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Caregivers of People with Mild Cognitive Impairment and Dementia: Characterizing Social and Psychological Outcomes

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Abstract

Background: Little is known about caregiving across the spectrum of cognitive impairment (mild cognitive impairment (MCI) to dementia) and how early life and sociocultural factors affect caregiver health. In this study, we characterized differences between caregivers of those with MCI versus those with dementia.

Methods: A total of 158 caregivers were enrolled in this cross-sectional study, most of whom were dementia caregivers (65%). Caregivers completed questionnaires on depressive symptoms, self-rated health (SRH), perceived burden and stress, as well as psychosocial and demographic measures.

Results: Caregivers of those with MCI reported fewer depressive symptoms and lower stress and burden compared to dementia caregivers. In adjusted analyses- caregivers with greater stress reported more depressive symptoms. For SRH, at lower stress levels, having a sibling die before age 18 (i.e., early life adversity) was associated with poorer SRH; at higher stress levels, having early life adversity was associated with better SRH. At lower burden levels, more live births was associated with worse SRH; at higher burden levels, more live births was associated with better SRH.

Conclusions: Early life factors are relevant for caregivers of those with cognitive impairment and targeted prevention and early intervention may be helpful in alleviating caregiver burden and stress.

Keywords

dementia; caregiving; adversity; stress; resilience

INTRODUCTION

In the U.S., the older adult population is rapidly increasing, and accompanying this growth is the number of family caregivers of people with cognitive impairment related to dementia.¹ While caregiving may be associated with positive rewards and feelings of satisfaction,

certain challenges may place caregivers at risk for significant health and mental health problems.² Caring for older adults with chronic health conditions, such as dementia, contributes to psychiatric morbidity in the form of higher rates of depressive and anxiety disorders.³ Moreover, caregivers of those with dementia often face a greater emotional and physical burden than caregivers of older adults with other health conditions.⁴ Hence, caregiving for a family member with cognitive impairment has become a public health issue and is expected to become increasingly prominent with the aging population.⁵

Caring Across the Spectrum of Cognitive Impairment

Although there is a substantive literature on dementia caregiving and health, less is known about those who care for individuals diagnosed with mild cognitive impairment (MCI). MCI is an early stage of memory loss or other cognitive impairment in individuals who maintain the ability to independently perform most activities of daily living.⁶ The prevalence of MCI varies widely; the 2022 Alzheimer's Disease Facts and Figures⁶ report that approximately up to 18% of people aged 60 or older live with MCI. The role of caring for someone with MCI differs from that of caring for someone with dementia.⁷ Factors such as the clinical course and prognosis of MCI and uncertainty about the development of dementia pose a unique set of challenges for the caregivers of these individuals. While those with MCI might not need caregivers in the same sense that those with dementia do, MCI caregivers (or companions/care partners at this point), may be just starting caregiving activities. The term MCI and whether or not those with MCI need caregivers is a clinical and diagnostic question, separate from the reality of those families who have a family member with diagnosed cognitive impairment, diagnoses that can occur in a variety of places and have varying levels of accuracy. Some individuals diagnosed with MCI may actually be closer to dementia, and so require a fair amount of help, especially if their family member is limited beyond cognitive issues (e.g., physical disability, limited English proficiency, etc.). Research has shown that MCI is associated with significant morbidity, potential economic loss to the individual and family, and frustration and distress in caregivers,^{8,9} and that MCI caregivers' needs revolve more around their person's neurobehavioral symptoms rather than functional disability needs for AD caregivers.¹⁰ Understanding caregiving across the spectrum of cognitive impairment has implications for early intervention and treatment.

Social and Contextual Factors Associated with Caregiver Outcomes

Compared to non-Hispanic White (NHW) adults, in general, racial and ethnic minority people are more likely to take on the burden of caregiving and are at greater risk for depression.¹¹ Worse caregiver distress and burden may exacerbate existing health and healthcare disparities. Yet the study of racially and ethnically diverse caregivers across the spectrum of cognitive impairment related to Alzheimer's disease and related dementias (ADRD) remains an unexplored area. Moreover, much of the research on caregiving centers focuses on individual- and family level factors associated with stress; few studies focus on the social and life-course context of caregiving, which can strongly impact caregivers. Thus, it is unclear whether sociocultural (e.g., familism) and early life adversity variables, which are more prevalent in certain racial and ethnic populations, impact caregiver health.

