

# Anxiety, depression, and strain among caregivers of terminally ill patients

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## Aim

To describe the characteristics of informal caregivers of terminally ill (hepatic, cardiac, and renal failure) patients and their care recipients and to examine the relationship between depression, anxiety, and burden among informal caregivers.

## Participants and methods

This was a cross-sectional study, in which 51 caregivers of terminally ill (hepatic, cardiac, and renal failure) patients were recruited from among inpatients of Internal Medicine Department, Kasr Al Aini, Faculty of Medicine, from September 2011 to April 2012. The patients were subjected to a Caregiver Questionnaire, Hamilton Anxiety Rating Scales, and Hamilton Depression Rating Scales, and the Modified Caregiver Strain Index was determined.

## Results

Most of the caregivers experienced high levels of burden, severe anxiety, and mild depression. Several factors showed a statistically significant correlation with caregiver burden, anxiety, and depression including the care recipient's functional status, personality changes, mental functioning, the presence of comorbidity, the Palliative Prognostic Score, being the main caregiver, duration of caregiving, the caregiver's employment status, perceived health, and impact on social activities. Caregiver burden, anxiety, and depression were significantly correlated.

## Conclusion

Caregivers of terminal organ failure (hepatic, cardiac, and renal) patients experience high levels of burden, severe anxiety, and mild depression. Predictors of anxiety, depression, and burden include being the main caregiver, duration of caregiving, the caregiver's employment status, perceived health, and impact on social activities.

## Keywords:

caregiver, informal caregivers, organ failure, terminal illness

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## Introduction

An individual is considered to be terminally ill when his/her life expectancy is 6 months or less if the illness runs its normal course (Medicare Benefit Policy Manual, 2004).

Informal or family caregivers are unpaid friends or family members who 'provide, arrange, or oversee needed services because of functional disabilities or health needs' (Gaugler *et al.*, 2003).

Changes in the healthcare delivery system, including shorter hospital stays, have led to a shift in the cost and responsibility for the care of loved ones from healthcare providers to family caregivers (Levine, 1998).

Family caregivers require a greater capacity to understand health and medical information; they seek out and use the patchwork of community resources; and navigate the increasingly complex, fragmented, and costly healthcare and home and community-based service system (Feinberg, 2001).

In day-to-day practice, family physicians are likely to see patients who serve as caregivers. In fact, a study of

patients in a family practice reported that 21% of the patients had caregiving responsibilities for individuals with chronic medical conditions (Andolsek *et al.*, 1988).

The role of a caregiver can be stressful, and the identification of these patients can provide the family physician opportunities to help them cope with the challenges of the caregiver's role. Family physicians have a systematic approach for assessing the degree of caregiver burden in these patients. As caregivers are at an increased risk of depression and anxiety, screening should be carried out to exclude the presence of either disorder. If there are problems, family physicians should provide practical counseling about common caregiving stresses and about resources that benefit caregivers. Helping the caregiver learn strategies for coping with difficulties may help reduce some of the stress the caregiver is experiencing (Parks and Novielli, 2000).

Research has uncovered the enormous physiological, psychological, and financial costs associated with informal caregiving. Informal caregivers have increased stress and depression (Clyburn *et al.*, 2000), worsened social and family life (Cameron *et al.*, 2002), physical illness

(Vitaliano *et al.*, 2003), increased feelings of burden, and decreased quality of life (Argimon *et al.*, 2004). Informal caregivers are less likely to be employed and more likely to miss days of work and to quit or to retire early (Ho *et al.*, 2005).

It is equally important that the emotional and physical health of family caregivers has been shown to correlate with the health and successful rehabilitation of those with chronic illness (Han and Haley, 1999).

Across more than 20 studies published in the past decade, there was consistent evidence that caregiving placed family members at risk of depression (Deimling *et al.*, 2001).

In fact, caregivers had higher rates of depression than the general population (Jackson and Cleary, 1995).

Multiple studies have shown that the incidence of depression in caregivers is high, ranging from 18 to 47%, and caregivers who are depressed experience higher degrees of burden (Lawton *et al.*, 1991).

