

Caring for a relative with dementia: family caregiver burden

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Abstract

Title. Caring for a relative with dementia: family caregiver burden

Aim. This paper is a report of part of a study to investigate the burden experienced by families giving care to a relative with dementia, the consequences of care for the mental health of the primary caregiver and the strategies families use to cope with the care giving stressors.

Background. The cost of caring for people with dementia is enormous, both monetary and psychological. Partners, relatives and friends who take care of patients experience emotional, physical and financial stress, and care giving demands are central to decisions on patient institutionalization.

Method. A volunteer sample of 172 caregiver/care recipient dyads participated in the study in Cyprus in 2004–2005. All patients were suffering from probable Alzheimer's type dementia and were recruited from neurology clinics. Data were collected using the Memory and Behaviour Problem Checklist, Burden Interview, Center for Epidemiological Studies-Depression scale and Ways of Coping Questionnaire.

Findings. The results showed that 68.02% of caregivers were highly burdened and 65% exhibited depressive symptoms. Burden was related to patient psychopathology and caregiver sex, income and level of education. There was no statistically significant difference in level of burden or depression when patients lived in the community or in institutions. High scores in the burden scale were associated with use of emotional-focused coping strategies, while less burdened relatives used more problem-solving approaches to care-giving demands.

Conclusion. Caregivers, especially women, need individualized, specific training in how to understand and manage the behaviour of relatives with dementia and how to cope with their own feelings.

Keywords: caregiver burden, coping, dementia, empirical research report, family carers, nursing

Introduction

Caregiver burden has been defined as a negative reaction to the impact of providing care on caregivers' social, occupational and personal roles (Given *et al.* 2001). It is also well-established that the symptoms of dementia are an important

source of caregiver burden and stress, which in turn is a major determinant of institutionalization for dementia sufferers (Donaldson *et al.* 1998). There is also evidence that chronic stress exposure in caregivers of patients with dementia is associated with physical health decline, psychiatric morbidity and poor quality of life (Rose-Rego *et al.*

1998, Clyburn *et al.* 2000, Bell *et al.* 2001, Connell *et al.* 2001). All these factors may result in poor standards of care, neglect or even abuse of the patient, and indicate the need for patient institutionalization.

To reduce stress and strengthen partnerships, nurses need to understand better individual carers' experiences and be more in tune with their worries and concerns, so that appropriate care and support can be provided. The recognition of high levels of caregiver morbidity demands a holistic approach and nurses need to be more responsive to the needs of both carers and care-recipients rather than focussing on the patient alone (Cheung & Hocking 2004).

Background

Theoretical framework

The burden of dementia care giving was explored within the framework of the general stress theories. Like stress, caregiver burden is hypothesized to be an acute reaction to providing care that arises as new care demands are introduced or existing care demands intensify (Given *et al.* 1999). When care demands become increasingly challenging, caregivers respond by employing strategies to meet care demands and decrease the burden of providing care (Sherwood *et al.* 2005). Caregivers who are unable to adapt or modify their strategies to meet care demands experience burden (Given *et al.* 1999). Pearlin *et al.* (1990) have incorporated the problematic areas of care into a 'model of care for patients with Alzheimer's disease', which is a specific application of the stress-coping model of Lazarus and Folkman (1984). They claim that care giving stress is a multidimensional phenomenon that consists of four major domains: the framework of care (including the characteristics of the caregiver, type of the dyadic relationship and availability of social support); the stressful situations of care giving, which may be primary (such as the problematic behaviour of the patient) or secondary (such as other commitments of the caregiver); factors (such as the coping strategies and management of care) that moderate the perception of stress and consequences of care giving for the general wellbeing of the caregiver.

