Alzheimer’s disease: the psychological and physical effects of the caregiver’s role. Part 1

Abstract
Caring for a person with Alzheimer’s disease can cause emotional, psychological and physical problems. In most cases of Alzheimer’s disease, at least two individuals are affected: the person with the condition and the caregiver. This article is the first of two about Alzheimer’s disease and its effect on informal carers. The first discusses the literature that relates to the physical and psychological effects of caring for a person with Alzheimer’s in the home. The second article summarises a quantitative study of 42 caregivers in the west of Ireland, and the physical and psychological effects of the caregiving role on them.

Alzheimer’s disease attacks the brain and impairs memory, thinking and behaviour, eventually rendering patients incapable of caring for themselves (Tabak et al 1997; Query et al 2005). It is devastating for those afflicted, their family members who often care for them and the healthcare system (Yin et al 2002). As this form of dementia develops, many family members are likely to assist the patient with daily necessities such as feeding, grooming, bathing and dressing (Vrabec 1997). Current health and social care policy is reliant on the continued availability of family or friends to provide, on a voluntary basis, the care required in the community (Timoney 2004).

Dementia has not been a healthcare priority (Jones 2005). Government investment in treating and providing resources to help affected people has been inadequate (Boland and Sims 1996, Skillet 2005). According to the Alzheimer Society of Ireland (2006), there is a need to increase awareness about the growing number of people with dementia and the significant cost involved (Adams 1996, Wilkinson 2005). In most cases of Alzheimer’s disease, at least two individuals are affected: the person with the condition and the caregiver (Skaff et al 1996).

The Alzheimer Society of Ireland (2006) says that the wellbeing of a person with dementia depends directly on the wellbeing of the person who is providing his or her care (Boland and Sims 1996). Query et al (2005) define the caregiver as a family member or significant other who provides the majority of support and personal care to a patient (Ferry 2001). As the disease progresses, caregivers often find themselves cut off from friends and regular social activities (Alzheimer Society of Ireland 2006).

Nurses need to become more aware of the nature and demands of family caregiving in relation to Alzheimer’s disease in order to campaign for better statutory services for caregivers. This will help to influence public policy with regard to care (Ferrario et al 2003). It is hoped that this research will generate interest and awareness of the effects of caring for a person with Alzheimer’s disease and will create a sense of urgency surrounding dementia, inspiring action among the general population, third party groups,
healthcare providers and policymakers at every level (Bond et al 2005).

**Physical effects on the caregiver**

Caring for a family member with dementia is regarded as a chronically stressful process, with potentially negative physical health consequences (Vitaliano et al 2003; Mahoney et al 2005). Vitaliano et al (2003) found in a meta-analysis of 23 studies that caregivers of people with dementia face five to 15 years of exposure to physical and psychosocial demands (Thomas et al 2006). They shoulder the burden of household chores and are exposed to symptoms of depression, anger, agitation and paranoia in their care recipients (Tarrier et al 2002; Rinaldi et al 2005).

Thomas et al (2006) undertook a descriptive study to determine parameters that influence caregivers’ quality of life and found that behavioural problems such as patient depression, agitation and wandering are rated as most stressful by caregivers because they can occur unpredictably and often require continuous monitoring. Perlick et al (2005) say that, in addition, caregivers face the progressive deterioration of the personality of a loved one, or the ‘loss of self’ that occurs when spouses or parents who appear physically healthy lose their core personality (Rimmer et al 2005).

Pinquart and Sorensen (2004) propose from a meta-analysis of 60 articles on caregiver well-being that witnessing the decline, suffering and death of a relative from dementia is among the most traumatic aspects of care giving (Baker 1997; McConaghy and Caltaibano 2005).

Caregiving is also called the ‘unexpected career’ as what often begins as part-time assistance can become an all-encompassing role (Vitaliano et al 2003). Families commonly continue caregiving duties even after nursing home placement, averaging nine hours per week of continued caregiving.

Krach and Brooks (1995) conducted a descriptive survey to identify responsibilities and needs of working caregivers of older people. A 30-item questionnaire was completed by 760 caregivers employed at Purdue University, a large Midwestern university in Indiana, US, with a mean age of 52 and of whom 66 per cent were female.