Caregiver burden, which is the negative impact of caregiving on the caregiver's life, has been associated with depressive symptoms (Land *et al.*, 2003) and suicidal ideation. The consequences of a high caregiver burden include an increased risk of the need to place the family member in a long-term care facility as well as an increased use of formal in-home services (Brown *et al.*, 1990). The societal and economic benefits of reducing the amount of caregiver burden are evident (Livingston *et al.*, 1996). It is clear that family caregivers provide a substantial amount of free labor that undergirds the entire healthcare system (Arno *et al.*, 1999).

The aim of our study was to describe the characteristics of the informal caregivers of terminally ill (hepatic, cardiac, and renal failure) patients and their care recipients and to examine the relationship between depression, anxiety, and burden among informal caregivers of terminally ill patients (hepatic, cardiac, or renal failure).

## Participants and methods

The current study was a cross-sectional descriptive study. Fifty-one caregivers, recruited from among inpatients of Internal Medicine Department, Kasr Al Aini, Faculty of Medicine, Cairo University, were interviewed from September 2011 to April 2012. Interviews were conducted twice/week throughout the period of research. Caregivers who contributed to the research were informed on the project and provided verbal consent to processing of personal data. The interview lasted for 45–60 min.

### Pilot study

A pilot study was carried out over a 1-month-period from September to October 2011. Five informal caregivers participated in the pilot study. This pilot study was useful in determining the applicability of the Palliative Prognostic Score (PaP Score) in the terminally ill (organ failure) patients. It also helped in the modification of the

Caregiver Questionnaire in order for it to be more easily understood by the informal caregivers and in identifying the proper method of interviewing the caregivers. It helped in identifying the time required for the completion of the four questionnaires. The informal caregivers of terminally ill (hepatic, cardiac, and renal failure) patients were recruited from among inpatients of Internal Medicine Department (in the Internal Medicine Hospital). Consent of the attending medical staff members was obtained before processing the patients' data and before the interview with the caregivers.

The inclusion criteria included informal caregivers of both sexes and free of major psychiatric disorders while the inclusion criteria for care recipient are patients have terminal organ failure (hepatic or cardiac or renal) also, their PaP Score: 5.6–11 (risk group B: 30–70%, 30-day survival rate) odds ratio (OR) 11.1–17.5 (risk group C: <30%, 30-day survival rate).

Informal caregivers with major psychiatric disorders were excluded. Furthermore, care recipients without terminal organ failure and patients with only respiratory failure were excluded.

The Caregiver Questionnaire, the Hamilton Depression Rating Scale, the Hamilton Anxiety Rating Scale, and the Modified Caregiver Strain Index were used for the assessment of the informal caregivers.

### Caregiver Questionnaire

The Caregiver Questionnaire a modified version of the Canadian Study of Health and Aging-3 Caregiver Questionnaire. It is a carefully designed questionnaire that includes data of the caregiver such as age, sex, and marital status; data of the care recipient such as age, sex, and marital status; the relationship between the caregiver and the care recipient; residency and the number of residents in the caregiver's and care recipient's households; assessment of the functional activity by Activities of Daily Living (ADL) (Katz *et al.*, 1963) and Instrumental Activities of Daily Living (IADL) by Lawton and Brody (1969); duration of caregiving and other caregivers involved in the caregiving process; impact of the caregiver's physical health and emotional problems on his/her social activities; data of the caregiver's medical health problems; and positive aspects of caregiving.

### Hamilton Depression Rating Scale (Hamilton, 1980)

It provides an indication of depression and, over time, a guide to recovery. It is one of the most widely used and accepted outcome measures for evaluating the severity of depression symptoms. Although the version of the Hamilton Depression Rating Scale used in the research lists 21 items, only the first 17 are scored. The remainder provides additional clinical information. It takes about 20 min to complete the interview and score the results. Eight items are scored on a five-point scale ranging from 0 = not present to 4 = severe. Nine items are scored from 0 to 2. The sum of the total of the first 17 items is used to obtain the total score. A score of 0–7 is considered 'normal', a score of 8–13 is interpreted as 'mild

depression', 14–18 as 'moderate depression', 19–22 as 'severe depression', and more than or equal to 23 as 'very severe depression' (Hamilton, 1959).

