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GERIATRIC DISORDERS (H LAVRETSKY, SECTION EDITOR)

Caregiver Health: Health of Caregivers of Alzheimer's and Other Dementia Patients

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Abstract Alzheimer's disease (AD) is the most common type of dementia and is a significant public health problem that will intensify as the population ages. The behavioral and psychological symptoms of dementia (BPSD) present a significant burden to patients, their families, and their caregivers. The majority of care is provided at home by family caregivers. Caring for a person with AD and other dementias is associated with significant risk to the caregiver's health and well-being. Healthcare providers must recognize that family caregivers often present as secondary patients. Given the importance of these caregivers to patients with AD and other dementias, it is vital to understand the risk factors that impact caregiver health and well-being. Non-pharmacological interventions can reduce the negative impact of caregiver burden on caregiver health, reduce premature institutionalization of patients, and improve quality of life for patients, their families, and their caregivers. This article summarizes recent relevant research concerning AD and dementia caregiver health and psychosocial interventions.

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Introduction

Alzheimer's disease (AD) is the most common type of dementia and is a significant public health problem that will intensify as the population ages. In 2010, there were an estimated 4.7 million Americans over the age 65 years with AD [1] and approximately 35.6 million people over the age 60 years with AD globally [2]. It is projected that by 2050 there will be 11 million to 16 million people with AD in the United States [3•]. The behavioral and psychological symptoms of dementia (BPSD) present a significant burden to patients, their families, and their caregivers. Families are the major providers of unpaid care outside of institutions for individuals with AD and other dementias. Over 15 million Americans provided an estimated total of 17.4 billion hours of unpaid care to persons with Alzheimer's disease and other dementias in 2011, which amounted to 80 % of home care [3•]. Caring for a person with AD and other dementias is associated with significant risk to the caregiver's health and well-being. This article summarizes recent relevant research concerning the health of informal caregivers of patients with Alzheimer's disease and other dementias. An overview of interventions is provided as well as recommendations for referral resources (Table 2).

Who Are Caregivers of Alzheimer's and Other Dementia Patients?

There is currently no centralized national-level surveillance system on informal caregivers of older disabled adults. Data on caregivers of AD and other dementias come primarily from two sets of national level surveys: the 2009 version of the annual Behavioral Risk Factor Surveillance System (BRFSS) surveys coordinated by the Centers for Disease Control and Prevention [4]; and the surveys conducted for the Alzheimer's Association by the National Alliance on Caregiving (NAC) and the AARP. Although there is variance in data collection methodology across these surveys [5], a synthesis of reliable data is contained within the Alzheimer's Association's annual report: Facts and Figures [3•].

The Alzheimer's Association and NAC/AARP surveys show that caregivers of AD and dementia are typically female (60 %), are 55 or older (56 %), have less than a college degree (67 %), are the primary breadwinners of their household (55 %), and are employed at least part time (44 %). Nearly half of informal care is provided by adult children, and between 6 to 17 percent is provided by a spouse [3•]. The data on the distribution of minority group caregivers varies between surveys, and is limited due to low inclusion rates of non-white caregivers. Hispanic and non-Hispanic African American caregivers spend more hours per week providing care and experience higher caregiving burden than Non-Hispanic white and Asian American caregivers [6].

Caregiver Burden

Dementia is an acquired decline in global cognitive functioning. Dementia most commonly starts with difficulty recalling new information followed by progressive deterioration in memory, language, and/or judgment with disturbance in perception, mood, and behavior resulting in functional impairment. Eventually patients with AD and other dementias need constant care. The majority of this care is received at home and eighty percent is provided by family caregivers [3•]. Family caregivers provide assistance in all aspects of daily living activities (ADLs and IADLs) including preparation of meals, household chores, transportation, medications, bathing, dressing, and feeding. On average, caregivers for AD and other dementia patients provide care for more years than other caregivers and many continue to assist the care recipient even after they are placed in an assisted living or nursing facility [7]. Overall caregiving is fiscally, physically, and emotionally demanding and caregivers experience burden with significant implications for their health and well-being.

Various definitions of caregiver burden are present in the literature. At simplest, it is defined as the "subjective assessment of stress and anxiety which may result from the perception that external caregiving demands exceed available resources" [8]. However, it is better understood as a multidimensional construct encompassing caregiver struggles in fiscal, physical, psychological or emotional, and social well-being [9]. In recent research three dimensions of caregiver burden have emerged: stress burden (tension and anxiety), objective burden (time infringements), and relationship burden [9, 10]. Furthermore, many variables increasing the risk of caregiver burden have been identified [8, 11–16]. An overview of these risk factors is presented in Table 1.

