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Review Article

Caregiver Burden and Psychoeducational Interventions in Alzheimer's Disease: A Review

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Key Words

Alzheimer's disease · Caregiver burden · Caregivers · Carer stress · Care for the aged

Abstract

Background: Caring for a patient with Alzheimer's disease (AD) is associated with poor quality of life and deteriorating health for the caregiver. **Methods:** This comprehensive review was performed to investigate the current literature on caregiver burden, factors affecting caregiver burden and the effectiveness of different types of intervention. **Results:** Successful psychoeducational interventions for caregivers have included provision of information about AD, care planning, advice about patient management and the importance of self-care, skills training to aid patient management, stress management training, and problem-solving and decision-making guidance. **Conclusion:** Interventions that are individually tailored to the caregiver are particularly effective at reducing caregiver burden and should be further investigated. The use of effective pharmacological treatment for the improvement and/or stabilisation of AD symptoms in the patient is also likely to improve caregiver burden.

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Introduction

This review concerns the burden placed on caregivers of patients with dementia, particularly Alzheimer's disease (AD). AD is a chronic neurodegenerative disease that is characterised by impaired cognitive function, leading to deficits in a number of domains, including memory, language, judgement, decision-making, orientation and learning [1, 2]. AD, the most common cause of dementia, accounts for approximately two-thirds of all cases in old-

er adults and leads to significant changes in a person's daily life and activities [1]. The global prevalence of AD is currently estimated to be as high as 24 million and is predicted to more than double every 20 years through to 2040 [3].

AD is one of the most significant health, social and economic challenges of the 21st century. In the UK, 820,000 people have dementia, and two-thirds of them are cared for informally at home by a friend or relative [4]. Indeed, the contribution of informal caregivers in AD is considerable. In the United States, in 2010, nearly 15 million family members and other unpaid caregivers provided an estimated 17 billion hours of care to people with AD and other dementias, a contribution valued at more than USD 202 billion [5]. Caregivers are a crucial part of the overall care of patients with AD, and their contribution should not be underestimated.

Definitions of caregiver burden vary in the literature. The definition proposed by George et al. [6] is widely accepted and has been used for the purpose of this review: caregiver burden is 'a perceived complex and multidimensional construct, which includes the physical, psychological or emotional, social and financial consequences that can be experienced by family members caring for dementia patients' [6, 7]. Although there is evidence of positive aspects of informal caring [8–13], it is well documented that caring is associated with poor quality of life and deteriorating health for many caregivers, especially in cases where care is extremely demanding and long-term [8]. This nonsystematic review of the available literature aims to identify factors that contribute to caregiver burden and discusses interventions that may reduce the burden of caring for patients with AD.

Methods

Search Strategy

A search of the online Medline (<http://www.ncbi.nlm.nih.gov/pubmed>) and Google Scholar literature databases was performed in January 2012 using combinations and synonyms of the following terms: Alzheimer's disease, caregiving, caregiver burden, interventions and support. Articles were limited to those published in the English language. No publication date limits were applied. The search results were then assessed for relevance using the publication titles and abstracts. Further relevant references were selected from the bibliographies of the identified papers. Eight of the key studies identified by the search are described in more detail in table 1.

Results

Consequences of Caregiving

When examining caregiver burden, both the positive and negative effects of caregiving should be taken into account. Although there is evidence for some positive effects of caregiving, negative effects on the physical, social, emotional and financial status of the AD caregiver can be devastating [7, 14]. Moreover, it has been reported that some of these negative effects may persist for up to 12 months after caregiving ceases [15]. For these reasons, this review focuses predominantly on the negative effects of caregiving.