#### Hamilton Anxiety Rating Scale

The Hamilton Anxiety Rating Scale is a 14-item clinician-rated instrument designed to assess and quantify the severity of anxiety. Each item is rated on a five-point Likert-type scale ranging from 0 to 4, with higher scores indicating more severe anxiety. Although the scale assesses a broad range of symptoms that are common to all eight of the *Diagnostic and Statistical Manual of Mental Disorders*, 4th ed. Anxiety Disorders, it is most often used to assess the severity of generalized anxiety disorder (GAD). It comprises a psychic and a somatic subscale. The psychic subscale (items 1–6 and 14) addresses the more subjective, cognitive, and affective complaints of anxiety (e.g. anxious mood, tension, fears, and difficulty in concentrating). The somatic component (items 7–13) emphasizes features of GAD such as autonomic arousal, respiratory, gastrointestinal, and cardiovascular symptoms.

#### Modified Caregiver Strain Index

It is a tool that can be used to quickly screen for caregiver strain with long-term family caregivers. The Modified Caregiver Strain Index is a version of the Caregiver Strain Index developed in 1983. It is a 13-question tool that measures strain related to care provision. There is at least one item for each of the following major domains: employment, financial, physical, social, and time. Scoring is 2 points for each 'yes' and 1 point for each 'sometimes' response. Higher the score, higher the level of caregiver strain (Thornton and Travis, 2003). The Modified Caregiver Strain Index is a brief, easily administered, self-administered instrument. Long-term family caregivers were not comfortable with the dichotomous choice on the Caregiver Strain Index and the modified instrument provides the ability to choose a middle-category response best suited to some situations. The Modified Caregiver Strain Index clarifies and updates some of the items on the original instrument. The tool is limited by the lack of a corresponding subjective rating of caregiving impact. There is no breakdown of score in low, moderate, or high caregiver strain; hence, professional judgment is required to evaluate the total score, the level of caregiver strain. The tool effectively identifies families who may benefit from a more in-depth assessment and follow-up (Thornton and Travis, 2003). A score of greater than 6 was used to indicate a high degree of caregiving burden; this cutoff has been used previously among caregivers of stroke patients.

#### Palliative Prognostic Score

The PaP Score was implemented to identify care recipients with terminal organ failure. Accurate prognostic information is important for patients, families, and physicians. The PaP uses the Karnofsky Performance Score (KPS) and five other criteria to generate a numerical score from 0 to 17.5 to predict a 30-day survival (higher scores predict shorter survival). The PaP was originally developed for use in cases of solid tumors and has been validated in large prospective studies in such patients.

More recently, the PaP has been shown to be reliable in patients with various noncancer diagnoses (e.g. organ failure syndromes, AIDS, and neurological diseases), but large-scale validation studies have not been published (Wilner and Arnold, 2006).

#### Statistical analysis

The data were computerized and analyzed statistically using the statistical package for social science (SPSS Inc., Chicago, Illinois, USA), version 15.

## Results

Table 1 shows that 78.4% of the caregivers were women, 66.7% were older than 30 years of age, 64.7% were married, and 60.8% were housewives, whereas 70.6% of the care recipients were women, 58.8% were older than 60 years of age, 52.9% were married, and 64.7% were housewives. In addition, 80.4% of them were illiterate.