Cultural values such as familism may influence response to the caregiving role, and variability and use of coping strategies by minority caregivers. Familism is a core cultural value that includes commitment to support family members and deferring to family for how one should think or behave.¹² Stronger adherence to familism may help caregivers assume the caregiver role with less apprehension or distress. Although familism is a universal value and not unique to any racial or ethnic group, individuals and cultures can vary in the degree to which collectivistic values, such as familism play a role in their behaviors.¹³

Ecological-contextual theories of caregiving suggest that neighbors and the surrounding context can be important sources of support for caregivers.^{14,15} Thus, even though caregiving may be difficult, social support might protect against caregiver stress.¹⁶ Lastly, life course theories suggest that early life adversity is a key factor that could exacerbate the stress of caregiving, particularly for racial and ethnic minorities, but has not been deeply examined in the caregiving literature.¹⁷ Early life adversity, including childhood exposure to violence, abuse, neglect, and financial hardship, is an important determinant of adult health and linked to an increased risk of many physical conditions (e.g., diabetes, cardiovascular disease). Furthermore, early life adversity may amplify stress reactivity and impede mechanisms for adaptive coping in caregivers.¹⁸

Present Study

The current study aims to address the gap in caregiving research regarding how early life adversity and sociocultural and contextual factors contribute to caregiver health, and to do so in a diverse population of caregivers (e.g., including MCI and dementia caregivers). The objectives of the study were to examine differences between caregivers of those with MCI vs. those with dementia as well as the role of caregiver stress and burden on caregiver depressive symptoms and self-rated health. Figure 1 illustrates our conceptual model. We hypothesized that (1) there would be heterogeneity in caregiver depressive symptoms and self-rated health that differed by sociocultural and contextual variables, and (2) that the association between caregiver stress and burden and caregiver depressive symptoms and self-rated health would be moderated by early life adversity and social support, such that the negative impact of caregiver stress and burden on outcomes would be exacerbated by early life adversity and mitigated by social support.

METHODS

Sample and Design

Caregivers were recruited from two major sources – the community and an Alzheimer’s Disease Research Center (ADRC). Caregivers in the community were recruited through caregiver workshops held at the University of California, Davis (UCD), fliers placed in clinics, and word of mouth. Caregivers recruited from the UCD ADRC were included if they were listed as a caregiver or family member of a research participant diagnosed with MCI or dementia in the ADRC. The ADRC cohort is a longitudinal study of cognitive aging in an educationally, ethnically, and cognitively diverse cohort of older adults. The cohort has wide variability in educational attainment and spans the spectrum from normal cognition to MCI to dementia.¹⁹

Caregivers were included if they (a) self-reported as NHW, Hispanic/Latino, Black/African American, or Asian/Pacific Islander; (b) spoke English or Spanish; and (c) were currently providing care to a family member with diagnosed MCI/questionable cognitive impairment or dementia. Caregivers who met eligibility criteria and were interested in participating completed a psychosocial survey either online (via REDCap) or by mail.^{20,21} Participants read an information letter about the study that indicated that by virtue of completing the survey, they provided consent to participate. This study was approved by the Institutional Review Board of UCD.

Measures

Caregiver psychosocial variables.—We used the Zarit Burden Inventory (ZBI)^{22,23} and Cohen's Perceived Stress Scale²⁴ to assess perceived burden and stress, respectively. The outcome variables in the study were depressive symptoms, as measured by the Center for Epidemiologic Surveys-Depression (CES-D)²⁵ scale, and self-rated health measured via a single item on a scale from 1-5.²⁶

Caregiving variables.—Caregiving context variables included length of time caregiving (in years) and hours spent caregiving (per week), diagnosis of the care recipient (MCI or dementia), care recipient-caregiver relationship (spouse or equivalent vs. parent/parent-in-law), and whether or not the caregiver lived with the care recipient (yes/no).

Social support.—The Lubben Social Network Scale (LSNS-6) is a brief 6-item measure of perceived social support²⁷ and was developed for use in the older population. Items ask about size, closeness, and frequency of contacts with relatives and also with friends.

Early life adversity.—We used items from the Life Experiences and Activities Form (LEAF) developed by faculty at the UC Davis ADRC. Questions ask about whether or not caregivers had any siblings die before age 18, the number of live births caregiver's mother had (e.g., number of siblings), maximum number of kids living in the home, and whether or not the person ever went hungry as a child. These items have been used in studies assessing associations between early life adversity and cognition.^{28,29} For example, in the literature on early life adversity, having a high number of children might indicate lower SES.²⁸

Contextual variables.—Health literacy of the caregiver is important given that their care recipient relies on them for issues of health management (e.g., reading and understanding a medication prescription).³⁰ Health literacy was assessed using a question adapted from the 2007 California Health Interview Survey (CHIS) that asks about difficulty understanding and reading information related to their health (e.g., instructions on a prescription bottle).³¹ Neighborhood cohesion was assessed using an average of two items also adapted from the CHIS that asks whether or not people in the neighborhood are willing to help each other and whether or not people in the neighborhood can be trusted. Item responses ranged from *disagree* to *strongly agree*.

