



Published in final edited form as:

*Curr Psychiatry Rep.* 2011 June ; 13(3): 219–224. doi:10.1007/s11920-011-0187-1.

## A Review on the Psychobiology of Dementia Caregiving: A Focus on Resilience Factors

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### Abstract

The recent aging trend in the United States has resulted in an exponential growth in the number of informal dementia caregivers. Caring for a family member with dementia has been associated with negative health outcomes likely associated with physiologic changes resulting from stress. Yet caregiving is not always associated with health morbidity. In this review, we highlight resilience factors that appear to have a beneficial relationship with health outcomes. We highlight eleven studies that examined the relationship of one of three broad resilience domains (personal mastery, self-efficacy, and coping style) to caregiver health outcomes. Our main findings were that higher levels of personal mastery and self-efficacy, and increased use of positive coping strategies appear to have a protective effect on various health outcomes in dementia caregivers. Continued research is warranted to help guide prospective directions for caregiver interventions focusing on increasing caregiver resilience and the corresponding impact on caregiver health.

### Keywords

Biomarkers; caregivers; resilience; health; coping; stress; morbidity

### Introduction

The U.S. Census Bureau projects there will be a 2.8% annual increase in the population of adults over the age of 65 over the next two decades [1]. Consequently, this rapid growth in the geriatric population will result in an exponential rise in the number of individuals with geriatric diseases, and an accompanying increase in the need for informal caregivers. Currently, in the United States alone, there are more than 65 million individuals (roughly 29% of the U.S. population) providing care for a loved-one with a disability [2]. Given the expected increase in need for informal caregivers in the coming years, it is evident that research related to caregiving is of paramount importance.

Being a caregiver can be highly stressful and challenging, particularly when caring for an individual with chronic and degenerative illnesses. Caregivers can be expected to serve in this role for as many as 15 years [3], during which time a combination of physical and psychological stressors may tax the caregiver's physical and psychological resources. Not surprisingly, scientists have rallied to study the impact of caregiving stress on caregivers' health, and over the past 2 decades caregiving research has greatly expanded. Early studies

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highlighted the negative psychological and subjective health consequences of caregiving, finding that caregivers are significantly more likely than non-caregivers to experience symptoms of depression [4], anxiety [5], and to report that their health is “not as good as it used to be” [6]. Later, caregiving research broadened in focus from “subjective” health outcomes to more “objective” indicators of health, including downstream health outcomes such as hypertension [7], cardiovascular illness [8–10], and mortality [11]. Furthermore, this “second wave” of caregiver research explored intermediary biological outcomes to help elucidate the potential mechanistic explanations for why caregivers experienced greater physical morbidity [12–15]. A PubMed search of “*caregiving and physical health*” results in over 400 articles, suggesting this is a growing field with continued interest.

More recently, however, the field has taken a new turn. Although there continues to be interest in finding biological mechanisms for morbidity, increased attention has been given to the fact that not all caregivers experience negative health outcomes. A PubMed search using the search terms, “*coping and biomarker*” and “*resilience and biomarker*” for the years of 2000–2008 yielded a total of 160 articles on the relations between coping/resilience factors and biomarker outcomes. Over the past two years, there have been 81 manuscripts on this topic, demonstrating a significant expansion in this line of research. The purpose of this review is to highlight some findings from the past decade related to resilience in dementia caregiving and physical health outcomes (broadly defined). Specifically, this review will focus on three broad resilience domains: a) Personal mastery, b) Self-efficacy and c) Coping styles, in regards to their relationship with various health outcomes in caregivers.

## Personal Mastery and Health Outcomes

Roepke and colleagues [16] tested the association between personal mastery and sympathoadrenal medullary (SAM) arousal in a sample of 69 spousal caregivers of Alzheimer’s patients. Participants acted as the primary caregiver and lived in the same residence as the care recipient. In this study, caregivers had blood samples drawn before and after a stressful speech task in order to assess plasma norepinephrine (NE) reactivity to an acute stressor. In addition to evaluating NE reactivity, participants indicated the extent to which they felt life circumstances were under their control (i.e., personal mastery) using the full 7 item Pearlin scale [17]. Results indicated that higher levels of personal mastery were associated with reduced NE reactivity to the stressor ( $r = -.29$ ). These results suggest that stronger control beliefs may aid in reducing physiological reactions to stress, which in turn may have downstream health benefits.

