Prevalence and Predictors of Burden in Caregivers of People with Dementia

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Objective: *To examine prevalence and predictors of burden in caregivers of people with dementia attending memory clinics.* **Methods:** *This Prospective cohort study conducted at nine memory clinics in Australia rated 732 outpatient attendees and their primary caregivers at baseline and at 3, 6, 12, 24, and 36 months. Ratings were based on the following: dementia diagnosis according to the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Mini-Mental State Exam, Alzheimer's Disease Assessment Scale—Cognitive, Functional Autonomy Measurement System, Neuropsychiatric Inventory, use of psychotropic and antidepressant medications, patient and caregiver resource use, and the Zarit Caregiver Burden Interview (ZBI).* **Results:** *Half the caregivers had significantly high levels of burden, rising to 57.7% at 12 months; with moderate to severe burden rates, rising from 14.7% at baseline to 22.8% at 12 months; and mean ZBI levels rising from 22.9 at baseline to 25.5 at 6 months and 27.7 at 12 months. Caregiver predictors of 6- and 12-month burden were their neuroticism and baseline ZBI score. Patient predictors were their level of behavioral symptoms, use of antipsychotics and antidepressants, and more rapid functional decline. Other predictors (female caregiver, level of cognition and function, diagnosis of frontotemporal dementia) were not significant in regression analyses.* **Conclusion:** *Caregivers of people with dementia have high and persistent rates of burden. Identification of caregivers likely to have high levels of burden at 12 months may allow more accurate targeting of interventions.* (Am J Geriatr Psychiatry 2013; ■:■−■)

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INTRODUCTION

Dementia represents a significant challenge in terms of healthcare resources and also places a high burden on caregivers.[1] In Australia, it has been predicted that as the population ages, the number of people with dementia will grow from over 300,000 in 2013 to almost a million in 2050.[2] People who care for patients with dementia, usually spouses or family members,[3] have high levels of burden.[1,4–7]

Burden is a multidimensional construct[8] comprising objective burden, which is the practical care of the person with dementia such as supervision and helping with daily tasks, and subjective burden, which may be divided further into personal strain and role strain.[1,9] The most widely used scale to measure burden is the 22-item Zarit Burden Scale, which has high internal consistency and good test–retest reliability.[10–12]

High caregiver burden is associated with depression in caregivers, earlier nursing home placement, and poorer outcomes for the patient.[6,13–17] Interventions for caregivers that can reduce their levels of depression and psychological morbidity[18,19] and delay the time to institutionalization are possible,[18,20,21] usually desirable to both the patient and caregiver, and economically beneficial.[22]

Resources allocated for supporting caregivers are limited, and identifying those who could potentially benefit the most would allow for efficient allocation of services and assist clinicians in arranging services and making appropriate referrals. We examined rates and levels of caregiver burden and risk factors associated with higher caregiver burden in a population of patients and caregivers attending memory clinics in Australia and developed a model to identify those most at risk of greater caregiver burden.

METHODS

PRIME (Prospective Research In MEmory Clinics, NCT002972971) was a nonprescriptive longitudinal convenience cohort study. The primary purpose of PRIME was to provide a cohort of patients that could be examined to quantify complex relationships between a number of interrelated predictor and outcome variables. As such, no a priori sample size was calculated. A description of Australian memory clinics has been previously published.[23] Ethics approval was obtained from institutional ethics committees associated with individual referring centers.

Participants

Patients were recruited from one of nine participating memory and dementia clinics across Australia from August 2005 to July 2011. Patients who were undergoing specialist assessment or continued treatment were identified by clinicians at each clinic. Patients were eligible for inclusion if they had been diagnosed with dementia using the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition*[24] criteria or mild cognitive impairment by the Petersen criteria,[25,26] were living in the community with less than 40 hours/week nursing care, had a caregiver willing to provide consent for required components of the study, were fluent in English, and could provide informed consent themselves or through a legal guardian/proxy. Patients were excluded if they had any concomitant life-threatening illness considered likely to interfere with the patient's ability to complete the study, were concurrently participating in a clinical trial of an investigational drug (phase I, II, or III), or were diagnosed with mild cognitive impairment *and* prescribed a cholinesterase inhibitor or memantine (due to prescribing regulations).

In this study, we focused on 732 patients with dementia. Patients were diagnosed as Alzheimer disease (AD), vascular dementia, mixed (AD and vascular dementia), or frontotemporal dementia (FTD).

Measures

All patient and caregiver data were collected at the participating clinics. Prospectively collected data included baseline demographics and baseline, 6-month, and 12-month follow-up results for the following instruments: Clinical Dementia Rating Scale (CDR) scored from 0 to 3, with higher scores indicating greater severity;[27] Mini-Mental State Exam (MMSE) scored between 0 and 30, with lower scores indicating greater cognitive impairment;[28] Alzheimer's Disease Assessment Scale–Cognitive (particularly for those with MMSE scores $\geq$ 25) measuring cognitive impairment, with total scores ranging from 0 to 70 (higher scores indicate greater cognitive impairment);[29] Functional Autonomy Measurement System (SMAF), a 29-item scale