Familism scale.—The familism scale³² taps into three different dimensions: familial obligations, perceived support from the family, and family as referents. Sample items

include, “*One should make great sacrifices in order to guarantee a good education for his/her children,*” and “*When one has problems, one can count on the help of relatives.*” The scale has good internal consistency.³³

Positive aspects of caregiving scale.—The positive aspects of caregiving scale (PAC)³⁴ has two subscales: self-affirmation and outlook on life. The self-affirmation factor (n=6 items) describes the confident and capable self-image brought by the caregiving role. The outlook on life factor (n=3 items) describes enhanced interpersonal relationships. Caregivers rate the extent to which they agree with items such as, “*Made me feel strong and confident,*” and “*Made me feel needed.*”

Covariates.—Demographic covariates of the caregiver included where caregiver was recruited (community vs. ADRC), gender, age, race/ethnicity (NHW vs. racial/ethnic minority), marital status, primary language (English, Spanish, or Other), and education level (categorical variable: high school or less, some college, or college or higher). Care recipient variables included diagnosis (MCI vs. dementia) and age of care recipient.

Data Analysis

Descriptive statistics and multivariable linear regression models examining cross-sectional associations between perceived stress and burden with self-rated health and depressive symptoms were estimated using SAS version 9.4.³⁵ For all analyses, both p-values and confidence intervals were used to determine statistical significance.

To estimate the most parsimonious regression model, we first conducted univariate linear regressions of each variable with the outcome of depressive symptoms and self-rated health. Next, we included all variables in the univariate models that were significant at $p < .10$ (with either outcome) in a multiple regression model. Prior to building the final multivariate linear regression model, we checked for collinearity among the variables using the SAS VIF option and excluded any variable whose VIF value was greater than 10. Then, we estimated interaction terms of perceived stress by social support and perceived stress by early life adversity variables, as well as burden by social support and burden by early life adversity variables. We added each interaction term one by one to the linear regression models to assess for effect modification.

RESULTS

Descriptive Characteristics

The majority of the sample were women ($n = 138$, 87%) and recruited from the community ($n = 100$, 63%). Participants' ages ranged from 25 to 95 years, with a mean age of 65 years. Chi-square and t-tests were conducted to test whether key characteristics differed by diagnosis of the care recipient. As seen in Table 1, results indicated that caregivers of those with dementia were more likely to be from the community (72.5%) than caregivers of those with MCI (41.2%). Caregivers of those with MCI reported lower (i.e., better) scores on depressive symptoms (12 vs. 15.2), perceived stress (13.37 vs. 16.03), and burden (27.49 vs. 35.88).

Regression Analyses

Prior to conducting the regression analyses, we ensured that all normality assumptions of the outcomes were met. Table 2 shows results of the univariate regression analyses separately for depressive symptoms and self-rated health. For depressive symptoms, we found that perceived stress (standardized beta (β) = 0.722), caregiver type (β = 0.157), health literacy (β = -0.19), familism (familial support; β = -0.176), caregiver age (β = -0.227), NHW race (β = -.174), social support (β = -0.305), PAC (positive outlook on life; β = -0.285), and burden (β = 0.401) were significant at $p < .10$. For self-rated health, we found that perceived stress (β = -0.312), number of live births (β = 0.036), going hungry as a child (β = 0.246), familism (familial support; β = 0.168), having a college degree or higher (β = 0.298), marital status (β = 0.146), and neighborhood cohesion (β = 0.217) were significant at $p < .10$. Thus, all of these variables were included in the final models for both outcomes.

Table 3 shows multivariate regression model results for depressive symptoms and self-rated health. In adjusted analyses, caregivers who reported greater stress (β = 0.92, 95% CI: 0.72, 1.11) reported more depressive symptoms. No other variables were associated with depressive symptoms. Caregivers who reported greater stress (β = -0.05, 95% CI: -0.08, -0.02) and who went hungry as a child (β = -0.55, 95% CI: -1.06, -0.04) reported worse self-rated health. Caregivers who had a college or higher degree (β = 0.58, 95% CI: 0.06, 1.10) reported better self-rated health. In moderation analyses, no significant interactions emerged for depressive symptoms. For self-rated health (data not shown), there was a significant perceived stress by sibling death (β = 0.08, 95% CI: 0.02, 0.15) and caregiver burden by number of live births interaction (β = 0.01, 95% CI: 0.0004, 0.01).