Mausbach et al. [18] conducted a study examining the potential protective effect of personal mastery on the relationship between stress and plasma levels of the Plasminogen Activator Inhibitor (PAI)-1 antigen. PAI-1 is an inhibitor of fibrinolysis, and has been implicated in the development of cardiovascular disease. In their study, 71 in-home spousal caregivers of Alzheimer’s patients were assessed for plasma levels of PAI-1 antigen, negative life events, caregiver distress, and personal mastery. A moderator analysis indicated that when mastery was low, stress was significantly and positively related to PAI-1 levels. However, when mastery was high, no relationship was observed between stress and PAI-1. The authors concluded that mastery may protect individuals from biological changes that may occur as a result of stress, and ultimately may help reduce cardiovascular risk.

Two additional studies by Mausbach and colleagues using similar caregiving samples examined the direct relations between personal mastery and  $\beta_2$ -adrenergic receptor sensitivity [19, 20]. The model tested in these studies posits that chronic stress results in activation of the autonomic nervous system. Previous studies have shown that continuous activation of the autonomic nervous system over time, may cause desensitization of the  $\beta_2$ -

adrenergic receptors on immune cells [21, 22].  $\beta$ 2-adrenergic receptors have been implicated in T-cell and natural killer cell functions, including cytokine production [23]. Therefore, desensitization of these receptors may ultimately affect immune system functioning. The first manuscript [19] reported results from cross-sectional data and found that a greater sense of personal mastery was associated with increased  $\beta$ 2-adrenergic receptor sensitivity, even when controlling for demographic and health characteristics such as age, obesity, and blood pressure. The second manuscript [20] utilized 5-year longitudinal data from the same subjects and examined the correlation between personal mastery and  $\beta$ 2-adrenergic receptor sensitivity across time. Results indicated that greater levels of mastery were associated with increased receptor sensitivity suggesting that increased mastery may serve as a resilience factor for better health in this population.

Another study examined the 5-year longitudinal correlations between personal mastery and subjective health [24] in 130 in-home spousal Alzheimer caregivers. This study explored the co-variation between caregiver stress (i.e., role overload), personal mastery, and depressive and health symptoms over time. Analyses revealed a mastery-by-overload interaction such that caregivers endorsing higher levels of role overload and lower levels of mastery were more likely to report increased depressive symptoms as measured by the Hamilton Rating for Depression scale (HAM-D). Post-hoc analyses indicated that when mastery was low, there was a significant relationship between overload and health symptoms. However, this relationship was not significant when mastery was high. These findings are important in that they lend further support to the hypothesis that personal mastery may have a buffering impact on the detrimental effects of stress on caregiver health

## Self-Efficacy and Health Outcomes

Self-efficacy has been defined as the belief that one has the capability to successfully engage in specific actions and exercise control over events that affect one's life [25]. Throughout the years, there have been several studies examining the relationship between self-efficacy and various health outcomes among caregivers. Indeed, Mausbach et al. [26] conducted a study to explore whether coping self-efficacy might have a protective effect on the relationship between caregiving stress and the proinflammatory cytokine interleukin IL-6, which has been shown to be a risk factor for future cardiovascular disease. A total of 62 elderly adults providing in-home care to a spouse with Alzheimer's disease answered questionnaires probing their degree of role overload and coping self-efficacy. In addition, participants had blood drawn to determine circulating levels of plasma IL-6. Results indicated that there was a significant interaction effect between caregiver stress and self-efficacy on circulating levels of IL-6 after controlling for theoretically and empirically relevant covariates. Specifically, there was a significant positive association between caregiver stress and IL-6 levels for caregivers with low self-efficacy, but not for caregivers with high self-efficacy, indicating that self-efficacy may have a protective impact on caregiver health.

Another study looked at the three different subscales of self-efficacy to determine whether high levels of self-efficacy were related to several mean resting blood pressure (BP) outcomes in a sample of 100 elderly spousal Alzheimer caregivers [27]. All participants completed an abbreviated 13-item Coping Self-efficacy Scale [28] and had a visiting nurse take 3 serial blood pressure readings, which were then averaged. Multiple regression indicated that there were no significant relationships between mean arterial pressure (MAP) and self-efficacy for stopping unpleasant thoughts/emotions or self-efficacy for getting social support. However, higher levels of self-efficacy for using problem-focused coping were associated with significantly lower MAP. Additional secondary analyses revealed that higher levels of self-efficacy for problem-focused coping were also associated with

significantly lower systolic BP and pulse pressure. These results suggest that higher levels of self-efficacy for problem-focused coping may have physiological advantages, perhaps ameliorating the increase in BP associated with chronic stress.