Negative Effects of Caregiving

Caregiving is associated with a range of psychological and physical symptoms [16–19] (fig. 1). Misunderstanding or lack of knowledge about the course of AD as well as beliefs about the moral duty of family members to provide care, possibly resulting in an unwilling-

Table 1. Studies investigating interventional support for caregivers of patients with AD

Reference	Interventions	Study design	Inclusion criteria	Results	Comments/conclusions
Brennan et al., 1995 [51]	Computer-based support as needed (n = 51) vs. control (n = 51)	Randomised controlled 12-month study	Caregiver: primary caregiver, access to telephone, able to read and write in English; Patient: not specified	Caregivers' decision-making confidence was improved; Caregivers' decision-making skill was unaffected; No changes in social isolation	Improvements observed in caregivers' decision-making confidence alone
Mahoney et al., 2003 [21]	Computer-mediated automated interactive voice response ^a (n = 49) vs. usual care (n = 51)	Randomised controlled study over a period of 18 months (12 months of treatment and 6 months of follow-up)	Caregiver: ≥18 years, minimum of 4 h care per day for 6 months for patient with impaired ADLs; Patient: MMSE score ≤23	Significant effect of intervention for caregivers with low mastery at baseline, with decreases in the levels of bother (p = 0.04), anxiety (p = 0.01) and depression (p = 0.007) vs. the control group	Caregivers who exhibited low mastery and high anxiety at baseline benefited the most; The authors concluded that, to optimise outcome effects, similar interventions should be individualised to the caregiver
Winter and Gitlin, 2006 [50]	Tele-support linking 5 caregivers per group for 1 h/week (n = 58) vs. usual care (n = 45)	Randomised controlled 6-month study	Caregivers: female, ≥50 years, providing care for ≥6 months, weekly access to telephone for 1 h; Patient: physicians diagnosis of AD or related dementia	Minimal benefits for tele-support vs. usual care: Aged 50–64 years: burden (p = 0.490), gain (p = 0.932), depression (p = 0.121); Aged ≥65 years: burden (p = 0.352), gain (p = 0.086), depression (p = 0.014)	The authors concluded that the benefits of tele-support were minimal and only observed in older female caregivers (aged ≥65 years)
Eisdorfer et al., 2003 [55]	SET (n = 75) vs. SET plus CTIS (n = 77) vs. minimal support (n = 73)	Randomised (stratified according to ethnicity) controlled 18-month study (12 months of treatment plus 6 months of follow-up)	Caregiver: cohabit and provide minimum of 4 h care per day for prior 6 months; Additional family member: provide emotional or instrumental support; Patient: MMSE score <24 with impaired ADLs	Reduction in depression in the SET plus CTIS group at 6 months, which differed according to ethnicity (Cuban American or White American) and relationship to patient	Information technology has a promising role in alleviating distress and depression among groups of AD caregivers; Interventions have differential impacts according to ethnic group and the caregiver-patient relationship
Mittelman et al., 2004 [47]	Multicomponent, individualised counselling and support (n = 203) vs. usual care (n = 203)	Randomised controlled study (results presented for 4-year analysis)	Caregiver: spouse of patient with AD, cohabiting, and with primary responsibility for care	Rates of behaviour problems increased over time and did not differ with intervention method; Caregivers in the control group appraised behaviour as increasingly distressing over the 4-year period; Caregivers in the treatment group rated behaviour as less and less distressing over the same period	The authors concluded that psychosocial intervention can provide caregivers with strategies to help them manage their reactions to behaviour problems more effectively
Martin-Carrasco et al., 2009 [45]	PIP plus standard care (n = 60) vs. standard care alone ^b (n = 55)	Multicentre prospective randomised 10-month study (4 months of treatment plus 6 months of follow-up)	Caregiver: minimum of 4 h per day for patient with impaired ADLs and baseline Zarit score >22; Patient: MMSE score 10–26 and receiving rivastigmine (≥6 mg/day) for prior 6 months	Zarit scale: mean score reduction in PIP group greater than in control group (p = 0.0083); SF-36: mean scores significantly higher in PIP than the control group in all the dimensions (p < 0.05) except for mental health	Supports the efficacy of PIP in reducing caregiver burden in AD; The reduction in burden seems to improve the quality of life in relation to health and rates of psychiatric morbidity; The positive effects of PIP continued to last for at least a further 6 months
Burns et al., 2003 [46]	Training in behaviour management (n = 85) vs. training in behaviour management plus training to cope with stress (n = 82)	Randomised (with stratification according to race and gender) 24-month study	Caregiver: >21 years, minimum of 4 h care per day for ≥6 months; Patient: MMSE score <24	Behaviour management plus coping skills improved general well-being (p = 0.004) and depression (p = 0.007) over time	The authors conclude that brief primary care interventions may be effective in reducing caregiver distress and burden in the long-term management of AD patients; Interventions that focus only on care recipient behaviour, without addressing caregiving issues, may not be as adequate for reducing caregiver distress as combined approaches