Variables related with caregiver burden in dementia

Many researchers have assessed and described in different ways the individual characteristics of both the patient and caregiver that predispose caregivers to burden. Regarding the patient, studies have found a statistically significant correlation between burden and the functional condition or ability

of the patient to cope with the daily living activities (Schumacher *et al.* 1993, Faison *et al.* 1999, Clyburn *et al.* 2000, Gallant & Connell 2003). Burden has also been related to certain characteristics of the relative, such as age and the presence of illness (Connell *et al.* 2001), and burden may be an important criterion for moving the patient into institutional care (Yaffe *et al.* 2002). Recent meta-analyses (Pinquart & Sorensen 2003) support the fact that physical dependency is positively related with caregiver depression, but in the case of patients with dementia this problem is of secondary importance, given the priority of behavioural disorders like aggressiveness, wandering and disorientation. More recent studies report a negative correlation between physical dependency and burden (Sherwood *et al.* 2005). It is possible that in cases when the need for physical care is apparent, the extended family tends to offer more support to the primary caregiver (Given *et al.* 1999).

Research on patients' behavioural problems is more clear and the results are more consistent in relation to the correlation of problematic behaviour with burden (Baumgarten *et al.* 1992, Schulz *et al.* 1995, Donaldson *et al.* 1998, Faison *et al.* 1999, Robinson *et al.* 2001, Gallicchio *et al.* 2002, Hooker *et al.* 2002, Rymer *et al.* 2002, Andrieu *et al.* 2003, Covinsky *et al.* 2003). These problems have also been described as a major risk factor in moving the patient into institutional care (Acton 1997, Chou 1999, Armstrong 2000, Clyburn *et al.* 2000, Bell *et al.* 2001, Hebert *et al.* 2001, Rees *et al.* 2001).

The relationship between cognitive impairment and burden is less clear, either giving a positive correlation (Matsuda 1995, Nagatomo *et al.* 1999) or no direct relation (Gonzales-Salvador *et al.* 1999, Coen *et al.* 2002).

Consequences of burden

Family caregivers of patients with dementia experience increased physical and psychological morbidity (Clyburn *et al.* 2000, Bell *et al.* 2001, Connell *et al.* 2001), and may develop hyperlipidaemia, hyperglycaemia (Vitaliano *et al.* 1995, Davies 1996) and insufficiency of the cellular immune system (Kiecolt-Glaser *et al.* 1995, Davies 1996, Irwin *et al.* 1997, Vendhara *et al.* 1999, Mills *et al.* 2004, Thomson *et al.* 2004). A consistent finding is that depression is a major consequence of care (Malone-Beach & Zarit 1995, Teri 1997, Clyburn *et al.* 2000, Marriot *et al.* 2000, Gallicchio *et al.* 2002) which remains even after the institutionalization or death of the patient (Bass *et al.* 1991, Zarit & Whitlach 1992, Bodnar & Kiecolt-Glaser 1994, Aneshensel *et al.* 1995, Wright *et al.* 1999, Gallagher-Thompson *et al.* 2001).

The diagnosis of a relative with dementia leads to many losses, and caregivers experience grief which is very similar to that of death (Rudd *et al.* 1999) or even worse. This is described as 'disenfranchised grief' (Doka 1989) because the loss cannot be recognized openly or publicly and the relative is not accepted in expressing grief and is socially supported, as happens with real death.

Gender differences in the experience of burden

Caregiver sex is another frequently mentioned variable in the literature. It has been observed that women are more likely to experience social restrictions because of their caring role (Stoller 1990, Kramer & Kipnis 1995, Montgomery 1996), and they experience higher levels of burden when compared with men caregivers (Barusch & Spaid 1996, Wallsten 2000, Gallicchio *et al.* 2002, Thomson *et al.* 2004). The greatest proportion of caregivers (73%) of patients with dementia consists of women (Ory *et al.* 1999), and this increases their vulnerability to depression (Yee & Schultz 2000). High levels of stress, tension (Collins & Jones 1997, Gallicchio *et al.* 2002), paranoid symptoms (Parks & Pilisuk 1991), perception of ill health (Collins & Jones 1997) and lower levels of quality of life (Collins & Jones 1997, Rose-Rego *et al.* 1998) are also found.

Sex differences have been reported in the ways people use to cope with the several stressors of caregiving. Women seem to have lower levels of mastery (Rose-Rego *et al.* 1998) and use less effective coping strategies (Thoits 1995), while men use mostly problem-solving approaches (Thomson *et al.* 2004). Some authors explain sex differences by suggesting that men receive more informal support than women (Allen *et al.* 1996, Ingersoll-Dayton *et al.* 1996).

