

Next Steps in Caregiving Research

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The Past Three Decades: A Steady Rise in Caregiver Research

Three decades ago, research on dementia caregiving appeared to be an afterthought. For example, a PsycInfo search for scientific publications with “caregiver or caregiving” and “dementia or Alzheimer’s” in the title indicates only one publication in 1982, none in 1983, and one in 1984. However, as time moved on and scientists began understanding that caregiving had emotional and physical consequences, interest began to grow. Using these same search terms, the ‘first’ decade from 1982-1991 produced a total of 103 dementia caregiving manuscripts. During the second decade from 1992-2001 this total rose to 381, and from 2002-2011 there were 817 journal publications on dementia caregiving, with 114 in 2011 alone (see Figure 1). This represents nearly an 800% increase in research from the first decade to the latest. While this trend may reflect scientific trends unrelated to caregiving research (e.g., a greater number of scientific journals, greater number of academic researchers, and increased financial allocation to research in general), these factors do not completely account for the growth. By comparison, a PsycInfo search for scientific publications with “aging or elderly” in the title indicates a 223% growth over the same time period. Clearly, research on caregiving has had strong growth over the last 3 decades, and this interest appears to be growing.

What does the Literature Tell Us about Caregiving?

The scientific literature is replete with evidence that caring for a loved-one with dementia is a chronically stressful life experience that results in increased psychological¹⁻³ and physical morbidity,⁴⁻⁷ ultimately disposing distressed caregivers to increased risk for mortality.⁸ But what exactly “causes” caregivers’ health to decline? Over the years, a growing body of literature has identified some potential mechanisms by which caregivers might suffer premature morbidity or mortality. For example, caregivers appear to have compromised immune systems^{9,10} and are at increased risk for cardiovascular diseases,^{5-7,11} and caregivers appear to have biological profiles complicit in increasing these risks.¹²⁻¹⁹ Yet, not all caregivers suffer these outcomes. Always prevalent in caregiver research is the issue of resilience. Which caregivers are at risk and which are not?

While not a full review of the literature, social support,^{20,21} engagement in pleasant activities,²²⁻²⁵ personal mastery,²⁶⁻²⁹ self-efficacy,³⁰⁻³² and positive coping all appear to have some benefit to caregivers’ psychological and physical health despite the stresses they are experiencing. Yet the evidence to date regarding these relationships continues to be largely cross-sectional. These cross-sectional analyses are limited by providing a “snapshot” of a group of individuals and delineate whether two constructs are

associated at a particular point in time. While not unique to caregiving literature, much of the research to date regarding stress, resilience, and health has inferred causal relationships or made within-person inferences by comparing differences in these constructs across individuals.³³ At a basic level, this traditional analytic approach (of examining differences between individuals) assumes that if two individuals differ by 10 points on some variable (e.g., depression score) and also show a significant difference in some outcome (e.g., inflammation), then if one individual's depression score changes 10 points, that individual's inflammation level should also significantly change. However, between-person and within-person correlations can differ in both magnitude and in direction, whereby a statistically significant between-person correlation can occur even when not a single individual in the sample shows a positive within-person association. Inferring within-person effects from between-person analyses cannot be made without observing individuals when they are experiencing high and low levels of stress and coping across time.³³ Thus, a strong (and emerging) future in caregiver research is to examine longitudinal associations between stress, coping, and health outcomes. Many common statistical software programs now make multilevel analyses a common feature, thereby making within- and between-person analyses more amenable to researchers. This line of research could utilize daily diary approaches with stress, coping, and health outcomes, or might use longer time frames with several assessments across years of study. This approach would provide novel contributions to the literature by explicitly examining these within-person correlations, which can help answer intraindividual questions that may be of particular importance to clinicians (e.g., for informing interventions of appropriate treatment targets), as well as move closer to a mechanistic understanding of the effects of stress on health and well-being.

