

ORIGINAL ARTICLE

# Impact of Alzheimer's disease on family caregiver psychosocial health. Prague's experience

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## Abstract

**BACKGROUND:** The objective of the study was to assess the degree of burden and its possible change in family caregivers of the long-term sick family member with progressive Alzheimer's disease (AD) during eight-month monitoring.

**METHODS:** In addition to the common psychiatric examination the Mini-Mental State Examination (MMSE) was administered in patients to indicate the severity of the dementia and the Zarit Burden Interview (ZBI) was administered in caregivers to assessed degree of burden. The total of 60 people has been examined – 30 patients with AD and 30 their caregivers (CGs) were recruited from the Department of Psychiatry.

**RESULTS:** At the beginning of the study there were 18 patients with mild stage of AD (60%) and 11 patients suffered from moderate or severe stage of AD (36%). After 8 months from the beginning of the study there were 19 patients with moderate or severe stage of AD(63%) and two patients suffered from severe stage of AD (6,6%). The change in the degree of caregiver burden was examined during the whole study. During the study twenty two caregivers (75 %) asked for the professional psychiatric help.

**CONCLUSIONS:** Intervention and support must therefore be carefully targeted, recognising those components of a potential care package that will be useful in the particular circumstances. It is also important to promote measures to soften the impact that the patient has on the caregiver, and that, at the same time, improves the quality of life of the patient.

## INTRODUCTION

Alzheimer's disease is a progressive, irreversible neurodegenerative illness and the most common of the dementing disorders. Only few diseases disrupt patients and their relatives so completely or for so long a period of time as Alzheimer's. (Butcher *et al* 2001).The gradual and continuous decline caused by Alzheimer's disease is characterized by cognitive deterioration, changes in behaviour, loss of functional independence, and increasing requirements for care.

Individuals with moderate to severe dementia often require special care, including supervision (sometimes 24 hours a day), specialized communication techniques and management of difficult behaviour. They may need help with activities of daily living, such as bathing, eating, transferring from bed to a chair or wheelchair, toileting and/or other personal care. People with cognitive impairment may experience a range of behavioural problems that can be frustrating for caregivers. These might include communication difficulties, aggressive or impulsive behaviours, perse-

veration (fixation on/repetition of an idea or activity), memory problems, lack of motivation, paranoia, poor judgment, incontinence and wandering. Some people may develop behavioural problems early on, while others go through their entire illness with only minor issues. Most cognitively-impaired persons fall somewhere in the middle, having bad days and good days (or even bad or good moments). It's important to remember that it's the disease, not the person, causing the behaviour. Each care giving family faces unique circumstances. Caregivers often learn, through trial and error, the best ways to help an impaired relative maintain routines for hygiene, eating and other activities at home. Very important for caregivers is to get good and enough information about the disease. Caregiving is stressful, particularly for those caring for someone with dementia. It is necessary for caregivers to take care of themselves. (Parks & Novielli 2000). Caregivers are more likely than their noncaregiving peers to be at risk for depression, heart disease, high blood pressure and other chronic illnesses, even death. Caregivers of persons with dementia are at even higher risk for poor health. (Schulz *et al* 2006). Caring is held to be very demanding and emotionally involving. Caregivers have been described as "hidden patients." Caregivers should be assessed for their level of perceived burden and for the presence of affective disorders such as depression and anxiety. (Alzheimer's Association 2012). Caregiver burden has been defined as a multidimensional response to emotional, social, physical, psychological, and financial stressors associated with the caregiving experience. (Kasuya *et al* 2000). Family support, specifically frequent visits by other family members and the presence of a strong social network correspond with lower levels of caregiver burden. (Parks & Novielli 2000).

## SUBJECTS AND METHODS

Participants were recruited from the Department of Psychiatry, 1st Faculty of Medicine, Charles University, Prague, Czech Republic between 2010 and 2011. The total of 60 people has been examined. The change in the degree of caregiver burden was examined after 4 and 8 months after the baseline of the study. In addition to the common psychiatric examination the Mini-Mental State Examination (MMSE) was administered in patients to indicate the severity of the dementia. We have involved into this project 30 outpatients with AD and 30 their informal caregivers (24 females, 6 males). All AD patients met NINCDS-ADRDA criteria for probable AD and intellectual impairment was documented with neuropsychological testing. (Dubois *et al* 2007). The mean age of demented people was  $70.3 \pm 6.3$  (SD) years. All 30 family members were in a role of an informal caregiver for more than 12 months. 18 of them were wives and 4 were husbands of patients. One caregiver was a daughter-in-law and 7 caregivers were children of patients (2 sons and 5 daughters). At the

beginning of the study there were 18 patients with mild stage of AD (60%), 11 patients suffered from moderate or severe stage of AD (36%) and 1 patient's MMSE was below 6 points. The Zarit Burden Interview (ZBI) was administered in caregivers to assess degree of burden. ZBI is originally a 29-item scale; the 22 item version is more commonly used. The Zarit Burden Interview was developed to measure subjective burden among caregivers of adults with dementia. Items were generated based on clinical experience with caregivers and prior studies resulting in a 22-item self-report inventory that examines burden associated with functional/behavioural impairments and the home care situation. The items are worded subjectively, focusing on the affective response of the caregiver. Each question is scored on a 5 point Likert scale ranging from – never to nearly always present. Total scores range from 0 (low burden) to 88 (high burden). Score values and interpretation are guidelines only. (Bedard *et al* 2001). The change in the degree of caregiver burden was examined after 4 and 8 months after the baseline of the study. In addition to the common psychiatric examination the Mini-Mental State Examination (MMSE) was administered in patients to indicate the severity of the dementia.