As shown in Figure 2a, at low levels of stress, having a sibling die before age 18 (i.e., early life adversity) was associated with poorer self-rated health, but at higher levels of perceived stress, having early life adversity was associated with better self-rated health, compared to those who didn't have a sibling death. In Figure 2b, at low levels of burden, a high number of live births (i.e., early life adversity) was associated with worse self-rated health, but at higher levels of burden, having early life adversity was associated with better self-rated health, compared to those who with a low number of live births.

DISCUSSION

We hypothesized that there would be heterogeneity in caregiver depressive symptoms and self-rated health and that the association between caregiver stress and burden and caregiver outcomes would be moderated by early life adversity and social support, such that the negative impact of caregiver stress and burden on outcomes would be exacerbated by early life adversity and mitigated by greater social support. We found that caregivers of those with MCI versus dementia differed in that the latter reported greater stress and burden. Some research suggests that the uncertainty that comes with an MCI diagnosis (e.g., not knowing whether it would eventually lead to dementia) would elicit greater stress and anxiety on the part of caregivers. However, this was not the case in the present study. Rather, the toll of caregiving for someone with dementia appears to be greater. Studies have consistently shown that caregivers of those with dementia face greater burden and stress compared to caregivers of those with other chronic health conditions.³ However, the literature is less clear

when it comes to caregiving along the spectrum of cognitive impairment. Our study suggests that regardless of the potential anxiety that might come with the uncertainty of caring for someone with MCI, caring for those with dementia is more burdensome and stressful. This may be due to the behaviors and personality symptoms of those with dementia. Data from the Sacramento Aging and Latino Study revealed the highest levels of depression in non-spousal caregivers of cognitively impaired individuals with high levels of neuropsychiatric symptoms (Hinton et al., 2003). Although we didn't have data on specific behaviors, those with dementia may be more agitated and/or have sleeping or wandering behaviors that make caregiving stressful.

Our hypotheses regarding caregiver burden and stress were only partially supported. While we did find that perceived stress was associated with both depressive symptoms and self-rated health, caregiver burden was not associated with these outcomes. It may be that the measure of caregiver burden in this study, although a widely used measure for assessing burden, did not capture the full psychosocial spectrum of health. Although caregiver burden was low to average in our sample, and caregivers of those with dementia did report higher burden, there may not be sufficient variation in caregiver burden for it to associate with outcomes. It also may be that the association between caregiver burden and outcomes differs by racial/ethnic group. Lastly, the negative impacts of caregiver burden may be offset by positive aspects of caregiving, as noted in other studies.³⁶

Lastly, our results indicated that early life adversity did moderate the association between caregiver stress and burden and self-rated health, but in a direction opposite of our hypothesis. It appears that early life adversity is associated with poorer self-rated health at low levels of stress or burden; however, at higher levels, it potentially has a protective effect on self-rated health. That is, at high levels of caregiver stress and burden, early life adversity- namely, sibling death and having a high number of live births or children in the family, is associated with better self-rated health. These findings were unexpected and contrary to studies indicating that adversity may exacerbate the effect of later life stress and burden on health outcomes.³⁷ However, other work has shown that early life adversity, as measured by food deprivation and being thinner in childhood, was associated with a slower rate of cognitive decline in older African Americans.³⁸ Similarly, Xiang, Cho, Sun, Wang³⁹ found that parental substance abuse in childhood was associated with a lower risk of incident cognitive impairment in the Health and Retirement Study. Our findings suggest that resilience and post-traumatic growth may be possible mechanisms in this sample of caregivers.⁴⁰ However, these ideas are speculative and warrant future research.

Social support did not moderate the association of caregiver stress and burden on depression and self-rated health. This result was surprising and contrary to previous research.^{41,42} The non-significant result in our analysis may be due to the fact that we also included caregivers of individuals with MCI. As indicated in the results, burden and stress were lower for this group of caregivers and may have contributed to the lack of a significant association. It may also be due to the somewhat smaller sample size of our study.