Rabinowitz and colleagues [29] sought to expand upon the existing caregiving literature by examining the relationship between self-efficacy for handling situations related to three domains of caregiving (i.e., obtaining respite, controlling upsetting thoughts, and responding to disruptive behaviors) and cumulative health risk, as determined by caregiver health behavior patterns such as smoking, exercise, and diet. Caregivers were at least 21 years of age, and lived with and provided four or more hours of care daily to family members with a diagnosis of Alzheimer's disease or related dementias or had a recent Mini-Mental State Examination (MMSE) score  $\leq 23$  out of 30. Care recipients also had impairments in at least two instrumental activities of daily living (IADL) or one activity of daily living (ADL). The findings suggested that self-efficacy for obtaining respite and self-efficacy for controlling upsetting thoughts were associated with significantly lower cumulative health risk for the caregiving sample. One plausible explanation for this finding is that caregivers with a higher sense of control engage in fewer maladaptive coping behaviors, which may result in more positive health decisions.

Another study highlighting the role of perceived self-efficacy on health in Alzheimer family caregivers was conducted by Fortinsky, Kercher, and Burant [30]. This study measured self-efficacy in two conceptual domains (i.e., self-efficacy for dementia symptom management and self-efficacy for use of community support services) to determine each construct's association with caregiver health and well-being. One-hundred ninety-seven family caregivers participated in telephone interviews. Caregiver self-efficacy was assessed using 10 questions inquiring how confident respondents were that they could manage their relative's dementia symptoms and how confident they were that they could arrange support services in their community. Depressive and physical health symptoms were measured with the 10-item short form of the Center for Epidemiological Studies-Depression (CES-D) inventory [31] and a 12-item physical signs and symptoms subscale from the Hopkins Symptoms Checklist [32] respectively. Findings indicated that there was a negative relationship between self-efficacy and both mental and physical health in Alzheimer caregivers, whereby higher levels of symptom management and community service use self-efficacy were associated with fewer depressive and physical health symptoms.

## Coping and Health Outcomes

In addition to studies exploring the buffering effects of high levels of mastery and self-efficacy on caregiver well-being, some researchers have investigated how caregiver coping styles may relate to differences in physical health outcomes. For example, Aschbacher et al. [33] examined a sample of 60 spousal Alzheimer caregivers and 33 noncaregiving controls to see if approach/problem-solving versus avoidant coping processes impacted caregiver health, as measured by caregivers' D-dimer coagulation stress response to a 3 minute speech task. The hypercoagulability biomarker D-dimer is a fibrin degradation product and has been reported to be an excellent measure of hemostatic functioning because it is highly sensitive and is relatively more detectable in human plasma than many other hemostasis factors [34]. D-dimer was measured at three separate time-points including baseline (after 20 minutes of rest), directly after a speech stressor task, and during recovery (15 minutes following the stressful speech task). Results indicated that subjects who reported greater levels of approach and problem-solving strategies had lower levels of D-dimer at all three time points. Results also indicated a three-way interaction between problem-solving approach strategies, caregiver status, and collection time of D-dimer. Follow-up analyses of this

interaction suggested that caregivers who used fewer problem-solving strategies had higher stress reactivity compared to their non-caregiving peers.

A study by Rabinowitz et al. [35] used a sample of 256 Latina and Caucasian female caregivers of elderly relatives with dementia to explore the association between positive and negative religious coping and cumulative health risk. Self-reported caregiver health behaviors including smoking, alcohol consumption, weight maintenance, exercise, and diet were collected and summed (exercise was reverse coded) to indicate low or high cumulative health risk. In addition to these variables, information about religious coping styles as assessed by the long form of the Brief Religious Coping Scale was collected to measure positive and negative coping styles [36]. Caregivers who endorsed more negative coping styles (e.g., “Wondered whether God has abandoned us”) had significantly higher cumulative health risk, particularly an increased likelihood for weight gain and increased dietary restriction. In contrast, positive religious coping (e.g., “Tried to find the lesson from God”) was associated with lower cumulative health risk including decreased likelihood for weight gain, but only in Latina caregivers. Taken together, these results imply that differences in religious coping styles may relate to differences in caregiver health risk and that future studies may want to further investigate the link between spirituality and health.

## Conclusion

The past 2 decades have produced numerous studies demonstrating that the chronic stresses associated with caring for a loved one are associated with physical and mental health consequences. The “first wave” of research demonstrated that caregivers suffered negative psychological and self-rated physical health outcomes. The “second wave” has focused on how stressed caregivers’ ‘objective,’ physiologic (e.g., biomarker) indicators of physical health are compromised relative to non-stressed populations (e.g., non-caregivers). Yet, while caregiving may be generally deleterious to one’s health, some caregivers escape these negative outcomes. Thus, in the past decade there has been a “third wave” of caregiving research that has examined resilience and coping factors that may protect caregivers from physical health risks. The current review highlights three resilience domains that may be ‘protective’ to caregivers, namely personal mastery, self-efficacy, and coping. We reviewed studies demonstrating either a direct or interactive effect of these resilience factors on physical health outcomes, with results demonstrating they may have broad, beneficial effects on biomarkers and clinical markers of disease (e.g., blood pressure).

