (2006). Enhancing the quality of life of dementia caregivers from different ethnic or racial groups: a randomized, controlled trial. Ann Intern Med 145:727–738.

Benbow SM (2001). Part of their lives. Community care for older people with dementia. Psychiatrist 25:405.

Boucharlat M, Montani C, Myslinski M, Franco A (2006). How can psychological help be provided for the patient/caregiver tandem home? Encephale 32:92–96.

Burns B (1993). The impact of symptoms of dementia on care givers. Br Jor Psych 170:62-68.

Burns A, Guthrie E, Marino-Francis F, Busby C, Morris J, Russell E, *et al.* (2005). Brief psychotherapy in Alzheimer's disease: randomised controlled trial. Br J Psychiatry 187:143–147.

Campbell J (2009). A model of consequences of dementia caregivers' stress process: influence on behavioral symptoms of dementia and caregivers' behavior-related reactions. Res Theory Nurs Prac 23:181–202.

Coen RF, Swanwick GRJ, O'Boyle CA, Coakley D (1997). Behaviour disturbance and other predictors of carer burden in Alzheimer's disease. Int J Geriatr Psychiatry 12:331–336.

Conde-Sala JL, Garre-Olmo J, Turró-Garriga O, López-Pousa S, Vilalta-Franch J (2009). Factors related to perceived quality of life in patients with Alzheimer's disease: the patient's perception compared with that of caregivers. Int J Geriatr Psychiatry 24:585–594.

Connell CM, Janevic MR, Gallant MP (2001). The costs of caring: impact of dementia on family caregivers. J Geriatr Psychiatry Neurol 14:179–187.

Donaldson C, Tarrier N, Burns A (1997). The impact of the symptoms of dementia on caregivers. Br J Psychiatry 170:62–68.

Donaldson C, Tarrier N, Burns A (1998). Determinants of carer stress in Alzheimer's disease. Int J Geriatr Psychiatry 13:248–256.

Elliottt AF, Burgio LD, DeCoster J (2010). Enhancing caregiver health: Findings from the resources for enhancing Alzheimer's caregiver health II intervention. J Am Geriatr Soc 58:30–37.

Etters L, Goodall D, Harrison BE (2008). Caregiver burden among dementia patient caregivers: a review of the literature. J Am Acad Nurse Pract 20: 423–428.

Georges J, Jansen S, Jackson J, Meyrieux A, Sadowska A, Selmes M (2008). Alzheimer's disease in real life-the dementia carer's survey. Int J Geriatr Psychiatry 5:551.

Gormley N (2000). The role of dementia training programmes in reducing caregiver burden. Psychiatr Bull 24:41–42.

Huang CY, Sousa VD, Perng SJ, Hwang MY, Tsai CC, Huang MH, *et al.* (2009). Stressors, social support, depressive symptoms and general health status of Taiwanese caregivers of persons with stroke or Alzheimer's disease. J Clin Nurs 18:502–511.

Jönsson L, Jönhagen ME, Kilander L, Soininen H, Hallikainen M, Waldemar G, *et al.* (2006). Determinants of costs of care for patients with Alzheimer's disease. Int J Geriatric Psychiatry 21:449–459.

Kaufer DI, Borson S, Kershaw P, Sadik K (2005). Reduction of caregiver burden in Alzheimer's disease by treatment with galantamine. CNS Spectr 10: 481–488.

Mittelman MS, Roth DL, Coon DW, Haley WE (2004). Sustained benefit of supportive intervention for depressive symptoms in caregivers of patients with Alzheimer's disease. Am J Psychiatry 161:850–856.

Moraes SR, Silva LS (2009). An evaluation of the burden of Alzheimer patients on family caregivers. Cad Saude Publica 25:1807–1815.

Reine J, Zarit S, Greene R, Townseud A (2003) Treatable conditions and use of health care services among patients with dementia. Psychiatric Ser 55:70-75.

Schneider S (1999). The influence of neuro psychological functions on neuro psychiatry problems in dementia. J Neuro Psych 19:54-59.

Schene S, Wijngatchen W (1992). Quality of life in patients with Alzheimer. Int J Geriatric 3:551-559.

Schneider J, Murray J, Banerjee S, Mann A (1999). EUROCARE: a cross-national study of co-resident spouse carers for people with Alzheimer's disease: I-factors associated with carer burden. Int J Geriatr Psychiatry 14:651–661.

Schulz R, Belle SH, Czaja SJ, McGinnis KA, Stevens A, Zhang S (2004). Long-term care placement of dementia patients and caregiver health and well-being. JAMA 292:961–967.

Soliman H (1996). The Arabic version of defense style questionnaire-40. Egypt J Psychiatr 19:129-136.

Soliman H (1997). The Arabic version of defense style questionnaire-40. Egypt J Psychiatr 20:75-83.

Tarrier N, Barrowclough C, Ward J, Donaldson C, Burns A, Gregga L (2002). Expressed emotion and attributions in the carers of patients with Alzheimer's disease: the effect on carer burden. J Abnorm Psychol 111:340–349.

Thompson J, Spilsbury A (2007). Disease management program for families of people withdementia. Psychiatric Ser 59:433-436.

Wilson RS, McCann JJ, Li Y, Aggarwal NT, Gilley DW, Evans DA (2007). Nursing home placement, day care use and cognitive decline in Alzheimer's disease. Am J Psychiatry 164:910–951.

Yeung S, Lui MH, Ross F, Murrells T (2007). Family carers in stroke care: examining the relationship between problem-solving, depression and general health. J Clin Nurs 16:344–352.