Geriatric health care professionals should have at their disposal an array of clinical tools with which to assess the level and scope of caregiver well-being, including burden. While a number of psychometrically validated measures are available, three are noted here that clinicians may find useful to incorporate in their practice:

Caregiver Burden Interview Developed in 1980 by Zarit and colleagues [17], this widely used measure is designed to assess caregivers' subjective appraisal of burden. Available in the original 22-item version (ZBI) as well as the shortened 12-item version (ZBI-SF) [18], the scale has been used in numerous clinical and research settings and with a diverse range of caregivers. Flynn Longmire and Knight [19] performed a confirmatory factor analysis of a shortened version of the ZBI in a cross-race comparison of black and white dementia caregivers. Results indicate that a three factor model [20] was metrically invariable across both race groups in overall placement of the items and the inter-relationship of items and factors. Findings suggest that caregiver needs may differ; the ZBI is a valid measure of subjectively-perceived caregiver burden.

Montgomery Borgatta Burden Measure Aimed at assessing the caregiver's perception that caregiving responsibilities are interfering with their daily life and other responsibilities

Table 1 Caregiver burden-risk factors

Caregiver factors	Female gender
	Advanced age
	Decreased emotional state and poor physical health
	Caregiver depression
	Caregiver stigma
	Poor current relationship with care-recipient
	Low intrinsic motivation
	High extrinsic motivation
	Decreased quality of life
	Hours providing care
	Low income
	Low self-efficacy
	Coping styles
Care-recipient factors	Medical co-morbidities
	Cognitive impairment
	Behavioral problems
	ADL-impairment
	Ambulation
	Decreased mobility

(objective burden), producing strain in the relationship between caregiver and care receiver (demand or relationship burden), and creating stress and anxiety (stress burden) [10, 21]. The Montgomery Borgatta Burden Measure is a 16-item measure that can easily be administered to caregivers in the clinical setting.

Caregiver Well-Being Scale Grounded in a strengths-based perspective, the Caregiver Well-Being Scale (CWBS) was originally created for use in the clinical setting. The original 45-item scale assesses two areas critical to the well-being of caregivers: basic needs and activities of living [22, 23]. With feedback from clinicians, a shortened version was developed and validated [24] that enables the practitioner to more easily and quickly assess caregiver strengths and areas in which support can be provided.

Risks to Caregiver Health

Caregivers have been shown to be at risk for mental and physical health problems as a result of caregiver burden and in effect become a secondary patient with the AD or dementia care-recipient. Given the importance of the caregivers to patients with AD and other dementias, it is important to understand the risk factors that impact caregiver health and well-being.

Physical Health

The stress of caregiving has been shown to have negative effects on the physical health of caregivers. Dementia caregivers are more likely to report poor health, worsening health due to caretaking, and find health maintenance troublesome [3•]. Decline in physical health may be due to physical exertions caring for the family member with dementia, less time available for exercise and preparing healthy meals, and stress-related physiological changes [25]. One of the physiological changes associated with caregiver stress is increased levels of cortisol. Cortisol not only contributes to impaired cognitive function, but also toward developing other risk factors associated with cognitive impairment, such as obesity, hyperinsulinemia, and inflammation [26]. Higher levels of C-reactive protein [26–28] and interleutkin-6 [27, 28] inflammatory mediators are also seen in dementia caregivers.

Variables associated with poorer physical health among dementia caregivers include: care-recipient behavioral problems and cognitive impairment, duration of caregiving, higher caregiver burden, higher caregiver depression, older age and lower socio-economic status [25]. As seen with perceived burden, caregivers with high neuroticism and low extraversion are more likely to report poorer physical health [29]. On the other hand, caregivers perceive better physical health when care recipients have a more agreeable personality [30]. Objective physical health consequences for caregivers are increased stress hormones and inflammatory markers [26–28], hypertension [31, 32], and metabolic syndrome which can increase the risk for cardiovascular disease [33].

Caregiving may be a risk factor for mortality. There is some evidence that spousal caregivers are at a higher risk for all-cause mortality [34, 35]. However, several studies have found lower mortality amongst caregivers compared to non-caregivers [36–39]. Perkins and colleagues [40] report that high caregiving stress is associated with increased mortality compared to caregivers experiencing less stress independent of physical health factors. It is unclear if the act of caregiving increases the risk of mortality; however there is an association of high levels of self-reported stress and mortality in caregivers, which suggests that measures of stress are integral to identifying caregivers at risk of negative health outcomes.