**Table 1 Characteristics of the caregivers and care recipients according to the Caregiver Questionnaire**

Variables	N (%)	
	Caregiver	Care recipient
Age (years)		
<20	2 (3.9)	1 (2.0)
20–30	15 (29.4)	0 (0)
30–40	16 (31.4)	2 (3.9)
40–50	12 (23.5)	4 (7.8)
50–60	1 (2.0)	14 (27.5)
>60	5 (9.8)	30 (58.8)
Sex		
Male	11 (21.6)	15 (29.4)
Female	40 (78.4)	36 (70.6)
Marital status		
Never married	11 (21.6)	3 (5.9)
Married	33 (64.7)	27 (52.9)
Divorced	3 (5.9)	3 (5.9)
Widowed	4 (7.8)	18 (35.3)
Number of offspring		
0	13 (25.5)	4 (7.8)
1–2	16 (31.4)	2 (3.9)
3–5	19 (37.3)	24 (47.1)
6–10	3 (5.9)	21 (41.2)
Age of the youngest offspring (years)		
<1	2 (3.9)	0 (0)
1–5	11 (21.6)	0 (0)
5–10	8 (15.7)	0 (0)
10–15	3 (5.9)	4 (7.8)
15–20	3 (5.9)	9 (17.6)
20–30	8 (15.7)	23 (45.1)
30–39	2 (3.9)	11 (21.6)
>40	1 (2.0)	0 (0)
Not applicable	13 (25.5)	4 (7.8)
Educational level		
Illiterate	15 (29.4)	41 (80.4)
School (primary)	9 (17.6)	4 (7.8)
School (preparatory)	6 (11.8)	0 (0)
Diploma	13 (25.5)	3 (5.9)
College	8 (15.7)	3 (5.9)
Occupation		
Employee	6 (11.8)	2 (3.9)
Manual worker	10 (19.6)	11 (21.6)
Housewife	31 (60.8)	33 (64.7)
Retired	1 (2.0)	5 (9.8)
Student	3 (5.9)	0 (0)
Total	51 (100)	51 (100)

Table 2 shows that 47.1% of the caregivers were care recipients' daughters, 66.7% of them were urban residents, and 54.9% lived with the care recipients in the same house. The number of residents who lived in the same household as the care recipient ranged from five to nine members in 52.9% of cases. About 74.4% of the caregivers started helping the care recipients over 6 months ago, 72.5% of them had —one to two additional caregivers to help them, and 78.4% of the recruited caregivers were care recipients' main caregivers.

Table 3 shows that most of the care recipients could do the following activities with some help: feed themselves (41.2%), dress themselves (51%), take care of their appearance (37.3%), walk (47.1%), get in and out of bed (45.1%), bathe themselves (54.9%), use the toilet (51%), and handle their own medications (37.3%). In contrast, most of the care recipients were completely unable to go shopping for groceries or clothes (98%), prepare their own meals (98%), and do their housework (98%). In terms of the care recipients' abilities to handle their finances, 35.3% could do so with some help and 35.3% could do so without any help. However, 41.2% of the care recipients could use the phone without any help. As regards to the type of organ failure, most of the care recipients 51% had hepatic failure, while 17.6% had renal failure, and 17.6% had cardiac failure. The remainder of the care recipients had a combination of two organ failures (Table 4).

**Table 2 Characteristics of the relationship between the caregiver and care recipients according to the Caregiver Questionnaire**

Variables	N (%)
Relationship of CG to CR	
Wife	3 (5.9)
Husband	2 (3.9)
Daughter	24 (47.1)
Son	9 (17.6)
Sister	5 (9.8)
Daughter-in-law	5 (9.8)
Paid volunteer	1 (2.0)
Mother	2 (3.9)
Residency	
Urban	34 (66.7)
Rural	17 (33.3)
Does CG live with CR?	
Yes	28 (54.9)
No	23 (45.1)
Number of residents in CR's house	
< 5	12 (23.5)
5–9	27 (52.9)
10–15	11 (21.6)
> 15	1 (2.0)
Duration of caregiving	
< 6 months	13 (25.5)
6–12 months	10 (19.6)
1–2 years	10 (19.6)
2–5 years	9 (17.6)
5–10 years	5 (9.8)
> 10 years	4 (7.8)
Number of additional CGs	
1–2	37 (72.5)
3–4	9 (17.6)
5–6	2 (3.9)
0	3 (5.9)
Main caregiver	
Yes	40 (78.4)
No	11 (21.6)
Total	51 (100)

CG, caregiver; CR, care recipient.