The study

Aim

The aims of this study were to investigate the burden of giving care to a relative with dementia, consequences of care for the mental health of the primary caregiver and family strategies for coping with the stress of care.

The specific research questions addressed were

- What is the relationship of caregiver burden with the behaviour of the patient and the reaction of the caregiver to the patient's problems?
- Is there a relationship between the caregiver burden and the caregiver's depressive symptoms?
- Is caregiver burden related to specific coping strategies?
- Does institutionalization of the patient reduce caregiver burden?

Design

This was a cross-sectional, descriptive study in which several methods were used for the selection and analysis of data. The data were collected in 2004–2005 in Cyprus.

Participants

Families were recruited from neurology clinics and interviewed at their homes. A total of 200 families were approached, and 172 patient-primary caregiver dyads agreed to participate. The refusal of 28 families is indicative of the social prejudice towards the disease, which is considered a stigma in this society.

Of the 172 patients with the diagnosis of probable Alzheimer's disease, 130 were community residents and 42 were selected from long-term institutions to answer the research question about burden of care and negative consequences when the patient is institutionalized. Care-recipients' ages ranged from 52 to 97 years (mean = 75, SD = 7.93).

The inclusion criteria for caregivers were to have the most frequent contact with the patient and the greatest responsibility for care for at least 1 year, and not to have psychiatric illness or mental disability. The caregiver sample consisted of 40 men and 132 women. The relationship of the patient to the caregiver was that of a partner, daughter, son or other relative, such as a sister or a daughter in law.

Data collection

Data were collected using four instruments, which were completed by the researcher during an interview. The instruments measured the cognitive and behavioural status of the patient, level of burden of the caregiver, presence of depressive symptoms and strategies used by caregivers to cope with the stressors of care.

Cognitive and behavioural status of the patient

Care recipients' cognitive and behaviour status was assessed using the Memory and Behaviour Problem Checklist 1990 R (MBPC) (Zarit 1990). The purpose of the MBPC is to determine how frequently a patient with dementia engages in problematic behaviours and which problems are especially upsetting for family members. There are two parts to the MBPC, and it consists of 26 items. The first part determines the frequency with which common problems have occurred, and the care recipient's cognitive and behaviour status is scored on a Likert scale of 0–4 (0, never happens; 4, happens every day). The timeframe used was 1 week and this was selected to minimize the recall task for informants. The

second part of the MBPC obtains the informant's subjective appraisal of each problem and measures the degree to which behaviours 'bothered or upset' the caregiver.

In the current study, reliability was measured using Cronbach's alpha and was found to be high, with $\alpha = 0.85$ for frequency of problem behaviours and caregiver reaction to problem behaviours. Factor analysis was also performed to group the 26 items of the MBPC in a small number of important factors. The analysis gave seven factors, which explained 62.7% of the variation (see Papastavrou 2005, Papastavrou *et al.* 2006 for more details of the psychometric analysis).

Caregiver burden

Caregiver burden was assessed using the Burden Interview (BI), which was designed to assess the stress experienced by family caregivers of older people and disabled persons. Caregivers are asked to respond to a series of 22 questions about the impact of the patient's disabilities on their life. In the current study, Cronbach's alpha was found to be 0.93. Factor analysis gave four factors that explained 63.92% of the variation. These factors were taken as the dimension of burden and were: personal strain, role strain, relational deprivation and management of care (Papastavrou 2005, Papastavrou *et al.* 2006).

Center for Epidemiological Studies – Depression Scale

The Center for Epidemiological Studies – Depression Scale (CES-D) is a 20-item scale used to assess the overall level of depression experienced in the past week (Raddloff 1977). Psychometric properties have been shown to be strong in many studies, including the translated Greek version (Madianos *et al.* 1992). Cronbach's α in the present study was 0.69.

Ways of Coping Questionnaire

The Greek translation consists of 38 items with a Cronbach's alpha of 0.73. Factor analysis produced five factors that

explained 32.3% of the variation (Karademias 1998). These were positive approach, seeking social support, wishful thinking, avoidance strategies and assertiveness. In the present study, Cronbach's alpha for the overall scale was 0.85.