This study was not without limitations. Our study was cross-sectional and thus we cannot infer causality- for example, that caregiver burden and stress predicts poorer self-rated health

and greater depressive symptoms. Although we had a decent sample size, a larger sample of caregivers (especially those with MCI) would have allowed us to test other potential moderating factors (e.g., positive aspects of caregiving). It was unclear what specific tasks MCI caregivers in this study helped with, but Garand et al. reported that MCI spouses/caregivers endorsed caregiving responsibilities such as greater frequency of errands, more coordination of transportation, and greater management of medications and business affairs.⁸ Early life measures were proxies of adversity and may be limited in their actual measure of adversity; also they were self-report and may be subject to recall bias. Generalizability of the study and its findings are somewhat limited given our focus on caregivers from Northern California only. Lastly, our racial and ethnic minority participants had to be aggregated due to the smaller sizes of some groups (e.g., Asian Americans). Future studies should include larger samples with sufficient diverse representation to assess how factors that associate with caregiver outcomes may differ among different groups.

In spite of these limitations, this study contributes to the literature by including care partners of those with MCI as well as dementia, and highlighting the important role of contextual factors in caregiver outcomes. Early life adversity should be considered in models of caregiver stress and burden. Only recently have life-course models been referenced in the caregiving literature. Caregiving does not occur in a vacuum; rather, caregivers are surrounded by the social and early life context, and these factors also impact the caregiving experience. Further research is needed to replicate these findings in a larger and more diverse sample, and to see if these results may be even further nuanced depending on race and ethnicity of the caregivers.⁴³

Conflicts of Interest and Source of Funding:

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REFERENCES

1. Roberts AW, Ogunwale SU, Blakeslee L, Rabe MA. The Population 65 Years and Older in the United States: 2016. Washington DC 2018.
2. Yaffe K, Fox P, Newcomer R, et al. Patient and caregiver characteristics and nursing home placement in patients with dementia. *JAMA*. 2002;287(16):2090–2097. [PubMed: 11966383]
3. Schulz R, Sherwood PR. Physical and mental health effects of family caregiving. *Am J Nurs*. 2008;108(9 Suppl):23–27; quiz 27.
4. Caregiver Statistics: Demographics. 2016; <https://www.caregiver.org/resource/caregiver-statistics-demographics/>. Accessed June 20, 2023.
5. Talley RC, Crews JE. Framing the public health of caregiving. *American Journal of Public Health*. 2007;97(2):224–228. [PubMed: 17194871]
6. Alzheimer's Association. Alzheimer's Disease Facts and Figures. *Alzheimers Dement* 2022.
7. Blieszner R, Roberto KA. Care partner responses to the onset of mild cognitive impairment. *Gerontologist*. 2010;50(1):11–22. [PubMed: 19491355]