Table 5 shows that 88.2% of the caregivers experienced high caregiver burden. Affection of the social (88.2%) and time (88.2%) domains were most experienced by the caregivers.

Table 6 shows that 60.8% of the caregivers had severe anxiety, 13.7% had moderate anxiety, and 2% had mild anxiety; 45.1% of the caregivers were not depressed, whereas 43.1% had mild depression, 9.8% had moderate depression, and 2% had severe depression.

Table 7 shows that, on the basis of the PaP Score, 90.2% of the care recipients had a 30-day survival rate of 30–70%. The inability of the care recipients to walk ( $P = 0.04$ , OR = 7), to use the toilet by themselves ( $P = 0.04$ , OR = 7), to handle their own medications ( $P = 0.04$ , OR = 7), and to handle their own finances ( $P = 0.02$ , OR = 12.3) were significantly related to caregiver burden. The inability of the care recipients to feed themselves ( $P = 0.2$ , OR = 3.09), to dress themselves ( $P = 0.61$ , OR = 1.3), to take care of their

**Table 3 Care recipient's functional status (Activities of Daily Living and Instrumental Activities of Daily Living) according to the Caregiver Questionnaire**

Activity (in last month)	N (%)		
	Completely unable	With some help	Without any help
Feeding	16 (31.4)	21 (41.2)	14 (27.5)
Dressing	18 (35.3)	26 (51.0)	7 (13.7)
Taking care of appearance	18 (35.3)	19 (37.3)	14 (27.5)
Walking	22 (43.1)	24 (47.1)	5 (9.8)
Getting in and out of bed	21 (41.2)	23 (45.1)	7 (13.7)
Bathing	19 (37.3)	28 (54.9)	4 (7.8)
Toileting	20 (39.2)	26 (51)	5 (9.8)
Using the phone	13 (25.5)	17 (33.3)	21 (41.2)
Going to places out of walking distance	47 (92.2)	4 (7.8)	0 (0)
Shopping	50 (98)	1 (2)	0 (0)
Preparing meals	50 (98)	1 (2)	0 (0)
Housekeeping	50 (98)	1 (2)	0 (0)
Handling medicine	18 (35.3)	19 (37.3)	14 (27.5)
Handling finances	15 (29.4)	18 (35.3)	18 (35.3)

**Table 4 The care recipients' organ failure status and other medical problems according to the Caregiver Questionnaire**

Variables	N (%)
Type of organ failure	
Hepatic	26 (51.0)
Renal	9 (17.6)
Cardiac	9 (17.6)
Hepatic and cardiac	4 (7.8)
Cardiac and renal	2 (3.9)
Hepatic and respiratory	1 (2.0)
Duration of organ failure	
< 6 months	4 (7.8)
6–12 months	8 (15.7)
1–2 year	15 (29.4)
2–5 year	16 (31.4)
> 5 years	8 (15.7)
Duration of progression of organ failure	
1–2 months	25 (49.0)
2–4 months	10 (19.6)
4–6 months	4 (7.8)
6–8 months	3 (5.9)
> 1 year	9 (17.6)
Other health problems	
Present	14 (27.5)
Absent	37 (72.5)

**Table 5 Caregiver burden according to the Modified Caregiver Strain Index**

	N (%)		
	High	Low	Total
Overall burden	45 (88.2)	6 (11.8)	
Employment	13 (25.5)	38 (74.5)	
Financial	26 (51)	25 (49)	
Physical	40 (78.4)	11 (21.6)	
Social	45 (88.2)	6 (11.8)	
Time	45 (88.2)	6 (11.8)	
Total			51 (100)

**Table 6 Caregiver anxiety and depression measured by Hamilton Anxiety Rating and Hamilton Depression Rating Scales**

	N (%)			
	Normal	Mild	Moderate	Severe
Anxiety (HARS)	12 (23.5)	1 (2)	7 (13.7)	31 (60.8)
Depression (HDRS)	23 (45.1)	22 (43.1)	5 (9.8)	1 (2)

HARS, Hamilton Anxiety Rating Scale; HDRS, Hamilton Depression Rating Scale.