Importantly, the resilience factors that were identified have been quite frequently the targets of psychosocial interventions for caregivers. For example, cognitive-behavioral and psycho-educational interventions often seek to improve caregiver mastery, self-efficacy, and coping resources [37] as mechanisms for reducing distress. In one such study, Coon et al. [38] randomly assigned 169 women caring for a relative with dementia into a series of psychoeducational and skills training classes focusing on either anger management or depression management. Caregivers in these two groups attended a series of classes and were taught both cognitive skills (e.g., positive self-talk) as well as behavioral skills (e.g., engaging in more pleasurable activities). Results indicated that participants in both the anger management and the depression management groups had significant decreases in their levels of anger and depression when compared to a wait-listed control group, and this improvement was mediated by significant increases in self-efficacy.

Yet, none of the studies in our review were treatment studies examining whether improvements in resilience had corresponding improvements in physical health indicators. Thus, we believe our review lays an early foundation for a “fourth wave” of caregiver research that employs experimental designs (e.g., treatments) to study the role of resilience

in physical health among caregivers. Indeed, a 2010 study by Williams and colleagues [39] conducted a controlled clinical trial testing the efficacy of a “Video-based Coping Skills” intervention for Alzheimer caregivers targeting depression and biomarkers of distress including blood pressure, cortisol, and heart rate. Caregivers assigned to the Video-based Coping Skills intervention experienced improvements in depression, anxiety, perceived stress, and blood pressure. These gains were maintained even after a 6-month follow-up assessment. Our review emphasizes the importance of similar studies directly testing the positive impact of resilience factors on health outcomes.

It is worth noting that there are other potential coping and resilience factors that may also mitigate the impact of chronic caregiving stress on health outcomes. For example, factors such as social support [40, 41], engagement in pleasant activities [42], self-esteem [43], positive attitudes towards the caregiving role [44], hope [45], and optimism [46] have been associated with improved psychological and physical health in caregivers and a variety of other populations. Although the resilience factors discussed in this review do not encompass the entire scope of resilience factors found in the literature to date, they do serve as a prospective guide to promising areas of intervention. The responsibilities and stressors that caregivers face are complex and consequently may require researchers to employ multi-component, evidence-based treatment strategies and to better define clinical outcome goals. The fact that there is a large amount of heterogeneity among the caregiver population makes targeted interventions challenging. However, there will continue to be an undeniable need for interventions to protect and improve caregiver health, highlighting the importance of continued research of this kind.

Future research investigating protective factors for caregiver health should also take into account the heterogeneity of the caregiving population in the U.S. Much of the research presented in this review has been conducted with primarily Caucasian caregiver samples. More research is needed in order to establish whether resilience factors such as personal mastery, self-efficacy and coping style have similar health benefits for caregivers of other ethnic and cultural groups. For example, previous research on racial and ethnic differences among caregivers suggests that African American caregivers may rely on different coping strategies than White caregivers [47], and consequently, the effects of coping strategies on caregiver health may also differ across race or ethnicity as well. Further research should also investigate whether similar resilience factors have health benefits for the growing population of child caregivers (i.e., adults caring for a parent with dementia). Interestingly, the issues of caregiver ethnicity and relationship to the care recipient may be related, as Black and Hispanic caregivers are less likely than white caregivers to be caring for a spouse, and more likely to be caring for another family member [48]. Future research should directly examine how both ethnicity as well as the caregiver’s relationship to the care recipient may impact the effect of resilience factors on the health of the caregiver.

The need for research on dementia caregiving is increasing rapidly as the U.S. population ages and the need for informal caregivers grows. Early research on dementia caregivers focused on the negative impact of caregiving stress on psychological outcomes (e.g., depression and anxiety) and physiological health outcomes (e.g., hypertension and cardiovascular illness). More recent caregiving research has focused on resilience factors that may protect some caregivers from experiencing these negative health outcomes. The present review highlighted findings from the past decade regarding resilience factors in dementia caregiving, focusing on the broad domains of personal mastery, self-efficacy, and coping style. Increased levels of personal mastery and self-efficacy, and increased use of positive coping strategies (e.g., problem-focused coping) appear to have a protective effect on a variety of health outcomes in dementia caregivers. Future research should consider factors such as caregiver ethnicity and relationship to the care recipient that may impact the

role of resilience factors in caregiver health outcomes. Future research should also employ experimental designs, including treatment studies, to more directly investigate the impact of resilience factors on the physical health of dementia caregivers.

## Acknowledgments

Support for this manuscript was provided by the National Institute on Aging (NIA) through award R01 AG031090.

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