Treatments for Caregivers

A second direction for longitudinal studies is the continued emphasis on interventions to reduce caregiver distress. This avenue not only allows inference of causation, but allows us to understand how to improve psychological and physical well-being in this underserved population. For two decades, scientists have been fully aware of the consequences of caregiving, particularly to mental health and overall well-being. Thus, it is no surprise that over 120 intervention studies have been conducted for reducing caregiver distress over the past 3 decades.³⁴ The message derived from these studies is that interventions for caregivers, in general, are effective for reducing distress (e.g., burden, depression) and improving subjective well-being. Most notably, psychoeducation programs involving active participation of caregivers, as well as Cognitive-behavioral interventions, appear to have the strongest effects on a breadth of outcomes. In addition, a recent critical review identified numerous specific interventions that meet criteria to be considered "Evidence-based treatments" (EBTs) for reducing distress in caregivers.³⁵ These interventions are categorized into three broad categories: a) *psychoeducational-skill building* interventions, which are designed to increase caregivers' knowledge of Alzheimer's Disease and teach specific coping skills for managing problems associated with the disease, b) *psychotherapy-counseling*, which include individual or group-based therapies grounded in cognitive and behavioral theories, and c) *multicomponent interventions*, which incorporate at least two separate and unique therapeutic

strategies woven into one intervention package (e.g., skill-building combined with respite services). This identification of EBTs is extremely important, not only because EBTs are a cornerstone of medicine and psychology, but also because it provides scientists, clinicians, and caregivers with direction on what works for reducing distress in this population. Indeed, utilization of EBTs not only increases the likelihood that caregivers will experience improved quality of life, but may also reduce treatment costs via reducing social, functional, and medical consequences that may result from caregiver distress.

Yet, issues remain regarding intervention research. First, the implementation of these EBTs continues to be a challenge. A PsychInfo search with keywords “caregiver or caregiving”, “dementia or alzheimer’s”, and “implementation or implement or dissemination or disseminate” resulted in only 11 publications over the past three decades. Indeed, despite identification of EBTs for caregivers, it is unclear to what extent these interventions are being utilized. In 2007, the Rosalyn Carter Institute convened a workshop to discuss the use of EBTs for caregivers. The workshop, sponsored by the NIH, Veterans Administration, and the US Department of Health and Human Services, concluded that “The majority of effective interventions for caregivers were not being implemented through the aging network.”³⁶ However, it remains unclear what services caregivers are accessing across the United States, particularly EBTs. As but one glimpse, from 2001-2004, NIA funded the REACH 2 project, an intervention study designed to improve distress in caregivers. In this study, 647 participants from 5 cities were asked, prior to participating in the trial, whether or not they had visited a counselor or attended a support group within the past 30 days. Only 10% indicated they had seen a counselor and 14.5% had attended a support group. While this may be due to caregivers’ lack of desire for, or failure to seek interventions, a more likely scenario is that caregivers are not aware of or are not offered interventions (particularly EBTs) when seeking services. The mismatch between research knowledge and community practice is common in many fields, but scientists are in a unique position to identify methods and treatments that are best suited to bridge the gap between what is “effective” and what is utilized. Identification of the barriers to utilization of treatments in the community, from the perspective of both consumers and providers, is a needed avenue of research. Because clinical trials are often confined in terms of their reach, and are only capable of serving a very small portion of caregivers across the country, researchers will need to develop methods of testing evidence-based interventions via technology or in community-based settings in order to sustain adequate use of these interventions by providers across the country.

Second, given the number of caregiver intervention studies, along with the broad effects of these interventions on psychosocial outcomes, we are now positioned to test various interventions against each other in a comparative effectiveness trial. Conducting this trial has many scientific benefits. For example, currently, intervention studies to improve caregiver distress often differ not only on primary outcomes (e.g., burden, depressive symptoms, subjective well-being), but also which measures best assess these outcomes. Thus, comparative effectiveness studies allow for consistency in specific, well-defined outcome measures to adequately inform scientists of the interventions’ usefulness. When conducting this trial, strong consideration should be given to community input on the interventions themselves. What do consumers think of the interventions? How about providers? Willingness to use the intervention “in the real world” should be of strong consideration, lest we end up discovering which

intervention works best but nobody wants to provide it. Cost is likely to be of consideration, both to consumers and providers, and should be given careful consideration. Finally, to any extent possible, this type of trial could significantly advance the “real-world” care offered to caregivers if interventions were conducted by providers in the community (appropriately trained by scientific research teams), with secondary assessment of provider outcomes (e.g., turnover, satisfaction with the treatment, provider burden, cost), thereby enhancing our understanding of what interventions (and their characteristics) are most likely to be sustainable in the community.