**Table 7 The care recipient's Palliative Prognostic Score**

Score	N (%)
30-day survival, 30–70%	46 (90.2)
30-day survival, <30%	5 (9.8)

appearance ( $P = 0.53$ , OR = 1.38), to get in and out of bed ( $P = 0.19$ , OR = 4), to bathe themselves ( $P = 0.4$ , OR = 2.8), and to use the phone by themselves ( $P = 0.48$ , OR = 1.5) were predictors of caregiver burden. The inability of the care recipients to use the phone by themselves ( $P = 0.04$ , OR = 4), to handle their own medications ( $P = 0.01$ , OR = 6.4), and to handle their own finances ( $P = 0.01$ , OR = 5.8) were significantly related to caregiver anxiety. The inability of care recipients to feed themselves ( $P = 0.42$ , OR = 1.45), to dress themselves ( $P = 0.53$ , OR = 1.36), to take care of their appearance ( $P = 0.19$ , OR = 2.38), to walk ( $P = 0.34$ , OR = 2.4), to get in and out of bed ( $P = 0.2$ , OR = 2.92), and to use the toilet by themselves ( $P = 0.34$ , OR = 2.4) were predictors of caregiver anxiety. The inability of the care recipients to feed themselves ( $P = 0.45$ , OR = 1.31), to take care of their appearance ( $P = 0.45$ , OR = 1.31), to walk ( $P = 0.41$ , OR = 1.95), to get in and out of bed ( $P = 0.39$ , OR = 1.75), to bathe themselves ( $P = 0.62$ , OR = 1.24), to use the toilet by themselves ( $P = 0.41$ , OR = 1.95), to use the phone by themselves ( $P = 0.12$ , OR = 2.3), to handle their own medications ( $P = 0.08$ , OR = 2.96), and to handle their own finances ( $P = 0.08$ , OR = 2.75) were predictors of caregiver depression. The inability of care recipients to feed themselves ( $P = 0.42$ , OR = 1.45), to dress themselves ( $P = 0.53$ , OR = 1.36), to take care of their appearance ( $P = 0.19$ , OR = 2.38), to walk ( $P = 0.34$ , OR = 2.4), to get in and out of bed ( $P = 0.2$ , OR = 2.92), and to use the toilet by themselves ( $P = 0.34$ , OR = 2.4) were predictors of caregiver anxiety. The inability of the care recipients to feed themselves ( $P = 0.45$ , OR = 1.31),

to take care of their appearance ( $P = 0.45$ , OR = 1.31), to walk ( $P = 0.41$ , OR = 1.95), to get in and out of bed ( $P = 0.39$ , OR = 1.75), to bathe themselves ( $P = 0.62$ , OR = 1.24), to use the toilet by themselves ( $P = 0.41$ , OR = 1.95), to use the phone by themselves ( $P = 0.12$ , OR = 2.3), to handle their own medications ( $P = 0.08$ , OR = 2.96), and to handle their own finances ( $P = 0.08$ , OR = 2.75) were predictors of caregiver depression.

## Discussion

The result of this study showed that the care recipient's age was a predictor of caregiver burden, anxiety, and depression. This is consistent with the findings of other studies that conclude that the patient's age is one of the most important predictors of burden and depression (Dumont *et al.*, 2006; Papastavrou *et al.*, 2009).

This may be explained by the fact that 58.8% of the care recipients in the present study are older than 60 years of age. Aging is associated with physical decline and therefore, functional problems that may impose higher burden on the caregivers. However, other studies have reported that the patient's age is not an important predictor of burden or psychiatric morbidity. The care recipient's sex is a predictor of caregiver burden and anxiety. Caring for male care recipients was a strong predictor of caregiver burden, whereas caring for female care recipients was a predictor of caregiver anxiety. This is consistent with the findings of a study carried out by Mahoney *et al.* (2005), in which anxiety in caregivers was more frequent when the care recipient was a male patient. This also supports the results of the study of Bhattacharjee *et al.* (2012), carried out on caregivers of stroke patients, which concluded that the care recipient's sex is significantly related to caregiver burden.