8. Garand L, Dew MA, Eazor LR, DeKosky ST, Reynolds CF III. Caregiving burden and psychiatric morbidity in spouses of persons with mild cognitive impairment. *Int J Geriatr Psychiatry*. 2005;20:512–522. [PubMed: 15920711]
9. Laketos C, Lopez O, Jones B, Fitzpatrick A, Breitner J, De-Kosky S. Prevalence of neuropsychiatric symptoms in dementia and mild cognitive impairment: Results from the Cardiovascular Health Study. *Jama*. 2002;288:1475–1483. [PubMed: 12243634]
10. Ryan KA, Weldon A, Huby NM, et al. Caregiver support service needs for patients with mild cognitive impairment and Alzheimer disease. *Alzheimer Dis Assoc Disord*. 2010;24(2):171–176. [PubMed: 19571729]
11. Dilworth-Anderson P, Williams IC, Gibson BE. Issues of race, ethnicity, and culture in caregiving research: a 20-year review (1980–2000). *Gerontologist*. 2002;42(2):237–272. [PubMed: 11914467]
12. Llanque SM, Enriquez M. Interventions for Hispanic caregivers of patients with dementia: a review of the literature. *Am J Alzheimers Dis Other Demen*. 2012;27(1):23–32. [PubMed: 22467412]
13. Sayegh P, Knight BG. The effects of familism and cultural justification on the mental and physical health of family caregivers. *J Gerontol B Psychol Sci Soc Sci*. 2011;66(1):3–14. [PubMed: 20797972]
14. Aneshensel CS, Wight RG, Miller-Martinez D, Botticello AL, Karlamangla AS, Seeman TE. Urban neighborhoods and depressive symptoms among older adults. *The Journals of Gerontology Series B, Psychological Sciences and Social Sciences*. 2007;62(1):S52–59. [PubMed: 17284567]
15. Cagney KA, Browning CR, Jackson AL, Soller B. Networks, neighborhoods, and institutions: An integrated “activity space” approach for research on aging. In: Waite LJ, Plewes TJ, eds. *New directions in the sociology of aging*. Washington DC: National Academies Press; 2013.
16. Pinquart M, Sorensen S. Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: a meta-analysis. *Gerontologist*. 2005;45(1):90–106. [PubMed: 15695420]
17. Kiecolt-Glaser JK, Gouin J, Weng N, Malarkey WB, Beversdorf D, Glaser R. Childhood adversity heightens the impact of later-life caregiving stress on telomere length and inflammation. *Psychosomatic medicine*. 2011;73:16–22. [PubMed: 21148804]
18. Dich N, Hansen ÅM, Avlund K, et al. Early life adversity potentiates the effects of later life stress on cumulative physiological dysregulation. *Anxiety, stress, and coping*. 2015;28(4):372–390. [PubMed: 25268115]
19. Hinton L, Carter K, Reed BR, et al. Recruitment of a community-based cohort for research on diversity and risk of dementia. *Alzheimer Dis Assoc Disord*. 2010;24(3):234–241. [PubMed: 20625273]
20. Harris PA, Taylor R, Minor BL, et al. The REDCap consortium: Building an international community of software platform partners. *Journal of biomedical informatics*. 2019;95:103208. [PubMed: 31078660]
21. Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)--a metadata-driven methodology and workflow process for providing translational research informatics support. *Journal of biomedical informatics*. 2009;42(2):377–381. [PubMed: 18929686]
22. Bedard M, Molloy DW, Squire L, Dubois S, Lever JA, O’Donnell M. The Zarit Burden Interview: a new short version and screening version. *Gerontologist*. 2001;41(5):652–657. [PubMed: 11574710]
23. Ullman T. The ‘hidden’ victims of Alzheimer’s disease. *FDA Consum*. 2003;37(4):40.
24. Cohen S, Kamarck T, Mermelstein R. A global measure of perceived stress. *Journal of Health and Social Behavior*. 1983;24:385–396. [PubMed: 6668417]
25. Radloff LS. The CES-D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement*. 1977;1:385–401.
26. Ware J Jr, Kosinski M, Keller SD. A 12-Item Short-Form Health Survey: construction of scales and preliminary tests of reliability and validity. *Med Care*. 1996;34(3):220–233. [PubMed: 8628042]
27. Lubben J, Blozik E, Gillmann G, et al. Performance of an abbreviated version of the Lubben Social Network Scale among three European community-dwelling older adult populations. *Gerontologist*. 2006;46(4):503–513. [PubMed: 16921004]

28. Melrose RJ, Brewster P, Marquine MJ, et al. Early life development in a multiethnic sample and the relation to late life cognition. *J Gerontol B Psychol Sci Soc Sci.* 2015;70(4):519–531. [PubMed: 24389122]
29. Brewster PW, Melrose RJ, Marquine MJ, et al. Life experience and demographic influences on cognitive function in older adults. *Neuropsychology.* 2014;28(6):846–858. [PubMed: 24933483]
30. Lorini C, Buscemi P, Mossello E, et al. Health literacy of informal caregivers of older adults with dementia: results from a cross-sectional study conducted in Florence (Italy). *Aging Clin Exp Res.* 2023;35(1):61–71. [PubMed: 36260214]
31. California Health Interview Survey. 2007.
32. Sabogal F, Marin G, Otero-Sabogal R, VanOss Marin B, EJ P-S. Hispanic familism and acculturation: What changes and what doesn't? *Hispanic Journal of Behavioral Sciences.* 1987;9:397–412.
33. Campos B, Roesch SC, Gonzalez P, et al. Measurement Properties of Sabogal's Familism Scale: Findings from the Hispanic Community Health Study/Study of Latinos (HCHS/SOL) Sociocultural Ancillary Study. *J Lat Psychol.* 2019;7(4):257–272. [PubMed: 31853517]
34. Tarlow BJ, Wisniewski SR, Belle SH, Rubert M, Ory MG, Gallagher-Thompson D. Positive Aspects of Caregiving: Contributions of the REACH Project to the Development of New Measures for Alzheimer's Caregiving. *Research on Aging.* 2004;26(4):429–453.
35. SAS Institute 9.4 [computer program]. Cary, NC: SAS Institute Inc.; 2013.
36. Gray RS, Hahn L, Thapsuwan S, Thongcharoenchupong N. Strength and stress: Positive and negative impacts on caregivers for older adults in Thailand. *Australas J Ageing.* 2016;35(2):E7–e12.
37. Saxton K, Chyu L. Early life adversity increases the salience of later life stress: an investigation of interactive effects in the PSID. *J Dev Orig Health Dis.* 2020;11(1):25–36. [PubMed: 31221227]
38. Barnes LL, Wilson RS, Everson-Rose SA, Hayward MD, Evans DA, Mendes de Leon CF. Effects of early-life adversity on cognitive decline in older African Americans and whites. *Neurology.* 2012;79(24):2321–2327. [PubMed: 23233682]
39. Xiang X, Cho J, Sun Y, Wang X. Childhood adversity and cognitive impairment in later life. *Front Psychol.* 2022;13:935254. [PubMed: 36051218]
40. Bonanno GA. Loss, trauma, and human resilience: have we underestimated the human capacity to thrive after extremely aversive events? *Am Psychol.* 2004;59(1):20–28. [PubMed: 14736317]
41. Tough H, Brinkhof MWG, Fekete C. Untangling the role of social relationships in the association between caregiver burden and caregiver health: an observational study exploring three coping models of the stress process paradigm. *BMC Public Health.* 2022;22(1):1737. [PubMed: 36100842]
42. George ES, Kecmanovic M, Meade T, Kolt GS. Psychological distress among carers and the moderating effects of social support. *BMC Psychiatry.* 2020;20(1):154. [PubMed: 32252700]
43. Gilmore-Bykovskiy A, Johnson R, Walljasper L, Block L, Werner N. Underreporting of Gender and Race/Ethnicity Differences in NIH-Funded Dementia Caregiver Support Interventions. *American journal of Alzheimer's disease and other dementias.* 2018;33(3):145–152.

