

# The Burden of Caregiving: Assessing the Status of Current Clinical Research

Hamer N, Costello S, Hamerslag L, Haynes S, Roper S - Costello Medical Consulting Ltd, Cambridge, UK - [www.costellomedical.com](http://www.costellomedical.com)

## Introduction

The burden of caregiving is high. In 2009 there were an estimated 65.7 million caregivers in the U.S. (29% of the adult population) and these numbers are expected to swell in the coming years with the ageing population.<sup>1</sup> Caregiving impacts on the health, wellbeing and work productivity of the caregiver, therefore research aimed at recognising and reducing the burden of caregiving is warranted. The objective of this study was to assess the status of current clinical research into the burden of caregiving.

## Methods

In April 2011, the following key search terms were used to capture all relevant studies relating to the burden of informal caregiving listed on ClinicalTrials.gov: Caregiver burden, Carer burden, Care burden, Burden of care, Caregiver productivity and Informal caregiver. The search results were sifted to identify studies in which at least one aspect of caregiver burden (CB) was measured. CB could be physical, emotional, psychological, social or financial.

143 studies were found to be relevant for inclusion in the analysis. Relevant information pertaining to the care-recipient condition (CRC), the study focus, the measures of CB used and type of intervention being considered, were extracted.

## Results

### Care-recipient condition

Studies measuring the burden of caring for individuals with Alzheimer's disease and related dementias (ADRD) made the largest CRC group; accounting for 41% of the studies (Figure 1). The next most common CRCs identified were cancer (15%) and mental and behavioural disorders (10%), with the latter including the conditions of depression, eating disorders, and schizophrenia.

### Caregiver burden as a key focus

The role or burden of the informal caregiver was considered a key focus in just over half of the identified studies (53%). Figure 2 shows that studies involving the care of brain/spinal cord injury patients had the highest proportion of CB-focused studies (100%), followed by those investigating the care of cancer patients (76%). In the large CRC category of ADRD, only just over half (53%) of the studies had CB as a key focus of the study.

Figure 2: Caregiver burden as a key focus of identified studies

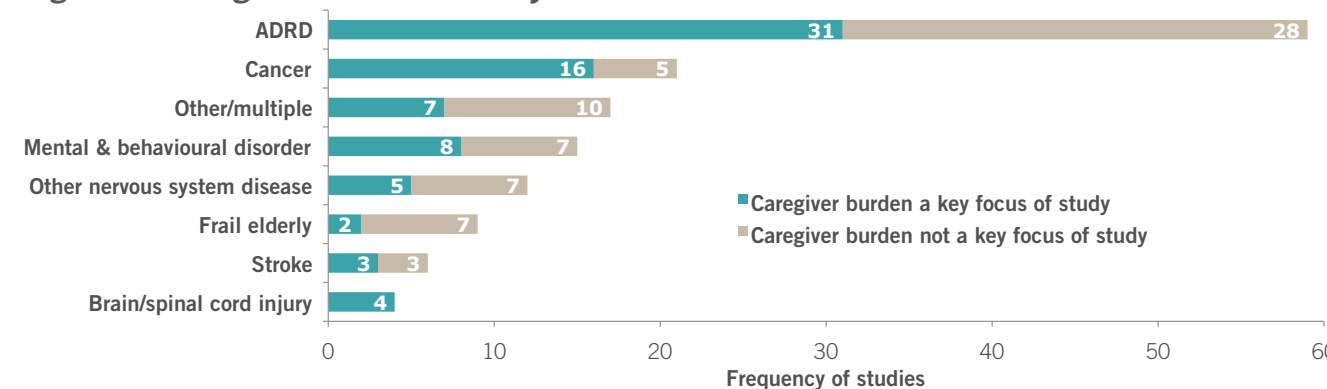
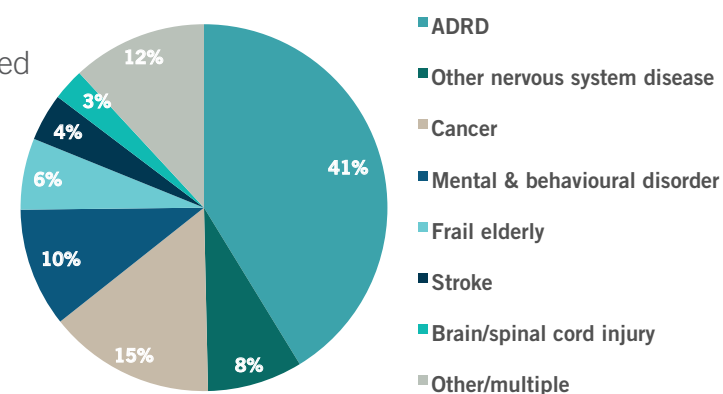