## RESULTS

We have examined 60 people: 30 outpatients with AD and 30 their informal caregivers (24 females, 6 males).

### Severity of dementia

At the beginning of the study there were 18 outpatients with mild stage of AD (60%), 11 outpatients suffered from moderate or severe stage of AD (36%) and 1 outpatient's MMSE was below 6 points. After 4 months from the baseline there were 15 outpatients (50%) with mild stage of dementia, 14 outpatients (46,6,3%), with moderate or severe stage of AD, and 1 outpatient's MMSE was below 6 points. After 8 months from the beginning of the study there were 9 outpatients with mild stage of AD (30%), 19 outpatients with moderate or severe stage of AD (63%) and two outpatients suffered from severe stage of AD (6,6%).

### Caregiver burden

The change in the degree of caregiver burden was examined during the whole study; at the baseline there were 8 caregivers with mild degree of burden, 22 caretakers with moderate, high or extremely high degree of burden from the total number of 30 responders (13, 8, and 1 caregivers), after next 4 months 24 caregivers exhibited moderate, high or extremely high degree of burden (17, 5 and 2 CGs). At the end of monitoring there were 27 caregivers who have scored these degrees of burden (13, 12 and 2 CGs) and 5 outpatients with AD were due to the caregiver burden institutionalised. During the study twenty two caregivers (75 %) asked for the professional psychiatric help.

## DISCUSSION

The main objective of the study was to assess the degree of burden and its possible change in family caregivers of the long-term sick family member with progressive Alzheimer's disease during eight-month monitoring. It is important to remember that the majority of participants had never been offered any education services and had, on average, spent over a decade dealing with their relative's illness with little information on the etiology of mental illness or coping strategies. Results may be related to participants' unassessed motivation for enrolling in the study. Individuals may have decided to participate in the project in order to receive specific information related to their relative's illness. The results found in the present study are similar in many aspects with those found in several other studies on the subject. The 24 caregivers of patients were women (80%), a similar ratio to that observed by several earlier studies showing rates of between 63.4% and 87.0% of female caregivers. In the majority of studies reviewed wives were more frequent than husbands. (Moscoso *et al* 2007) The literature reviewed suggested that caregiver burden was associated with many factors, including characteristics of the patient (severity and duration of dementia, difficulties with daily activities and behavioural problems), variables of the caregiver (age, tasks assigned to the caregiver, ability to solve problems, ability to perceive illness) and variables related to the environment (quality of relationship in the past, social support, financial resources). The burden seems to be a product of the dynamic interaction between objective external stressors and subjective perceptions by the caregivers concerning the patients with dementia. (Moscoso *et al* 2007). Our data support the assumption that the daily care of a family member suffering Alzheimer's dementia are negatively reflected on the overall health of family caregivers. With the decline in MMSE growing burden of caregivers. The higher is the psychological stress of family caregiving, the more adversely it is felt this role by and considerations of institutionalizing the demented individuals are more intensive.

## CONCLUSION

The burden associated with Alzheimer's disease is tremendous. Alzheimer's presents not only an escalating financial drain on the patient's family and estate but also a public health concern. Care of the individual with mild or moderate dementia is provided largely by loved ones and in part by formal sources like medical professionals and adult day care. The patient's functional deficiencies in day-to-day life-loss of skills like meal preparation, failure to remember medications, inability to recognize familiar people and objects-place a practical strain upon friends and family, while witnessing the patient's deterioration is likewise stressful and saddening. Approximately 50% of primary caregiv-

ers develop significant emotional distress, which can in turn lead to the necessity of psychiatric treatment. Treatment of Alzheimer's disease requires an alliance with both the patient and the patient's family. Once a person has received a diagnosis and completed a needs assessment, it will be easier for a family caregiver, possibly with help from a professional, to formulate a care plan – a strategy to provide the best care for a patient and him- or herself. It is important to set a time frame for any action or activities planned. Also, it is wise to have a back-up plan should something happen to a caregiver, both for the short-term and the long-term. Recognizing families' caregiving roles and knowledge needs, numerous treatment guidelines recommend that families receive psychosocial interventions that educate them about the causes and treatment of mental illness, coping strategies, and community resources (Lehman *et al* 2004). Because a lack of understanding about the family member's disease process may worsen caregiver stress, the caregiver's knowledge about the dementing illness and available resources should be explored and additional information provided when needed. Active coping strategies, such as constructing a larger sense of the illness, are associated with a lower incidence of depression among caregivers. (Parks & Novielli 2000). Numerous and varied family stresses develop around providing care to the family member. The primary caregiver can have difficulty accepting other family members' support while at the same time resenting a perceived lack of support. Efforts of identify and reduce caregiver burden are an important healthcare issue (Fam. Caregiver alliance 2006). While Alzheimer's disease is devastating for those who acquire it, AD can be equally devastating for the caregiver, whether that person is a professional or a family member. The severity of the disease plays an important role in reorganization of the family environment in families caring for patients not institutionalised. It is important to promote measures to soften the impact that the patient has on the caregiver, and that, at the same time, improves the quality of life of the patient. Intensive psychosocial interventions reduce depressive symptoms of caregivers of patients with dementia. The complexity of the treatment, the constant commitment of the person taking care of the AD patient, as well as the inadequacy of the public service; the consequent effects upon the emotional and interpersonal relations; the direct and indirect costs of care also play a major role in influencing the social, psychological and physical wellbeing of the caregiver and of his/her family. Developing good coping skills and a strong support network of society, family and friends are important ways that caregivers can help themselves handle the stresses of caring for a loved one with Alzheimer's disease. (Zvěřová 2012).

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