Ethical considerations

The study was approved by the research committee of the Institute of Neurology and Genetics and the Ministry of Health. All caregivers received an information sheet outlining the purpose of the study, names of the research centres undertaking the research and a statement that responses were anonymous. Contact details of the researchers were also given to allow participants to gain further details about the study. Signed consent was obtained.

Data analysis

The data were analysed using independent samples *t*-tests, correlation analysis and one-way ANOVA followed by *post hoc* adjustments for multiple comparisons.

Results

Most caregivers were daughters (48.3%), followed husbands or wives (41.3%), sons (5.8%) and others (4.1%). The mean age of caregivers was 56.80 years and that of care recipients 75.52 years, with standard deviations 13.38 and 7.93 years, respectively. Care recipients in institutions had a mean age of 79.76 years and those in the community had a mean age of 74.50 years.

Table 1 gives summary statistics for the main study variables for caregivers of patients in the community and in institutions. The variables are formed as overall indices from the series of questions for each. Since the data are approximately normally distributed, means and standard deviations are reported. In the same table, we also show the results from

Table 1 Summary statistics and independent sample *t*-tests for the main study variables ($n = 172$; 130 in community, 42 in institutions)

Variable	Place of residence	Mean	SD	<i>t</i>	<i>P</i> -value
Burden (BI)	Home	50.29	17.35	1.55	0.12
	Institution	45.60	16.13		
Behaviour/memory (MBPC)	Home	48.80	20.66	-1.29	0.20
	Institution	53.33	16.54		
Depression (CES-D)	Home	18.68	7.27	-0.28	0.78
	Institution	19.05	7.04		
Coping strategies (WCQ)	Home	47.65	21.42	-0.33	0.74
	Institution	48.69	16.22		

BI, burden interview; MBPC, memory and behaviour problem check list; CES-D, Centre of Epidemiological Studies – Depression; WCQ, Ways of Coping Questionnaire.

the independent samples *t*-tests, which identify significant differences in these variables between the community and institution participants. The *P*-values are all very high, indicating that there are no statistically significant differences between the two groups for any of the variables. Therefore, regarding the overall level of burden, there were no statistically significant differences when the patient was placed in a long-term care setting compared with living in the community ($P = 0.12$). However, when burden was represented by its four factors there were some differences. There was a difference in relational deprivation, which seemed to be higher when the patient lived at home (mean = 10.40 for community and mean = 8.69 for institution). It is also interesting that when the patient lived in a long-term care setting, factor 4 of the BI (management of care) was higher (community mean = 2.66, institution mean = 3.54). These differences are presented in Table 2.

Statistically significant correlations were found between the main study variables using Pearson correlation coefficients. Burden had a positive relation with overall MBPC score ($r = 0.54$), overall depressive symptoms ($r = 0.57$) and caregiver overall reaction to the patient's behavioural problems ($r = 0.63$). Moreover, MBPC was positively correlated with Ways of Coping Questionnaire (WCQ) ($r = 0.89$) and depression ($r = 0.35$), and reaction was positively correlated with depression ($r = 0.44$). All the correlations

were highly statistically significant, with *P*-values < 0.01 . If we consider the seven categories of MBPC separately, we can see that each category is positively related to burden. The highest correlation coefficient is 0.44 for factor 2, which means that the most stressful category of problems is the one containing questions related with the aggressive behaviour of the patient. These results are demonstrated in Table 3. In the same table, we can also see that, regarding patient behaviour problems (which are positively correlated with depression, previously noted), the kind of behaviour causing most caregiver depressive symptoms is related to apathy ($r = 0.29$).

The relationship between coping strategies and burden is shown in Table 4. The only statistically significant correlations are between burden and positive coping strategies (negative correlation, $r = -0.20$), and between burden and wishful thinking (positive correlation, $r = 0.16$). The first, negative correlation means that when caregivers use specific strategies such as problem-solving and seeking social support, the level of burden is lower. The positive correlation between burden and wishful thinking confirms the Lazarus and Folkman (1984) theory that emotionally focused coping strategies are positively related to stress. Finally, there is a statistically significant positive correlation between depression and three of the four factors of burden, i.e. personal strain, role strain and relational deprivation, with coefficients 0.56, 0.51 and 0.47, respectively.