Table 1 (continued)

Reference	Interventions	Study design	Inclusion criteria	Results	Comments/conclusions
Mittelman et al., 2008 [49]	Individual and family counselling with ad hoc telephone counselling plus donepezil treatment for patient (n = 79) vs. donepezil alone (n = 79)	Randomised controlled 24-month study (formalised counselling for 3 months followed by ad hoc counselling and follow-up for 21 months)	Caregiver: spouse of patient with AD, cohabiting and self-defined primary caregiver; Patient: probable AD, GDS score 4–5	Caregiver depression was significantly reduced at 3 months in those who received counselling compared with those who did not; The reduction in depression persisted for the entire 24 months of the study; Depression scores for caregivers who did not receive counselling increased over the study period	Effective counselling and support interventions can reduce symptoms of depression in caregivers; The authors recommend combining ChEIs and supportive counselling for patients with AD and their caregivers

ADLs = Activities of daily living; CTIS = computer/telephone-integrated system (information system and tele-support); GDS = Global Deterioration Scale; MMSE = Mini-Mental State Examination; PIP = psychoeducational interventional program; SET = structural ecosystems therapy (family therapy intervention).

^a Comprised caregiver stress monitoring and counselling information, personal voice mail linkage to AD experts, a voice mail telephone support group and a distraction call for care recipients.

^b Standard care comprised individual 90-min sessions, at 1- to 2-week intervals over 4 months, providing general information about how AD progresses, individualised information about the patient, both in person and over the telephone 'on demand', information leaflets about AD and information about resources directed at caregivers available in their community.

ness or inability to ask for help and withdrawal from wider society to care for a relative, can drive caregivers into a downward spiral of isolation, loneliness and depression [20–22].

Among caregivers of the general older population, including people likely to have a diagnosis of AD, Aggar et al. [23] identified disrupted daily routine, health problems, financial strain and a lack of family support as important causes of depression and anxiety. Furthermore, there is an association between depression in caregivers and reduced physical well-being, such as disrupted sleep patterns, increased incidence of cardiovascular and metabolic diseases, lowered immunity and early transition to frailty syndrome [17]. Some studies have reported that AD caregivers are at risk of depression [24, 25], with prevalence rates of self-reported depression among community-dwelling caregivers reported to be as high as 83% [25]. In a recent study, the caregivers' poor perceived health was associated with emotional exhaustion, depression, anxiety and increased levels of burden [26].

Positive Effects of Caregiving

Although most research has focused on the negative aspects of informal caregiving, there is also evidence of caregiver gain in AD. Positive caregiving outcomes reported include companionship, reward and enjoyment [8–13]. Among AD caregivers, personal factors associated with a positive caregiving experience include a good previous relationship with the patient, older age, good health, maintenance of leisure time, less venting of emotions, being the caregiver through their own choice and satisfaction with social support [8–13, 27].

Factors Contributing to Caregiver Burden

The level of burden experienced by the caregiver of a patient with AD depends upon both caregiver and patient factors [28] (fig. 2). It should be noted that the extent to which some of these factors are a consequence, or a cause, of caregiver burden is not always clear. For example, caregiver depression may increase caregiver burden, or may be a result of it.