This study found that subjects experienced a variety of health problems:
- 32 per cent had headaches
- 29 per cent had nervousness
- 29 per cent had insomnia
- 26 per cent had weight loss or gain
- 22 per cent had unusual drowsiness.

A major limitation of the study, as identified by the researchers, is that most subjects were white and lived in rural towns.

Gallant and Connell (2003) conducted a similar study and found that caregiving is associated with inadequate exercise, loss of sleep and weight gain or loss. This is supported by Sansoni et al (2004) who found that 56 per cent of caregivers experienced loss of energy, weight fluctuations and insomnia. However, the sample size was very small so caution must be exercised in generalising the findings (Polit and Beck 2001).

Suinn (2001) adds that caregivers often experience anger and anxiety that leads to unhealthy behaviours such as increased alcohol consumption, unhealthy diet, use of tobacco and disturbed sleep. Sansoni et al (2004) support this and state that carers who experience anger have a poorer self-rated health.

Gitlin et al (2003) propose that caregiving can affect caregivers’ immunity (Mills et al 1999). This is also identified as a factor in the study conducted by Cacioppo et al (1998), who investigated whether the stress of caregiving alters cellular immune responses to acute psychological stressors. Twenty seven women caring for spouses with a progressive dementia (high chronic stress) and 37 controls matched for age and income performed a 12-minute laboratory stressor. Cellular immune function was assessed by both functional and quantitative measures taken before (low acute stress), immediately after (high acute stress), and 30 minutes after exposure to laboratory stressors (recovery from stress). Results indicated that the chronic stress of caregiving is associated with a diminished leukocyte proliferation in response to the mitogen, concanavalin A, and caregivers were also characterised as having a lower percentage of natural killer cell cytotoxicity (caregivers = 54.88 per cent, controls = 64.51 per cent). These findings are consistent with earlier research showing that long-term caregiving for a spouse with Alzheimer’s disease is associated with a decrease in immunity (Mills et al 1999; Vedra 2000). Vitaliano et al (2002) state that there is extensive empirical support for the hypothesis that chronic stress is associated with cardiovascular disease (Mills et al 1999; Grant 1999; Grant et al 2002).

Uchino et al (1994) conducted a longitudinal study to examine the relationships between family caregivers’ construal of their pre-illness affectation and cohesiveness with the person with Alzheimer’s disease and subsequent cardiovascular functioning. In a study conducted two years later, 31 family caregivers of a patient with Alzheimer’s disease performed stress-inducing tasks while cardiovascular activity was monitored. Analyses...
revealed that caregivers relatively high in pre-illness affection for the person with Alzheimer’s were characterised by lower heart rate reactivity and resting diastolic blood pressure. In contrast, caregivers relatively high in pre-illness cohesion were characterised by higher resting systolic and diastolic blood pressure. The results suggest that a caregiver’s construal of his or her relationship with the person before the onset of Alzheimer’s disease predicts, if not contributes to, subsequent cardiovascular response.

Results from Vitaliano et al (2002) revealed that baseline coronary heart disease (CHD) prevalence in caregiver men was 20 per cent compared with 10 per cent in non-caregivers, and 27 to 30 months later this was 50 per cent in caregiver men and 25 per cent in non-caregiver men. Overall, the prevalence of CHD increased by 19 per cent in caregivers compared with 8 per cent in non-caregivers during the experimental period. One limitation of this study is that the sample size was reduced. Caution is required to avoid over-interpreting the data (Politi and Beck 2001).

Much of the research on Alzheimer’s disease and its physical and psychological effects on caregivers has used the method of self-report (Sansoni et al 2004). Hosaka and Sugiyama (2003) conducted a quantitative study using a self-report instrument and found that five out of 20 caregivers felt that they were completely healthy. This is supported by Perlick et al (2005) and Rinaldi et al (2005), who found that caregivers have poorer self-rated physical health. The inconsistencies in studies comparing caregivers and non-caregivers make it difficult to draw clear conclusions about the prevalence of poor physical health of caregivers. A reason for this is that there are sampling issues with caregiver research (Vitaliano et al 2003). Many studies on caregiving are based on non-representative samples that over-represent distressed caregivers (Pingenat and Sorensen 2003). Thus, caregivers might not experience significantly higher level of distress than the general population if they were sampled differently. Also many studies have large sampling errors due to small sample size (Schulz et al 2003).