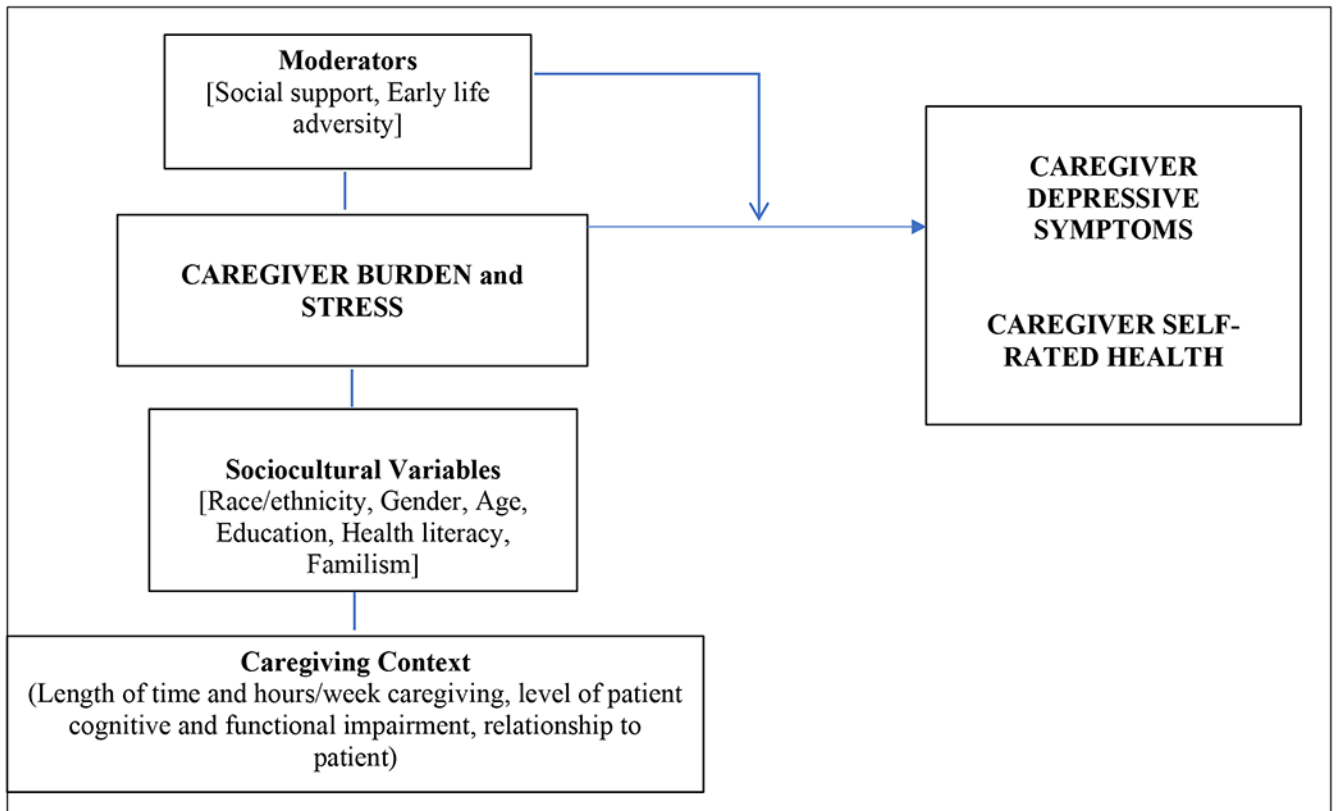


Figure 1.
Conceptual model of caregiver burden and stress and associations with caregiver outcomes.