Mental Health

Depression is a common mood disturbance among dementia caregivers. In a recent study, Joling and colleagues [41] found that spouses caring for dementia patients are four times as likely to have depression compared to non-caregivers and twice as likely to receive antidepressant treatment. Higher levels of stress are related to more depressive symptoms [42]. Caregivers with poor self-rated health experiencing some symptoms of depression without disorder are most likely to develop disorder [43]. Family members, usually adult children of dementia patients that require hospitalization, experience depression with greater severity. They also experience greater severity of grief and burden [44]. Protective factors for caregiver depression include: greater self-efficacy, frequency in leisure activities, and cognitive reappraisal which have been associated with decreasing depression over time [45]. Spirituality is found to be associated with lower levels of depression in caregivers [46].

Spousal caregivers of dementia patients may experience cognitive decline and may have additional risks for developing dementia. Spouses providing care for dementia patients have a six-fold greater risk of developing dementia after accounting for known risk factors such as age, education, socio-economic status, and genotype, in particular apolipoprotein E4 [47]. Possible factors attributing to greater risk of cognitive decline are psychosocial, behavioral, and physiological variables [28]. Subjective stress has been associated with poor cognitive functioning [48]. Stress also contributes to disturbances and dysregulations in the immune and endocrine systems [26–28]. Caregivers are at higher risk of developing depression and experiencing social isolation, loneliness, and disturbance in sleep, which can potentially contribute to cognitive decline.

Caregivers may experience poor sleep as a result of the dementia patients' sleep disturbances such as insomnia, sundowning, movement disorders, and behavioral problems. Caregivers' disturbances in mood, physical strain, disturbance in circadian rhythms and poor sleep hygiene may directly contribute to caregiver insomnia. Poor sleep is linked to diminished quality of life and depression in AD and dementia caregivers [49]. Although subjective reports of sleep disturbances are not parallel to objective measures of poor sleep [50], it may potentially contribute to poor psychological and physical health. Subjective poor sleep is associated with elevated atherosclerotic biomarkers such as fibrin D-dimer, von Willebrand factor antigen, C-reactive protein and interleukin-6, which can lead to increased cardiovascular risk [51].

Following nursing home admission of a dementia patient, caregivers may experience reductions in burden and depression [52, 53]. However, some caregivers continue to experience clinically significant depression and burden. A recent study by Gaugler et al. [52] found that wives and daughters of dementia patients were more likely to experience persistent burden following placement. Persistent burden was also related to care-recipient behavior problems, caregiver's subjective health impairment, caregiving duration, time providing care at home, and employment status. On the other hand, persistent depression was more likely in husbands of dementia patients. Givens et al. [54] found that continuing stress experienced by caregivers after nursing home admission was associated with several factors. Family members experience guilt with surrendering their caregiving duties to professionals. They may feel distressed while making advance care plans without a clear understanding of disease prognosis and information to guide their decisions. They also report dissatisfaction with the inadequate communication with physicians with inadequate patient personal care [54].

Caregiver Interventions

The risk for negative physical and mental health outcomes for AD and dementia carers is well documented. It is important that clinicians look for clinically significant depression and anxiety in caregivers and treat aggressively with antidepressants and psychosocial interventions. Several studies have focused on interventions designed to address the burden and stress these caregivers experience in order to promote caregiver health. Interventions on caregiver burden are focused on mediating and moderating variables in the impact of stress on caregiver health [55]. Caregiver interventions can be divided into two major groups: (a) those aimed at reducing the objective amount of care provided by caregivers (i.e., respite, interventions to enhance the competence of the care receiver to carry out ADL and IADL) and (b) those aimed at improving the caregiver's well-being and coping skills (e.g., pharmacotherapy, psychoeducational interventions; support groups) [56].

Prior reviews of the efficacy of caregiver interventions have shown relatively low to moderate effect sizes for outcome measures for depression, caregiver burden, subjective wellbeing, and caregiver satisfaction [56–58, 59••]. Several review and meta-analytical studies have highlighted the limitations of prior intervention studies due to cross-sectional rather than longitudinal design, convenience sampling, and small samples which may diminish adequate measurement of effect sizes [56–58, 60]. Despite these limitations, there is evidence to support the use of psychosocial interventions, and findings suggest statistically and clinically significant impact [59••]. Psychosocial interventions can be categorized into three types: psychoeducation-skill building, psychotherapy, and multicomponent [58].