Place of residence	Mean	SD	<i>t</i>	<i>P</i> -value
Factor 1: personal strain				
Home	23.30	8.12	1.48	0.14
Institution	21.14	8.51		
Factor 2: role strain				
Home	13.92	6.11	1.63	0.10
Institution	12.21	5.16		
Factor 3: relational deprivation				
Home	10.40	4.58	2.13	0.03
Institution	8.69	4.30		
Factor 4: management of care				
Home	2.66	1.64	-3.06	< 0.001
Institution	3.54	1.59		

Table 2 Burden factors in relation to patients' place of residence ($n = 172$; 130 in community, 42 in institutions)

Table 3 Correlation coefficients of burden and depression with the factors of the Memory and Behaviour Problem Checklist (MBPC)

	Factor 1: inactivity	Factor 2: aggressive behaviour	Factor 3: dangerous behaviour	Factor 4: attachment behaviour	Factor 5: memory problems	Factor 6: communication problems	Factor 7: depressive symptoms
Burden	0.37*	0.44*	0.36*	0.35*	0.22*	0.23*	0.25*
Depression	0.29*	0.26*	0.22*	0.24*	0.12	0.14	0.19†

*Correlation significant at 0.01 level.

†Correlation significant at 0.05 level.

Table 4 Relationship (correlation coefficients) between coping strategies and burden

	Burden
Positive approach	-0.20*
Seeking social support	-0.03
Wishful thinking	0.16*
Avoidance strategies	0.06
Assertiveness	0.13

*Correlation significant at 0.05 level.

Sex differences were also examined. Independent samples *t*-test analysis showed that burden was different between men and women (P -value = 0.048). More specifically, women had a higher burden score than men (50.57 and 44.45 respectively, with standard deviations 16.38 and 18.89). If we examine the factors of burden and their relation to sex, as shown in Table 5, we can see that factor 3 – relational deprivation – is the only one that statistically significantly affects gender differently (P -value = 0.02), affecting women more than men. Personal strain also showed a marginal difference for women (P -value = 0.09). Sex differences were also observed in the coping strategies used, where the results showed that women use 'seeking social support' (P -value < 0.01) and wishful thinking more than men (P -value = 0.03). Table 6 gives all the sex differences in coping strategies. Regarding depression, again there was statistical difference (P -value = 0.011), with women having higher depression scores than men (19.54 and 16.25, respectively, with standard deviations of 7.43 and 5.75).

An examination of burden in relation to other independent variables (one-way ANOVA) demonstrated that there were differences at the level of burden according to level of education ($F = 3.69$, $P = 0.01$) and level of income ($F = 3.2$, $P = 0.02$) of the caregiver. With regard to education, *post hoc* multiple comparisons (Bonferroni) showed that the statistically significant difference was between the lowest and highest levels of

education, where elementary school graduates had higher burden compared with MSc/PhD holders ($P = 0.046$). With regard to income, the multiple comparisons showed that caregivers with high income had lower scores on the burden scale, since the statistically significant difference was between the lowest income (up to 6000 CY pounds per annum, or €10.500 or US\$13.600 in approximate values) and the highest (over 12000 CY pounds per annum or €21.000 or US\$27.200 in approximate values) with the low income group having a higher burden (P -value = 0.03).

Finally, one-way ANOVA was used to examine whether burden was related to specific stress-coping strategies. Caregivers with low burden (score below the average) were examined to see if they used any strategy more than others. One-way ANOVA showed that there were indeed differences between the strategies ($F = 22.71$, $P < 0.01$). Multiple comparisons showed that strategy 5 (assertiveness) was used least, as seen by the smaller mean (1.08) and the small P -value. On the other hand, strategy 1 (positive approach) was the most often used since it had the largest (2.15) mean. Statistically significant differences in coping were also found between men and women caregivers, with women using more strategies like seeking social support (mean = 1.98, $P = 0.01$) and wishful thinking (mean = 1.92, $P = 0.01$).