Third, although there is a wealth of information on the efficacy of caregiver interventions,³⁴ the vast majority of the published research has examined treatment effects but was sufficiently underpowered to examine the relative efficacy of these interventions for racial/ethnic subgroups. It is interesting to note that the largest systematic review of caregiver interventions examined a number of treatment moderators (e.g., individual vs. group treatment; length of the intervention; age, gender), but race/ethnicity was not included. This review did not encompass the REACH studies, which consisted of significant numbers of ethnic minorities³⁷⁻⁴¹, but these important studies suggest that caregiver interventions may be moderated by race/ethnicity. While the development of interventions specific to ethnic groups is not new, there is much room for identifying what specific modifications are necessary to reduce these moderating effects. As examples, is there something about the intervention material that is not acceptable to certain racial/ethnic groups? Or is it the manner in which the material is delivered hindering treatment response, such that adaptations to delivery are needed? These and other cultural issues can be considered in treatment designs with adequate power to detect effects.

Fourth, as discussed above, much recent attention is being given to the biological and physical health of caregivers, particularly as it relates to stress and coping. Yet, very few intervention studies have examined the health benefits of reducing caregiver distress and boosting coping mechanisms. Research in this vein is important for several reasons. First, if interventions are efficacious for improving psychosocial as well as physical health outcomes, we are better informed about the biopsychosocial mechanisms inherent in the morbidity and mortality risks that caregivers face. Second, treatment benefits to physical health have strong potential to reduce the costs of caregiving, not only to the caregiver but to the healthcare system. This appears particularly true when considering that caregivers use a disproportionately high amount of healthcare services, including physician visits, prescription medications,⁴² emergency department visits, and hospitalizations.⁴³ These consequences appear most among caregivers suffering from greater depressive symptoms, suggesting that depression may be an early target for interventions for us to see health benefits. While more work is needed to identify the specific biological outcomes of interest, currently the evidence suggests these may broadly include markers of immune system functioning and cardiovascular risk, but can also include real-world clinical markers such as hospital visits/hospitalizations or diagnosis of clinical diseases (e.g., hypertension, CVD).

Summary and Conclusions

Clearly, caregiving continues to be a strong interest to researchers worldwide. It is our opinion that this trend will continue for the foreseeable future as the worldwide (and U.S.) elderly population continues to grow. This aging trend will likely result in a steady rise in the number of informal caregivers, many of whom will seek answers on how they can manage the stresses and consequences of providing care. Researchers and clinicians are well-suited to set up a network of information and care to meet this coming demand if we choose to invest in its development. As we have discussed in this document, development of this network will mean (a) understanding the longitudinal risks and mechanisms of caregiver health and well-being, that incorporate novel research designs (e.g., daily diary studies) and statistical techniques, (b) continued investment in interventions to reduce caregiving risks, particularly interventions that utilize technology or that are more easily implemented in community settings, (c) understanding what interventions are most effective for racial/ethnic minorities and what factors modify the effectiveness of existing interventions within minority groups, (d) conducting comparative effectiveness research trials to determine which interventions are most effective across a broad range of outcomes, and (e) well-designed intervention trials that provide a stronger understanding of the biopsychosocial mechanisms by which caregiving may or may not translate to physical illness.

In summary, we do not wish to suggest these are the only important topics for the future of caregiving research. Clearly there are many topics not discussed here that are important for understanding how best to help caregivers. What we hoped to provide was our opinions on how not only to understand how to best help caregivers manage their stress, but to put in place a solid foundation in which this understanding is made readily available to caregivers in their own communities. We sincerely hope you, the reader, will join us in achieving this goal.