Gender is an important moderator of caregiver health because female caregivers constitute the majority of those who provide care for older people and those with dementia (Ory et al 1999; Gallicchio et al 2002; Vitaliano et al 2003). Pezzini et al (2003) reported the oldest Alzheimer-disease caregiver ever, a 95-year-old woman who looked after her sister. She was neither burdened nor depressed and rated her health as excellent.

Chi-Jun (2005) conducted a cross-sectional study using structured questionnaires administered to 388 unpaid caregivers who were looking after a family member in the home. The Chinese Health Questionnaire and Self-Rated Health Scale were the instruments used to assess caregiver health. This study found that, compared to the male caregiver, the female caregiver more often reported lack of wellbeing, and a decrease in psychosocial health and overall self-rated health. Schulz and Beach (1999) conducted a similar study, which found that women reported greater health problems than did men, and Meller (2001) found that women were more stressed than men even though they had more social activities and telephone contacts (Fudge et al 1997). By contrast, men exposed to laboratory stressors show larger and more consistent increases in stress hormones, neurotransmitter metabolites, and blood pressure than do women (Rivera et al 1991, Bourgeois et al 1996). This may be further exacerbated when faced with a stressor such as caregiving, which is inconsistent with men’s traditional gender roles (Chi Jun 2005).

Dunkin and Anderson-Hanley (1998) maintain that these findings can be interpreted in many ways, including the possibility that they represent women’s greater comfort with expressing feelings, or that there are caregiving task differences between male and female caregivers, or the possibility that female caregivers have greater stress from multiple social roles than male caregivers. On the other hand, McConaghy and Caltabiano (2005) found in a cross-sectional research study that there were no differences in the perceived burdens of males and females. However, sample size was again small.

Goode et al (1998) maintain that caregivers who have a social network experience better self-rated health than those who do not (Gaugler et al 2003). Robinson and Steele (1995) conducted a qualitative study on 75 female spouses to identify social network and effect on caregiver burden. It was found that healthy caregivers were perceived to have significantly more people in their social networks. Gwyther and Strulowitz (1998) add that working outside the home is advantageous for caregivers. Perhaps through psychosocial logic mechanisms, including enhanced self-esteem, mastery or self-efficacy, or possibly because activities and employment outside the home inhibit social isolation, these participants benefit from their dual role.

Yet the removal of the person with Alzheimer’s does not appear to improve caregiver wellbeing. Grant et al (2002) conducted a longitudinal study of 119 caregivers to determine the extent to which...
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the chronic stress of Alzheimer’s disease caregiving may be alleviated by the placement or death of the person with Alzheimer’s. It was found that despite improvement in mood and other psychological symptoms among caregivers who place their spouses in care or experience their spouse’s death, there may be longer-term physiological alterations that cause the cardiovascular system to continue to respond to acute stressors, such as postural challenge, more actively for a period of up to 12 months after such transitions.

**Psychological effects**

The fact that caring for a person with dementia places the carer at greater risk of experiencing serious psychological disorders such as depression has been well documented (McConaghy and Calatubiano 2005). Sansoni et al (2004) conducted a descriptive study to assess anxiety and depression in female community-dwelling Italian Alzheimer disease caregivers. Findings indicate that 76 per cent experienced anxiety and 42 per cent experienced depression. This is supported by Alspaugh et al (1999). By contrast, Mahoney et al (2005) interviewed 153 Alzheimer’s disease caregivers as part of a larger representative study and found that 23.5 per cent experienced anxiety and only 10.5 per cent had depression. Anxiety and depression were assessed using the Hospital Anxiety and Depression Scale (Mykletun et al 2001), which, although it has good validity and reliability for detecting these states, is not a diagnostic tool based on gold standard criteria.