Discussion

Variables related with burden

Patient psychopathology

The primary finding of this study was that the majority of family caregivers experience high levels of burden and this is in agreement with other reports that caregiving for a relative with dementia is stressful and burdensome (Harper & Lund 1990, Aneshensel *et al.* 1995, Winslow & Carter 1999, Annestedt *et al.* 2000, Tornatore & Grant 2002). In

Table 5 Dimensions of burden as related to sex ($n = 172$; 40 men, 132 women)

Sex	Mean	SD	<i>t</i>	<i>P</i> -value
Factor 1: personal strain				
Men	20.57	9.65	-1.72	0.09
Women	23.45	7.70		
Factor 2: role strain				
Men	12.75	6.03	-0.92	0.36
Women	13.73	5.90		
Factor 3: relational deprivation				
Men	8.47	4.52	-2.42	0.02
Women	10.44	4.50		
Factor 4: management of care				
Men	2.65	1.29	-1.16	0.25
Women	2.95	1.77		

Table 6 Sex differences in coping strategies ($n = 172$; 40 men, 132 women)

Caregiver gender	Mean	SD	P-value
Positive approach			
Male	2.03	0.46	0.62
Female	2.08	0.53	
Seeking social support			
Male	1.66	0.67	<0.01
Female	1.98	0.65	
Wishful thinking			
Male	1.66	0.67	0.03
Female	1.92	0.65	
Avoidance strategies			
Male	1.59	0.48	0.09
Female	1.75	0.50	
Assertiveness			
Male	1.24	0.50	0.91
Female	1.23	0.62	

answering the first research question, we identified statistically significant positive correlations between total burden and total frequency of the patient's problem behaviour, as well as the reaction of the caregiver to these problems. These findings agree with previous reports that burden and depression are at the heart of dementia caregiving stress (e.g. Mittleman *et al.* 2004). The behaviour most strongly associated with burden was aggression ($r = 0.44$), which contains items such: patient is suspicious, makes accusations and becomes angry, talks in an aggressive or threatening manner. Anger, apathy, verbal aggressiveness and similar behaviours have also been mentioned in other reports (Cohen-Mansfield *et al.* 1995, Gonzales-Salvador *et al.* 1999, Annstedt *et al.* 2000, Robinson *et al.* 2001, Mourik 2004), while emotional instability and destructive behaviour were correlated with low levels of caregiver wellbeing, stress and depression (Croog *et al.* 2006). It has been suggested that burden is due to the continuous 'vigilance' that is imposed to the caregiver because of this behaviour (Mahoney 2003).

Our results agree with those of others that there is a weak association between cognitive impairment and the burden of care for patients with dementia (Coen *et al.* 2002, Pinquart & Sorensen 2003). The least burdensome behaviours were related to the fifth factor of the MBPC – assessing the patient's memory – with items such as: asks the same question over and over again, mixes up past and present, loses things, misplaces or hides things. It seems that these behavioural problems have a far greater impact on the caregiver's life than do cognitive or functional impairment and they also influence the decision of relatives to place the patient in a long-term institution (Cohen *et al.* 1993).

Burden and place of patient residence

The question of whether institutionalization would relieve caregivers from stress and reduce burden was rejected in this study because there was no difference in level of burden (according to overall BI score) when the patient resided in the community or a long-term care institution, confirming the results of other studies (Dellasega 1991, Zarit & Whitlach 1992, Dunkan & Morgan 1994, Almberg *et al.* 1997, Rudd *et al.* 1999, Winslow & Carter 1999, Annstedt *et al.* 2000, Keefe & Fanny 2000, Murphy *et al.* 2000, Bell *et al.* 2001, Tornatore & Grant 2002), but disagreeing with the results of some other researchers (Armstrong 2000, Yaffe *et al.* 2002). It has been suggested that the emotional bond in the caregiver-care recipient dyad is stronger than physical separation (Chambers *et al.* 2001) and some caregivers continue to deliver direct care because they perceive this as an expression of love and devotion to patient (Levensque *et al.* 1999).

