

# Promote the Health of Dementia Caregivers

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## Abstract

Caregivers of people with Alzheimer's dementia (AD) will become increasingly important as governments across the world cut health care funding. The vast majority of the care for people with AD is and will be carried out by informal caregivers, in other words, their spouses, children, and friends, people who typically have no training in this task and, certainly in the early days after diagnosis, little knowledge of what the person with AD is going through or what the future holds. The fact that people with AD face progressive cognitive and functional decline and that widespread individual differences are the norm rather than the exception makes it difficult to predict how quickly/slowly they will deteriorate. Caregiver-centered training and individual guidance based on the specific situation for informal dementia caregivers is going to become an international priority. We will need to care not only for the patient but also for their caregivers.

## Keywords

caregivers, dementia, health, burden, gain

Caregivers of people with dementia will become increasingly important, as governments across the world cut health care funding. The fact that fewer traditional health care resources will be available in the future is a worrying trend considering the aging of the population. The incidence of Alzheimer's dementia (AD), the most common form of all the dementias, increases proportionally with aging, and it has been estimated that 44.4 million people have some form of dementia currently, while 135.5 million will have it by 2050.<sup>1</sup> The vast majority of the care for people with AD is and will be carried out by informal caregivers, in other words, their spouses, children, other family members, and friends. The fact that people with AD face progressive cognitive and functional decline, that widespread individual differences are the norm rather than the exception making it difficult to predict how quickly/slowly they will deteriorate, and that they can live for 2 to 18 years after the initial diagnosis with an average of 7 years<sup>2</sup> makes the future for both the persons with AD and their caregiver uncertain. The unpredictability, the changing roles within the family unit, the financial strains, the underlying dynamics of the relationship between caregiver and recipient, and the individual characteristics of both members of the dyad can all have their toll. Indeed, caregivers of people with AD can have what is known in the literature as "caregiver burden."

Caregiver burden has no single, all-encompassing definition in the literature, but using Kasuya, Polgar-Bailey and Takeuchi, 2000 (p. 119) definition it encompasses "a multi-dimensional response to physical, psychological, emotional, social, and financial stressors associated with the caregiving experience"<sup>3</sup> which underlies the many different forms it can take. Furthermore, it has been assessed both objectively (eg, hours of caretaking) and subjectively (eg, typically using self-report questionnaires and/or interviews to assess the caregivers' depression levels). Caregiver burden has also

been explained using the "stress process model."<sup>4</sup> This model suggests that caregivers will have poorer health (than age- and sex-matched noncaregivers) because of the higher levels of stress that they have which in turn leads to poorer functioning, cognition, and general health. Caregiver burden has furthermore been linked with health-related problems in the caregivers themselves including immune dysfunction, more visits to the doctor, burnout, and some researchers have even found a heightened mortality rate and a higher risk of suicide.<sup>5</sup> Traditionally, women do most of the caring, and although some controversy exists in the literature, women report more burden than men.<sup>4</sup> The context (typically the living situation of the dyad), the education level of the caregiver (lower = more burden), and other factors also appear to be important.

It is not all "bad news" however. Some studies have found that caregiving can actually be beneficial to the caregiver, the so-called "healthy caregiver hypothesis"<sup>6</sup> supported by studies that have found better cognition, functioning, and health among caregivers. Caregiving may "buffer" the caregiver against deterioration it has been purported due to the need for multitasking, extra planning, and often more physical activity necessary in the role. Both quantitative (most) and qualitative (fewer) studies

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have been carried out to investigate the positive aspects of dementia caregiving. A matrix has also been developed with dimensions including who gains (caregiver, recipient, or both) and the nature of the reward/satisfaction.<sup>7</sup> Based on quantitative data, this matrix has also been recently supported by qualitative research.<sup>8</sup> Important conclusions of this research were that caregiver benefits did not just occur but came about due to the choices caregivers made and the (coping) strategies they employed.<sup>9</sup> Acceptance of the dementia diagnosis was the most important first step. Previous relationship quality and who the caregiver was (spouse or adult child) were also important factors as were the genders of the caregiver and the recipient.

Interventions should clearly aim for enhancing gain and decreasing burden, and both psychoeducational and pharmacological interventions have been investigated. A recent meta-analysis<sup>10</sup> of studies investigating caregivers of patients with chronic illnesses (not only dementia) showed that while most interventions reported gains (ie, reduced burden; effect size typically reported as Cohen d or Hedge q, where 0.2 is weak, 0.5 is moderate, and 0.8 is a strong effect), they were quite modest/weak. When pharmacological interventions were used (typically anticholinergics or antipsychotics employed to treat the patient's symptoms) the effect sizes were 0.18 to 0.27. When psychoeducational interventions were used the effect size was around 0.22 at 3 months, but this was lost by 6 months (0.08). A lot of studies found improved symptoms (anxiety, depression, etc) among caregivers even when caregiver burden was not improved. Adelman et al<sup>9</sup> concluded that caregivers of patients with chronic illnesses (including those with dementia) should be a priority for health care professionals not only because the care of their patients depends on the good health of the caregivers but also because caregivers are themselves at a high risk of becoming patients themselves.

Caring for the caregiver should therefore be a priority,<sup>10</sup> and some researchers are beginning to investigate in more detail which interventions work best for dementia caregivers. The longer the person with AD can stay at home, the more cost effective his or her care will be. Not only that, there are studies which suggest that the longer a dementia patient can be kept at home, the more likely they will live longer (institutionalization increases the risk of mortality 2-fold in patients with dementia<sup>11</sup>). McClendon et al<sup>12</sup> provided an important clarification to this finding, namely, that the risk of mortality decreases as the disease progresses. In other words, if placement is timed properly then both patient and caregiver can benefit, and caregivers need not feel guilty when they can no longer cope with caring for the patient at home.

Furthermore, institutionalization of the patient (like the likelihood of caregiver burden itself) has been found to depend on a number of factors including patient and caregiver characteristics and the context of the home environment (does the dyad live in the same house or not?). Caregiver characteristics which are predictive of placing the patient in a nursing home or other form of long-term care include subjective stress and depression, heightened self-estimate of caregiver burden, poor

objective and subjective health, low income, and when they have only recently taken on the caregiver role (people who have been caring longer for the patient tend to do so until that is no longer possible).<sup>12</sup>

Keeping the patient at home as long as possible is still desirable, however, given the high risk of mortality in the early period after diagnosis with institutionalization (10-fold in the first 6 months<sup>12</sup>). McClendon et al<sup>12</sup> suggested that an early transition to long-term care after diagnosis may be a "transplant shock," and this shock declines as patient awareness decreases as the disease progresses. However, these researchers say that an early move after diagnosis may help some patients namely those where the home environment is less than ideal and where the caregiver is in denial or depressed or in financial difficulties. Clearly, what will benefit both patient and the caregiver therefore needs to be weighed up and the specific situation considered before a decision is made.

Home care is the norm rather than exception however and that is only likely to increase in the current environment of health care cuts across the globe. Caregiver-centered training and individual guidance based on the specific situation for informal dementia caregivers is going to become an international priority, as populations' age and the cure for most forms of dementia remain elusive. We need to care not only for the patient but also for the caregivers.

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