Caregiver Attributes Affecting Caregiver Burden

Demographic and psychosocial attributes of the caregiver that predict greater burden include older age, lower socioeconomic status, family relationship, type of coping strategy and poor access to/low acceptance of social support [17]. The effect of gender is interesting, with a number of studies indicating that male caregivers are more susceptible to physical ill-

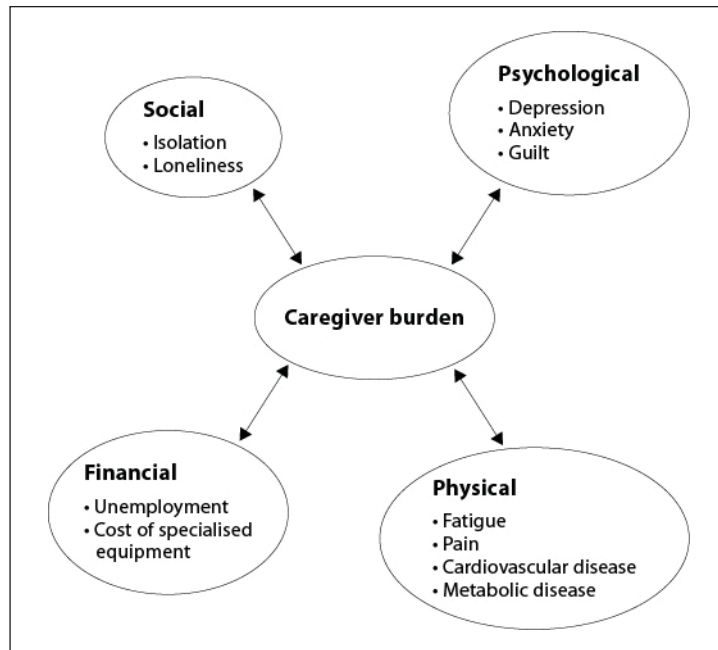


Fig. 1. The negative effects of caregiving in AD.

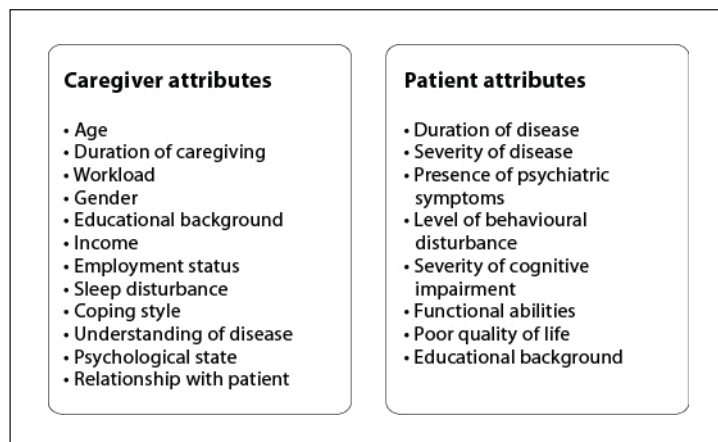


Fig. 2. Patient and caregiver attributes related to caregiver burden in AD.

nesses (such as cardiovascular disease) as a result of caregiving. Female caregivers have been found to be at higher risk of psychological symptoms (such as loneliness and depression) when compared with male caregivers [22, 28, 29].

The type of coping strategy is an important predictor of caregiver burden [30]. For example, caregivers who use wishful thinking and stoicism as coping strategies report a greater level of burden than those who confront problems and seek information and social support for dealing with them. A systematic review of 35 studies suggested that the most successful approach to deal with caring for a patient with AD combines emotion-based coping (accepting what cannot be changed) with problem-focused coping (considering the advantages and disadvantages and finding alternative solutions), covering the full range of coping strategies [30]. Furthermore, AD caregivers who believe they have more control over their caring role and those who accept challenges in life are less likely to suffer from depression than their counterparts [31].