Figure 1: The care-recipient conditions



Of the 28 ADRD studies where caregiver role was not a primary focus, 18 were trials investigating the efficacy of drug interventions in ADRD.

### Measuring caregiver burden

The specific instruments used to measure CB were explicitly stated in 47% of the ClinicalTrials.gov listings identified. A range of

questionnaire-based instruments were used across studies to evaluate the physical, emotional (psychological), social and financial impacts of caregiving. The most frequently used measure of general CB was the Zarit Burden Interview (reported in 28% of studies that stated use of specific instruments), although many other general CB instruments were reported. In several studies (predominantly in the CRC of ADRD), CB was measured using instruments specific to the CRC.

### Intervention type and target

Behavioural interventions (such as education about the condition, advice/training on caregiving and coping techniques, emotional support, cognitive therapy) were the most frequently investigated intervention type among the included studies (40%). Studies investigating drug and management strategy interventions were identified in similar numbers (22% and 23% of studies, respectively). Of note, only 2 of the 32 studies investigating a drug intervention measured CB as a primary focus of the trial. In contrast, the majority (93%) of the studies assessing behavioural interventions considered the role or burden of the caregiver as a key focus of the study.

The intervention under investigation or observation was targeted at the care-recipient in 65 studies (45%), the caregiver in 47 (33%), and both the care-recipient and caregiver in 31 (22%).

## Discussion

It is important to recognise that large numbers of informal caregivers in society provide an invaluable extension to formal healthcare systems around the world.<sup>1</sup> Assessment of CB in the clinical setting is necessary for identifying caregivers at risk of experiencing detrimental effects of caregiving on their own health and ability to care. Moreover, the assessment of CB in the experimental setting is essential for determining the effectiveness of interventions designed to alleviate the burdens of informal caregiving.

The burden of caregiving was the key focus in approximately half of the studies identified, and these typically investigated caregiver-targeted behavioural interventions that aimed to reduce the burden of caregiving. Those studies in which CB was measured, but was not the focus, were often evaluating the effectiveness of interventions that were targeted at improving the health and well-being of the care-recipient, which might also have knock-on beneficial effects of reducing CB.

This analysis highlights how current research into CB and the efficacy of interventions for reducing CB are typically concentrated in age-related CRCs such as Alzheimer's disease and dementia. This is likely due to the ageing population, the prevalence of dementia in elderly patients, and the observation that caring for someone with dementia can be associated with higher levels of stress than

caring for someone with functional impairment from another type of chronic disease.<sup>2</sup> However, conclusions drawn from the body of research into CB in these specific areas may not be applicable to CB in very different situations, such as the burden felt by parents of chronically ill children.

## Conclusion

- Current clinical research into the burden of informal caregiving is concentrated in age-related CRCs.
- Approximately half of the ongoing clinical trials that are measuring the burden of caregiving consider CB as a primary focus of the trial.
- Research interventions aimed at relieving CB are mostly behavioural in nature.
- The growing number of caregivers means that research into effective methods of reducing CB will be of ever increasing importance.

## References

- <sup>1</sup> National Alliance for Caregiving in collaboration with AARP. Caregiving in the U.S. Executive Summary. November 2009.
- <sup>2</sup> Parks SM, Novielli KD. A practical guide to caring for caregivers. Am Fam Physician. 2000 Dec;62(12):2613-22