References

1. Schulz R, O'Brien AT, Bookwala J et al. Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates, and causes. *Gerontologist* 1995;35: 771-791.
2. Mausbach BT, Chattillion EA, Roepke SK et al. A comparison of psychosocial outcomes in elderly Alzheimer's caregivers and non-caregivers. *Am J Geriatr Psychiatry* In press.
3. Pinquart M, Sörensen S. Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychol Aging* 2003;18: 250-267.
4. Vitaliano PP, Young HM, Zhang J. Is caregiving a risk factor for illness? *Current Directions in Psychological Science* 2004;13: 13-16.
5. Lee S, Colditz GA, Berkman LF et al. Caregiving and risk of coronary heart disease in U.S. women: A prospective study. *Am J Prev Med* 2003;24: 113-119.
6. Capistrant BD, Moon JR, Berkman LF et al. Current and long-term spousal caregiving and onset of cardiovascular disease. *J Epidemiol Community Health* 2012;66: 951-956.
7. Capistrant BD, Moon JR, Glymour MM. Spousal caregiving and incident hypertension. *American journal of hypertension* 2012;25: 437-443.
8. Schulz R, Beach SR. Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. *JAMA* 1999;282: 2215-2219.
9. Kiecolt-Glaser JK, Glaser R, Gravenstein S et al. Chronic stress alters the immune response to influenza virus vaccine in older adults. *Proc Natl Acad Sci U S A* 1996;93: 3043-3047.
10. Kiecolt-Glaser JK, Marucha PT, Malarkey WB et al. Slowing of wound healing by psychological stress. *Lancet* 1995;346: 1194-1196.
11. Mausbach BT, Patterson TL, Rabinowitz Y et al. Depression and distress predict time to cardiovascular disease in dementia caregivers. *Health Psychol* 2007;26: 539-544.
12. Kiecolt-Glaser JK, Preacher KJ, MacCallum RC et al. Chronic stress and age-related increases in the proinflammatory cytokine IL-6. *Proc Natl Acad Sci USA* 2003;100: 9090-9095.
13. von Känel R, Dimsdale JE, Adler KA et al. Exaggerated plasma fibrin formation (D-dimer) in elderly Alzheimer caregivers as compared to noncaregiving controls. *Gerontology* 2005;51: 7-13.
14. von Känel R, Dimsdale JE, Patterson TL et al. Acute procoagulant stress response as a dynamic measure of allostatic load in Alzheimer caregivers. *Ann Behav Med* 2003;26: 42-48.
15. von Känel R, Dimsdale JE, Ziegler MG et al. Effect of acute psychological stress on the hypercoagulable state in subjects (spousal caregivers of patients with Alzheimer's disease) with coronary or cerebrovascular disease and/or systemic hypertension. *Am J Cardiol* 2001;87: 1405-1408.
16. Mausbach BT, Roepke SK, Ziegler MG et al. Association between chronic caregiving stress and impaired endothelial function in the elderly. 2010;55: 2599-2606.
17. Vitaliano PP, Zhang J, Scanlan JM. Is caregiving hazardous to one's physical health? A meta-analysis. *Psychol Bull* 2003;129: 946-972.
18. Roepke SK, Mausbach BT, Patterson TL et al. Effect of Alzheimer caregiving on allostatic load. *J Health Psychol* 2011;16: 58-69.