Burden and caregiver income, education and sex

Our results and those of others (Sansoni *et al.* 2004) show that caregiver levels of education and income are related to burden. We found that caregivers with higher education and better remuneration had lower levels of burden, as in other studies; it seems that these factors may function as buffers to the stressors of caregiving. It is also possible that these caregivers have developed more effective skills in managing the problems of care and their own stress.

Another factor predisposing to burden is sex, since our results show that women have higher scores than men on the BI, confirming other reports (Russo & Vitaliano 1995, Schulz *et al.* 1995, Almberg *et al.* 1997, Collins & Jones 1997, Sparks *et al.* 1998, Faison *et al.* 1999, Leon *et al.* 2000, Wallsten 2000, Gallicchio *et al.* 2002, Thomson *et al.* 2004, Croog *et al.* 2006). This finding can be explained in several ways as elsewhere, in Cypriot society the caring role is ascribed to women and many women undertake this not by choice but because it is socially imposed on them. It is also expected that women will fulfil the difficult task of care without preparation or knowledge, because it is claimed to characteristic of their 'female nature' (Connell *et al.* 2001). Moreover, the traditional view that caregiving is an obligation and family responsibility creates increased feelings of tension and sadness in women, especially spouses (Gallicchio *et al.* 2002). An interesting observation when collecting our data was that in the case of a male caregiver there was always another member of the family near by to help and support, and it seems that the availability of another informal helper might have influenced the lower levels of burden found in men. Men and women do not seem to experience burden in the same way. Women caregivers suffer from social or

relational deprivation (Adams 2006, Croog *et al.* 2006), which other studies report as 'isolation factor' (Annestedt *et al.* 2000) or 'restriction in social life' (Almberg *et al.* 1997).

Burden and psychiatric morbidity of caregivers

In answering the second research question, our results show that 85 caregivers (49.41%) scored above the risk level for the development of clinical depression (Yee & Schultz 2000). This percentage is similar to that in other studies (Teri 1994, Covinsky *et al.* 2003, O'Rourke *et al.* 2003). This finding can be explained by the long duration of caregiving careers, which range from 1 to 13 years, and the tensions involved in this role. Our results are consistent with those of other reports that caregiver burden is positively correlated with depression (Schulz *et al.* 1995, Given *et al.* 1999, Bedard *et al.* 2000, Clyburn *et al.* 2000, Pinquart & Sorensen 2003, Sherwood *et al.* 2005), although there is a debate in the literature about whether burden precedes depressive symptoms (Clyburn *et al.* 2000, Sherwood *et al.* 2005).

In the dementia caregiving literature, recipient behaviour problems are overwhelmingly reported as predicting *caregiver depression* (Schulz *et al.* 1995, Yee & Schultz 2000). We found that caregiver depression was highly correlated with problematic behaviour ($r = 0.35$) leading to the conclusion that the patient's behaviour was predictive of caregiver depression as well as burden. Examples of this behaviour include: the patient does not recognize familiar people, is unable to keep occupied or busy by self and spends long periods of time inactive. Depressive symptoms in patients, such as 'crying, seems depressed or sad' were related with burden less strongly ($r = 0.25$) compared with the findings of Donaldson *et al.* (1998) ($r = 0.40$) and Robinson *et al.* (2001) ($r = 0.45$), while in Teri's (1997) report caregiver and patient diagnosis of depression were also statistically significantly correlated ($r = 0.34$).

This difference could be explained within the framework of 'attribution theory', according to which if the depressive symptoms of patients with dementia are attributed to the disease and not to the patient, the experience of caregiving is probably less stressful (Barrowclough *et al.* 1994, TARRIER *et al.* 2002). Similar findings were found in Italy, where caregiver depression was related to personal characteristics rather than to the patient (Zanetti *et al.* 1998).

Regarding depression and its relation to sex, a series of studies using the CES-D provide the evidence that women caregivers score higher than men (Lutzky & Knight 1994, Rose-Rego *et al.* 1998, Schulz & Williamson 1991), and the correlation of depression with burden confirms the lack of

social support and social transaction as a predisposing factor of psychiatric morbidity.