However, in this study, factors leading to increased caregiver burden included caring for a female patient. This may be explained by the fact that most of the caregivers in our study were female patients. It is culturally more acceptable to perform certain tasks for female care recipients (such as toileting and bathing) than for male care recipients. This may cause more burdens when providing care to male patients. However, caregiver anxiety is related to caring for female care recipients. These results may be attributed to the fact that the caregiver's personality trait and coping strategies have an effect on the degree of caregiver distress, rather than the caregiver's sex.

The care recipient's marital status (married) is a predictor of burden and anxiety. Taking care of a married patient usually means taking care of his/her partner as well, who is most probably an elderly suffering from comorbidity. This may impose more burdens on the caregiver.

However, other studies have reported that the experience of caregiving is not related to patient characteristics such as sex, age, or marital status (Janssen *et al.*, 2012).

This study found that caring for a care recipient who had other offspring is a predictor of caregiver burden. This can be explained by Egyptian families. About 54.9% of the caregivers live in the same house as their care recipients. About 52.9% of the care recipients have —five to nine individuals living with them and 21.6% of the care recipients have 10–15 individuals living with them. This large number of residents may cause more conflicts and, therefore, more burden on the main caregiver. However, this study also shows that taking care of care recipients who have no other offspring is a predictor of caregiver depression. This may be because of the fact that the caregiver will be the only responsible individual for the care recipient.

In the present study, the care recipient's educational level is a predictor of caregiver burden, anxiety, and depression. This is consistent with other studies that have concluded that the educational level of Alzheimer's dementia patients is strongly associated with caregiver burden (García-Alberca *et al.*, 2011; Rakoski *et al.*, 2012). This may be explained by the fact that less educated patients have poor knowledge and poor coping strategies for managing their chronic disease, further contributing toward functional disability. This leads to more care recipient distress, which means more caregiver distress.

In this study, the care recipient's occupational status is not correlated to caregiver anxiety, burden, or depression. This is most probably because of the fact that 64.7% of the care recipients are housewives.

Most of the informal caregivers in the present study were the care recipients' daughters. This is consistent with some studies. However, most of the studies have reported that the main caregivers are the patients' spouses (Pinto *et al.*, 2007; Razali *et al.*, 2011; Janssen *et al.*, 2012). Johansson *et al.* (2003) have reported that two-third of family caregiving is provided by women, wives, daughters, daughters-in-law, and other close female friends and female next of kin. When an older individual does not have a spouse, daughters and daughters-in-law are the major care providers (Nordhus *et al.*, 1998), and the traditional caregiving role is added to the family role and employment outside the home (Pearlin *et al.*, 1990).

Our study shows that the relationship between the caregiver and the care recipient is a predictor of caregiver anxiety and depression. This is consistent with the findings of other studies (Papastavrou *et al.*, 2009).

Our study showed that being the care recipient's daughter-in-law is a predictor of caregiver anxiety and depression. A study carried out on caregivers of stroke survivors in South Korea concluded that the caregiver being the daughter-in-law is one of the most significant predictors of caregiver burden (Choi-Kwon *et al.*, 2005). Egyptian daughters-in-law are likely to become caregivers on the basis of cultural expectations rather than affectionate relationships. In the Egyptian culture, the sons usually live in the same house as their parents. The daughters-in-law are socially obliged to take over the caregiving role. This social obligation may result in

more burden. A previous study on family caregivers of older patients with congestive heart failure did not show an association between the relationship of the caregiver to the patient and the caregiver strain (Barnes *et al.*, 2006). A study carried out by Razali *et al.* (2011) reported that burden of care is not significantly related to kinship.