19. Mausbach BT, von Känel R, Aschbacher K et al. Spousal caregivers of patients with Alzheimer's disease show longitudinal increases in plasma level of tissue-type plasminogen activator antigen. *Psychosomatic medicine* 2007;69: 816-822.
20. Franks M, Stephens A. Social support in the context of caregiving: husbands' provision of support to wives involved in parent care. *J Gerontol* 1996;51: P43-52.
21. Kim J, Knight B. Effects of caregiver status, coping styles, and social support on the physical health of Korean American caregivers. 2008;48: 287-299.
22. Pressman S, Matthews K, Cohen S et al. Association of enjoyable leisure activities with psychological and physical well-being. 2009;71: 725-732.
23. Mausbach BT, Chattillion E, Roepke SK et al. A longitudinal analysis of the relations among stress, depressive symptoms, leisure satisfaction, and endothelial function in caregivers. *Health Psychol* 2012;31: 433-440.
24. Mausbach BT, Coon DW, Patterson TL et al. Engagement in activities is associated with affective arousal in Alzheimer's caregivers: A preliminary examination of the temporal relations. 2008;39: 366-374.
25. Mausbach BT, Roepke SK, Depp CA et al. Integration of the pleasant events and activity restriction models: development and validation of a "PEAR" model of negative outcomes in Alzheimer's caregivers. 2011;42: 78-88.
26. Mausbach BT, Patterson TL, von Känel R et al. Personal mastery attenuates the effect of caregiving stress on psychiatric morbidity. 2006;194: 132-134.
27. Mausbach BT, von Känel R, Patterson TL et al. The moderating effect of personal mastery and the relations between stress and Plasminogen Activator Inhibitor-1 (PAI-1) antigen. 2008;27: S172-S179.
28. Mausbach BT, Mills PJ, Patterson TL et al. Stress-related reduction in personal mastery is associated with reduced immune cell beta2-adrenergic receptor sensitivity. *Int Psychogeriatr* 2007;19: 935-946.
29. Mausbach BT, Patterson TL, Von Känel R et al. The attenuating effect of personal mastery on the relations between stress and Alzheimer caregiver health: A five-year longitudinal analysis. *Aging Ment Health* 2007;11: 637-644.
30. Mausbach BT, von Kanel R, Roepke SK et al. Self-efficacy buffers the relationship between dementia caregiving stress and circulating concentrations of the proinflammatory cytokine Interleukin-6. *Am J Geriatr Psychiatry* 2011;19: 64-71.
31. Harmell AL, Mausbach BT, Roepke SK et al. The relationship between self-efficacy and resting blood pressure in spousal Alzheimer's caregivers. 2010.
32. Mausbach BT, Roepke SK, Chattillion EA et al. Multiple mediators of the relations between caregiving stress and depressive symptoms. *Aging Ment Health* 2012;16: 27-38.
33. Affleck G, Zautra A, Tennen H et al. Multilevel daily process designs for consulting and clinical psychology: a preface for the perplexed. *J Consult Clin Psychol* 1999;67: 746-754.
34. Pinquart M, Sorensen S. Helping caregivers of persons with dementia: which interventions work and how large are their effects? *Int Psychogeriatr* 2006;18: 577-595.

35. Gallagher-Thompson D, Coon DW. Evidence-based psychological treatments for distress in family caregivers of older adults. *Psychol Aging* 2007;22: 37-51.
36. Birkel R, Granberry L, Alston G. Evidence-based practices and the Rosilynn Carter Institute. *Generations* 2010;34: 13-19.
37. Burgio L, Stevens A, Guy D et al. Impact of two psychosocial interventions on White and African American family caregivers of individuals with dementia. *Gerontologist* 2003;43: 568-579.
38. Gallagher-Thompson D, Coon DW, Solano N et al. Change in indices of distress among Latino and Anglo female caregivers of elderly relatives with dementia: site-specific results from the REACH national collaborative study. *Gerontologist* 2003;43: 580-591.
39. Gitlin LN, Winter L, Corcoran M et al. Effects of the home environmental skill-building program on the caregiver-care recipient dyad: 6-month outcomes from the Philadelphia REACH initiative. *Gerontologist* 2003;43: 532-546.
40. Eisdorfer C, Czaja SJ, Loewenstein DA et al. The effect of a family therapy and technology-based intervention on caregiver depression. *Gerontologist* 2003;43: 521-531.
41. Belle SH, Burgio L, Burns R et al. Enhancing the quality of life of dementia caregivers from different ethnic or racial groups: a randomized, controlled trial. *Ann Intern Med* 2006;145: 727-738.
42. Haley W, Levine E, Brown S et al. Psychological, social, and health consequences of caring for a relative with senile dementia. *J Am Geriatr Soc* 1987;35: 405-411.
43. Schubert C, Boustani M, Callahan C et al. Acute care utilization by dementia caregivers within urban primary care practices. *J Gen Intern Med* 2008;23: 1736-1740.

Figure 1. Dementia caregiving publications in scientific journals over the past 3 decades.