Psychoeducation programs are one of the most common types of interventions to address caregiver well-being and have been shown to have the largest and most consistent positive effects [56, 58, 61]. Psychoeducation programs for AD and dementia caregivers typically provide the caregiver with information about the disease, caregiver role, and information on available resources. Examples include: lectures, discussions, written materials, and accessing online resources. Such programs often teach caregivers coping skills for emotional and behavior problems associated with AD and dementia (i.e., BPSD). This is an important aspect as caregiver's interpretation of problematic behaviors has been shown to be a significant predictor of burden and stress, and caregivers can benefit from help in coping with problem behaviors [61]. Psychoeducational interventions are shown to be most effective when caregivers actively engage in programs with structured components [25]. There is new evidence to support the use of technology to provide psychoeducation and support programs to caregivers [62]. However, the effectiveness of programs delivered through advanced internet technologies may be limited due to caregiver limitations relative to knowing how to use and having access to the internet.

There have been few randomized controlled trials (RCTs) on psychotherapy interventions for AD and dementia caregivers [59••]. Cognitive Behavioral Therapy (CBT) is the most commonly studied approach, and is shown to have positive outcomes for caregivers with depression [63] and

Table 2 Internet resources for family caregivers

- The Alzheimer's Association: www.alz.org
- The Caregiver Action Network (formerly the National Family Caregivers Association): www.caregiveraction.org
- Family Caregiver Alliance: www.caregiver.org
- Strength for Caring: www.strenghtforcaring.com

anxiety [64]. A recent RCT conducted by Glueckauf et al. [65] compared telephone based with face-to-face CBT for African American dementia caregivers with depression. The results show both modes of intervention reduce depression and burden in African American caregivers. The study authors suggest that issues of access to psychotherapeutic interventions and cultural barriers [66•] to seeking treatment can be addressed via telecommunication-based interventions [65].

Multicomponent interventions typically blend psychoeducation, psychotherapy, and supportive components into a unified and sustained approach. A review of psychosocial interventions by Parker et al. [60] concluded that multicomponent interventions can be effective at reducing caregiver burden and depression. Similarly, a review by Olazáran et al. [67] concluded that multicomponent interventions based on caregiver education and support delayed the institutionalization of AD patients with minimal amounts of resource utilizations [67].

Whitebird et al. [68] conducted a RCT investigating the effect of Mindfulness-based stress reduction (MBSR) for family caregivers of persons with dementia in comparison to an education and support intervention. Results show that MBSR was more effective than the psychoeducation/support intervention at improving overall mental health, stress reduction, and decreasing depression [68]. Lavretsky et al. [69] tested a yogic meditation intervention for family dementia caregivers with depressive symptoms. Results show that caregivers practicing brief daily meditation showed significantly lower levels of depressive symptoms and greater improvement in mental health and cognitive functioning than the relaxation control group [69]. Mittelman et al. [70] found psychosocial interventions combined with cholinesterase inhibitor therapy for the AD dementia patient can significantly reduce caregiver depression. Pharmacological interventions for caregiver depression should be considered, however few multicomponent treatment studies have included antidepressants as an adjunct treatment to psychosocial interventions in clinically depressed caregivers. Lavresky et al. [71] conducted a pilot randomized placebo-controlled trail of escitalopram as a treatment for caregiver depression. Results show that antidepressant use in family caregivers with major or minor depression can be used to improve symptoms of depression, anxiety, resilience, and subjective distress [71].

Conclusions

The vast majority of caregiving for AD and other dementia patients is provided by family caregivers. These carers are at increased risk for becoming physically and/or mentally ill, secondary to the stresses of caregiving. It is imperative that health-care providers identify at-risk caregivers of AD patients and recommend a variety of interventions including treatment of anxiety and depression. Caregiver interventions such as use of respite, stress reduction techniques, support groups, psychotherapy, and in particular CBT, psychoeducation, and a focus on spirituality can help caregivers to cope and prevent them from decompensating.

Health-care providers need to emphasize to caregivers of AD and other dementia patients the importance of maintaining their own physical and mental health so that they can continue to provide care for their loved one. Table 2 includes a list of recommended internet resources for family caregivers.

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- • Of importance
- •• Of major importance

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