Interestingly, adult children of patients with AD appear to be less adversely affected by caring for a parent than spousal caregivers [6]. Thus, within caregiving families, one's relationship to the care recipient is an important consideration [21].

Patient Attributes Affecting Caregiver Burden

Among the attributes of the patient, the most significant predictors of caregiver burden are reported to be the level of the patient's behavioural disturbance and cognitive function [16, 17, 19, 28, 32]. For example, disruptive behaviours, such as wandering and verbal assault, common in middle-stage AD, are frequently reported by caregivers as the primary cause of their burdensome feelings [21, 33, 34]. In a study involving 421 ambulatory AD patients with agitation or psychosis, increased severity of a patient's psychiatric and behavioural symptoms had a greater impact on caregiver burden than the patient's sociodemographic characteristics, functional abilities or intensity of care needed [19]. In addition to these specific AD-related symptoms and behaviours, caregiver burden in AD is also strongly associated with the duration of dementia, the educational level of the patient and the presence of depression in the patient [17, 19, 35].

As AD progresses, caregivers face increasing problems with administering medications [36], and, unsurprisingly, increased caregiver burden is associated with patient resistance to treatment [37, 38]. Interestingly, a number of studies have reported that caregivers are more satisfied when treatment administration is easier – for example, if the dosing schedule is simpler or the treatment takes less time and effort to administer. Indeed, evidence suggests that transdermal drug delivery is preferred over oral delivery, with the potential for increased adherence with this mode of administration [39–42].

Interventions to Support Caregivers of Patients with AD

As the burden of caregiving in AD can lead to both physical and psychological illnesses in caregivers, it is essential to ensure that caregiver well-being is maintained as the patient's disease progresses [18, 43]. Numerous studies have investigated interventions designed to support caregivers of patients with AD. Both face-to-face and telehealth interventions are discussed below. These are summarised in more detail in table 1.

Face-to-Face Interventions

Selwood et al.'s [44] systematic review of short- and long-term psychological interventions for caregivers suggested that teaching caregivers coping strategies is an effective method for relieving caregiver burden and that one-to-one teaching is more effective than group sessions. The authors found no evidence for the efficacy of interventions solely containing an educational component, group behavioural therapy or supportive therapy [44].

Face-to-face interventions that have been most successful are based on psychosocial training together with educational sessions. These interventions cover a number of different areas, including information about the disease, the organisation of care, practical advice for coping with AD, skills training for handling the behavioural problems of the patient, teaching decision-making skills, advice about the emotional repercussions of being a caregiver and advice about self-care [45–48].

Psychosocial interventions (including ad hoc tele-support) for caregivers in combination with cholinesterase inhibitor therapy for the patient have also proved successful for reducing caregiver depression [49]. Combined drug and psychosocial approaches in the management of patients with AD may be more effective in reducing caregiver burden, though further studies are warranted [49].

Telephone-Based Support Programmes

Telephone- or computer-based support programmes could be practical low-cost interventions for reducing caregiver burden in some situations. For example, in a study investigating an automated telephone support system for caregiving spouses of patients with disruptive behaviour, tele-support showed significant benefits when compared with a usual care control group [21]. Furthermore, spouses with low mastery and high anxiety scores at baseline derived the greatest benefit from this approach. In a separate study, groups of up to five caregivers were invited to take part in interlinked tele-support sessions facilitated by a social worker. Over the 6-month study period, the average session uptake was 14.6 out of 26 possible sessions, and caregivers aged ≥ 65 years reported fewer symptoms of depression than those in a control group. However, younger caregivers did not benefit from this approach [50].

Computer-Based Support Systems

Brennan et al. [51] investigated the effects of computer systems to provide information, decision-making support and communication to AD caregivers. Although they reported increased confidence in decision-making (a primary outcome) in the caregivers, there were no significant improvements in decision-making skills or social isolation. However, the researchers found that there was a wide variation in access to, and actual use of, the computerised intervention, which may have affected the overall results. Further investigations in this area may be of value, considering recent developments in computer technology.