Yee and Schultz (2000) reviewed a range of literature on psychiatric morbidity and depression among caregivers with respect to gender differences. They found that the majority of studies reported female caregivers having higher levels of depression than male caregivers (Dura et al 1991, Fudge et al 1997, Chii Jun 2005). However, Hinrichsen and Niederhefe (1994) reported inconsistent findings in terms of depression by gender. They did not find significant differences in depression between male and female caregivers.

According to Gallicchio et al (2002), female caregivers in general spend more time with the care receiver than male caregivers. This may put them at greater risk of psychological morbidity. They also provide more caregiving assistance in general than male caregivers (Yee and Schultz 2000). In addition, male caregivers tend to obtain more assistance from their families and friends, while female caregivers tend to receive less assistance (Lutzky and Knight 1994).

Previous studies have suggested that caregiver distress is more closely associated with behavioral disturbances such as wandering, repetitive vocalisation and physical aggression than...
with other dementia symptoms (Gaugler et al 2000; Mohide 2001; Morgan 2002). However, longitudinal analyses of the association between behavioural disturbances and caregiver depressive symptoms have generally relied on a small number of widely spaced observations over a one to two-year period (Baumgarten et al 1994; Als-paugh et al 1999; Hooker et al 2002) and some studies measured behaviour only at baseline (Baumgarten et al 1994; Li et al 1999). As noted by Hooker et al (2002), this approach may not capture the sporadic occurrence of behavioural disturbances or fluctuations in distress associated with these behaviours.

Gaugler et al (2005) conducted a study to determine how behaviour problems that occur early in the caregiving career influence time to nursing home placement and change in burden and depression over time. Caregivers who manage frequent behaviour problems earlier are more likely to institutionalise and have greater increases in depression over time. Shau Haim and Ross (2001) conducted a similar study and found that carers of patients with scores less than or equal to 20 on the Mini Mental Status Examination were 5.2 times more likely to experience depression than those who cared for patients with normal cognitive functioning.

Similarly, Morgan (2002) found that depression in the carer was predicted by depressive symptoms in the patient, and these carer symptoms increased over time. However, Shau Haim and Ross (2001) noted that only 1 per cent of their sample reported clinical depression. This may indicate an attempt to under-report the severity of depression symptoms so as to be able to continue as the primary caregiver.

Rinaldi et al (2005) suggest that a poor prior relationship is predictive of greater caregiver depression and burden. Yamashita and Amagai (2004) found in a qualitative study in Japan that good prior relationships were necessary for successful caregiving (Davies et al 1997). This is supported by Mahoney et al (2005) who concur that a poor prior relationship with the care recipient predicted depression in the caregiver. Individual variations in coping strategies help to explain differences in mental health outcomes (Davies et al 1997). A quantitative study of 315 caregivers to investigate different coping strategies and their effect on caregivers’ mental health found that emotion-focused coping – which Lutzky and Knight (1994) define as avoiding confrontation and accepting personal blame – was the coping strategy of choice. However, Zautra and Wrabetz (1991) found that active coping efforts, including seeking support, taking action and emotional expression, were related to less distress in caregivers.

Larkin (2004) suggests that psychological...
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Outcomes resulting from long-term caregiving remain present even when the care recipient dies (Larkin 2004).

Kiecolt-Glaser et al (2001) studied 49 former caregivers of a spouse with dementia and 49 current caregivers and 52 matched controls who were non-caregivers. It was found that even several years after a spouse’s death, former caregivers did not improve in several measures of psychological well-being. Forty one per cent of former caregivers had mild to severe depression two to three years after the spouse’s death, which was not significantly different from the 43 per cent depression rate among current caregivers. By contrast, the depression rate was 15 per cent among controls. Robinson-Whe lan et al (2001) found similar results. Larkin (2004) asserts that caregivers who care for their relatives until they die view caring as their mission, so when the person dies, they lose their goal in life.

Conclusion
This article summarised the literature on the physical and psychological effects of caring for someone with Alzheimer’s disease in the home. The following article describes the methodology, findings, recommendations and implications for practice and of a quantitative study conducted in the west of Ireland on informal caregivers.