This study showed that living with the care recipient in the same residence is a predictor of caregiver anxiety and depression. This supports the caregiving literature indicating that kinship, in terms of coresiding relatives, increases the vulnerability to caregiver burden (Soskolne *et al.*, 2007; Papastavrou *et al.*, 2009). However, not living with the care recipient in the same house is a predictor of caregiver burden. This is most probably because of the extra burden the caregiver experiences when he/she has to leave their home and children for several hours a day in order to take care of the care recipient.

There was a statistically significant correlation between caregiver anxiety and being the main caregiver. Being the main caregiver is a predictor of caregiver depression. This is mainly because of the fact that being the main caregiver means taking the main responsibility for caregiving, which is a very distressful job. Unexpectedly, our study found that having more than one additional caregiver to help is a predictor of caregiver anxiety and depression. This is supported by the results of a study carried out by Garlo *et al.* (2010), in which caregiver burden was higher among caregivers of patients who received hospice services and therefore, were presumably receiving an increased amount of formal caregiving services to relieve their burden. These results indicate that the strain of caregiving may be determined to a large extent by the caregivers' psychological response to their role, rather than by the objective tasks they perform to care for their patients. This conclusion is supported by a number of studies that have found a relationship between caregivers' personality attributes and/or coping strategies and caregiver burden (Lyons *et al.*, 2009).

However, a study carried out by Bhattacharjee *et al.* (2012) on caregivers of stroke patients concluded that the presence of additional caregivers is not significantly related to caregiver burden.

The present study shows that the duration of caregiving (>6 months) is significantly correlated to caregiver anxiety and depression, and is a predictor of caregiver burden. This is consistent with the findings of a study that was carried out on caregivers of Alzheimer's dementia patients (García-Alberca *et al.*, 2011). This may be because of the nature of organ failure patients and the unexpected fluctuating course of disease, which places more burden on the caregivers.

However, a study by Razali *et al.* (2011) shows that burden of care is not significantly related to the duration of caregiving. In contrast, McConaghy and Caltabiano, 2005 found that caring for a patient with dementia over a long period of time was associated with decreased levels of burden and increased well-being.

In the present study, most of the care recipients experienced severe functional decline, thereby necessitating the intervention of informal caregivers to help prevent potentially poor outcomes.

This is consistent with the findings of a study carried out by Rakoski *et al.* (2012) on informal caregivers of cirrhosis patients. Almost 20% of patients with cirrhosis experienced severe functional decline over a median of approximately 2 years, more than double the age-matched individuals without cirrhosis.

In this study, the activities that are significantly related to caregiver burden and anxiety are walking, toileting, using the phone, handling medications, and handling finances. A study carried out by Bhattacharjee *et al.* (2012) on caregivers of stroke patients reported that tasks such as medical and nursing care, emotional support to the patient, providing company and arranging transport, managing patient's finances, cooking, washing clothes, managing behavior problems, daily communication such as reading, writing, and planning daily activities for the patient resulted in higher burden in caregivers. Poor functional status of the caregiver has been found to be associated with depressive symptoms (Chung *et al.*, 2009) and burden (Rezende *et al.*, 2010) in them.

However, the findings of our study are not consistent with the findings of Garlo *et al.*, 2010, who reported that caregiver burden is not strongly associated with the patients' functional disability. Dealing with the moodiness of the patient and providing emotional support may be one of the most challenging tasks for family caregivers (Simpson *et al.*, 2010).

The present study shows that being an older caregiver (>20 years old) is a predictor of burden and anxiety, but not depression. This is consistent with the findings of Saunders (2008) and Papastavrou *et al.* (2009), which confirm that caregiver's age is a predictor of caregiver burden. A study carried out by Dreer *et al.* (2007) reported that the caregiver's age is not significantly correlated to caregiver's depression. This may be because of the fact that older the caregiver, the more the financial and health burden he/she has. Older caregivers are married and have to care for their own families as well as for the care recipient. However, other studies have reported that younger caregivers report more subjective burden than older caregivers (Given *et al.*, 2004).

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### Conflicts of interest

There are no conflicts of interest.

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