Discussion

This review represents a comprehensive summary of the most recent literature on the burden of caring for AD patients, the factors that affect the level of burden and the types of intervention that have been shown to reduce burden. Caregiving is associated with a range of negative psychological and physical symptoms as well as financial strains and social isolation. In combination, these symptoms can lead to a high level of burden for the caregiver. Factors that can influence the level of burden for an individual can be categorised into caregiver attributes, such as age, socioeconomic status and coping strategy, and patient attributes, such as the level of behavioural disturbance and cognitive function. The literature suggests that interventions that are individually tailored to a caregiver are particularly effective at reducing this caregiver's burden and should be further investigated [17, 44, 52]. It is paramount that health-care professionals are instrumental in providing help for caregivers of patients with AD and should aim to provide the means for caregiver education about dementia, psychological support and assistance in mobilising social support networks [53].

This evidence from studies investigating interventions for caregivers of AD patients, along with information from studies where a positive effect of caregiving has been documented, should be applied to future strategies aiming to decrease the burden of caregivers of individuals with AD (table 2). As such, there is a need for individualised educational and support programmes to teach caregivers positive coping techniques, together with ways to aid management of their care recipients with AD. Furthermore, the use of effective pharmacological treatment for the improvement and/or stabilisation of AD symptoms in the patient is also likely to improve caregiver burden.

The findings of this review have some limitations that should be noted. Data on certain types of interventions, such as computer-based support, are limited and could be considered out-of-date in view of recent advances in computer technology. Furthermore, comparisons between studies can be difficult due to the variety of tools used for assessment and differences in study design. Systematic reviews have shown that few studies investigating care-

Table 2. Recommendations for interventional support for caregivers of patients with AD

Caregiver education	Interaction with patient
Coping techniques	Participation in enjoyable activities
Managing patient's behaviour	Medication
Support from health-care workers	Easy route of administration
Frequent interaction with caregiver	
Availability for ad hoc sessions	

giver interventions in AD meet rigorous quality standards [44, 52, 54]. Thus, cross-study comparisons of caregiver burden in AD can be difficult given the number of assessments used. Frequently, measurement scales provide a total score and do not distinguish between different dimensions such as the condition of the patient, care requirements or the strain experienced by the caregiver or family [7]. Burden is a multidimensional construct, and a global score is unlikely to provide a complete and accurate assessment.

Conclusions

Caregiving in AD is associated with poor quality of life and deteriorating health for both the caregiver and the care recipient. Both caregiver and patient attributes contribute to the level of caregiver burden. Many studies have demonstrated benefits for strategies designed to relieve caregiver burden in AD; however, a lack of standardisation in study design, assessment of different outcomes and the use of a variety of different measurement tools make it difficult to judge which are the most effective. The available evidence suggests that caregiver support should enhance the positive aspects of their role as well as addressing problems arising from caregiving. Consequently, interventions should be tailored to the individual situation and aim to maintain mental well-being, encourage participation in educational and support programmes, and teach appropriate coping and dementia-specific management strategies. Strategies combining drug therapy for the patient and psychosocial approaches for the caregiver may be effective in reducing caregiver burden and should be investigated further. Additionally, the reporting of caregiver burden as a variable in clinical study designs for AD medications would focus attention on this current concern and enable the collection of data that can further characterise the humanistic and economic burden of disease. In turn, these data may be useful in the assessment of the relative effectiveness of interventions.

Acknowledgment

Editorial assistance for this paper was provided by Fishawack Communications; this was funded by Novartis Pharma AG.

Disclosure Statement

R. Brady is an employee of Atlantis Healthcare and D. Wade is a previous employee of Atlantis Healthcare. N. Beinart and J. Weinman act as consultants for Atlantis Healthcare. Atlantis Healthcare was commissioned by Novartis Pharma AG to develop a carer support program for patients prescribed the rivastigmine patch.

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