Coping strategies used in caring

In answering the third study question, it seems that burden is related to specific coping strategies. Positive coping had a negative correlation with caregiver burden ($r = -0.20$), while emotional coping was positively related with burden ($r = 0.16$). However, there was not an absolute division between negative and positive strategies, and the use of any of these may vary during the caregiving career as the care receiver's condition deteriorates (Kneebone & Martin 2003). At the primary stages of the disease when symptoms are mild, avoidance and denial may be useful, but strategies of this type cease to be effective when the symptoms become more intense.

As in other studies (McKee *et al.* 1997) using the same instrument, our low-burden caregivers used positive approaches and problem-solving to a greater degree than the more burdened ones. However, in comparing high and low burden caregivers there were no statistically significant differences in use of coping strategies, leading to the conclusion that there may be other more robust factors that could moderate the stress of giving care to a relative with dementia.

High burden caregivers used emotional coping strategies as 'Praying and seeking God's help', 'hoping for a miracle', 'day-dreaming'. Other studies found that wishful thinking and avoidance were related to caregiver's depression (Williamson & Schulz 1993, Fingerman *et al.* 1996, Powers *et al.* 2002) and lower patient's survival rates (McClendon *et al.* 2004) because these caregivers are less available for the patient, provided less patient-centred care and contributed unavoidably to the advancement of the patient's decline.

Coping strategies and sex

Women in our study reported that they used emotional coping strategies more than men, explaining to a degree their high levels of burden. In a similar way, Lutzky and Knight (1994) claim that high levels of depression are due to the fact that women use avoidance and escape strategies. However, beyond the role differences there is a possibility that certain male personality characteristics function as strong factors promoting resistance to stress (Thomson *et al.* 2004). It may also be possible that men have developed a stronger and wider repertoire of stress management techniques because of experiencing many years of paid employment and having a more positive approach to difficulties (Wallsten 2000). It has also been found that men caregivers tend to use mechanisms that create a psychological distance from the care receiver so as to reduce the stress of care (Collins & Jones 1997).

What is already known about this topic

- Families play an important role in the protection and care of patients with dementia and are a critical resource for healthcare systems.
- Family caregivers of patients with dementia experience burden and increased physical and psychiatric morbidity, which remains even after institutionalization or death of the patient.
- Burden is correlated with the characteristics of the caregiver and also with the behavioural, cognitive and functional impairment of the patient.

What this paper adds

- Women caregivers had higher scores for burden and depression and suffered from social or relational deprivation.
- Patients' behavioural problems had a far greater impact on caregivers' lives than cognitive or functional impairment, and influenced the decision of relatives to place the patients in long-term residential care.
- Understanding caregivers' experiences and coping reactions will assist healthcare workers, and especially nurses, to develop strategies to reduce caregiver burden and promote better coping with care-giving difficulties.

Study limitations

The generalizability of this study is limited because of possible self-selection bias inherent in any study that uses volunteers. Caregivers who volunteered to participate in this study may have been more aware of the possible impact of problem behaviours on caregiver well-being than the average caregiver. Another limitation is that patients were studied at different stages of their disease and selection was based on diagnoses and not clinical examination. A third limitation might be a possible 'response bias' (Robinson *et al.* 2001) because the instruments use self-reports and the answers could not be verified objectively. The use of structured instruments also did not allow the free expression of the caregivers' views, and a wealth of information is lost when using such methods.

Conclusion

Nurses working in the community are in the best position to assess, prevent or intervene in problems related by stressful care giving situations. Data from this study provide nurses with a more comprehensive understanding of the caregiving

role and could contribute to the development of effective intervention strategies to decrease negative consequences and highlight the positive dimensions of caregiving. This would optimize the caregiving environment for both patient and caregiver and might also delay admission to residential care for patients with dementia.

More intervention research is also needed to determine how best to support caregivers in managing problem behaviours at each stage of the disease and how to deal with their own feelings of loss. Replication studies with larger randomized samples, conducted over extended periods of time, are needed to validate instruments and avoid contradictory evidence.

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Author contributions

EP, PS, AK, SP and HT were responsible for the study conception and design and EP was responsible for the drafting of the manuscript. EP performed the data collection and data analysis. SP provided administrative support. PS, AK, SP and HT made critical revisions to the paper. HT provided statistical expertise. PS and AK supervised the study.

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