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. 2001).
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 needs to be more responsive to the needs of both carers and care-recipients rather than focusing 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).


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

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 of 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 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 (Radloff 1977). Psychometric properties have been shown to be strong in many studies, including the translated Greek version (Madianos et al. 1992). Cronbach’s $\alpha$ 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 (Karademas 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...
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.

<table>
<thead>
<tr>
<th>Place of residence</th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>t</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Factor 1: personal strain</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home</td>
<td>23.30</td>
<td>8.12</td>
<td>1.48</td>
<td>0.14</td>
</tr>
<tr>
<td>Institution</td>
<td>21.14</td>
<td>8.51</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Factor 2: role strain</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home</td>
<td>13.92</td>
<td>6.11</td>
<td>1.63</td>
<td>0.10</td>
</tr>
<tr>
<td>Institution</td>
<td>12.21</td>
<td>5.16</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Factor 3: relational deprivation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home</td>
<td>10.40</td>
<td>4.58</td>
<td>2.13</td>
<td>0.03</td>
</tr>
<tr>
<td>Institution</td>
<td>8.69</td>
<td>4.30</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Factor 4: management of care</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home</td>
<td>2.66</td>
<td>1.64</td>
<td>-3.06</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Institution</td>
<td>3.54</td>
<td>1.59</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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.
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 18.98). 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 = 0.01), 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 €10.300 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

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

<table>
<thead>
<tr>
<th>Sex</th>
<th>Mean</th>
<th>sd</th>
<th>t</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Factor 1: personal strain</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>20.57</td>
<td>9.65</td>
<td>-1.72</td>
<td>0.09</td>
</tr>
<tr>
<td>Women</td>
<td>23.45</td>
<td>7.70</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Factor 2: role strain</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>12.75</td>
<td>6.03</td>
<td>-0.92</td>
<td>0.36</td>
</tr>
<tr>
<td>Women</td>
<td>13.73</td>
<td>5.90</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Factor 3: relational deprivation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>8.47</td>
<td>4.52</td>
<td>-2.42</td>
<td>0.02</td>
</tr>
<tr>
<td>Women</td>
<td>10.44</td>
<td>4.30</td>
<td></td>
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<tr>
<td>Factor 4: management of care</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>2.65</td>
<td>1.29</td>
<td>-1.16</td>
<td>0.25</td>
</tr>
<tr>
<td>Women</td>
<td>2.95</td>
<td>1.77</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 6 Sex differences in coping strategies (n = 172; 40 men, 132 women)

<table>
<thead>
<tr>
<th>Coping strategy</th>
<th>Mean</th>
<th>SD</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive approach</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>2.03</td>
<td>0.46</td>
<td>0.62</td>
</tr>
<tr>
<td>Female</td>
<td>2.08</td>
<td>0.53</td>
<td></td>
</tr>
<tr>
<td>Seeking social support</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1.66</td>
<td>0.67</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Female</td>
<td>1.98</td>
<td>0.65</td>
<td></td>
</tr>
<tr>
<td>Wishful thinking</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1.66</td>
<td>0.67</td>
<td>0.03</td>
</tr>
<tr>
<td>Female</td>
<td>1.92</td>
<td>0.65</td>
<td></td>
</tr>
<tr>
<td>Avoidance strategies</td>
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<td></td>
<td></td>
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<tr>
<td>Male</td>
<td>1.59</td>
<td>0.48</td>
<td>0.09</td>
</tr>
<tr>
<td>Female</td>
<td>1.75</td>
<td>0.50</td>
<td></td>
</tr>
<tr>
<td>Assertiveness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1.24</td>
<td>0.50</td>
<td>0.91</td>
</tr>
<tr>
<td>Female</td>
<td>1.23</td>
<td>0.62</td>
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</tbody>
</table>

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, Annestedt 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, Annestedt et al. 2000, Keefe & Fanney 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’, ‘daydreaming’. Other studies found that wishful thinking and avoidance were related to caregiver’s depression (Williamson & Schultz 1993, Fingerman et al. 1996, Powers et al. 2002) and lower patient’s survival rates (McClenon 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).
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 decreases 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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