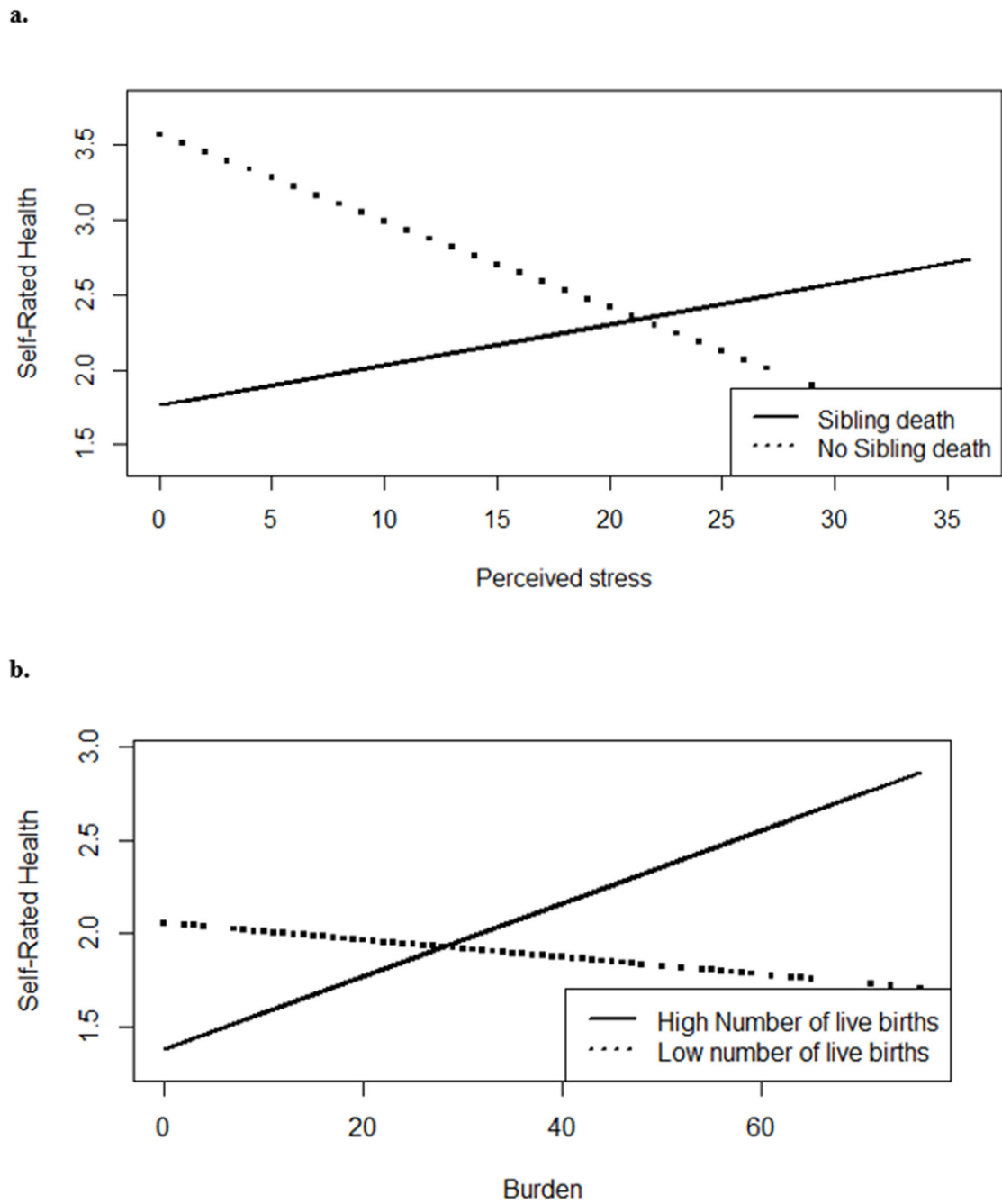


Figure 2.

(a) Perceived stress by early life adversity on health. (b) Burden by early life adversity on self-rated health. “High” indicates 1 SD above mean, “low” indicates 1 SD below mean.

Table 1.Sample Characteristics by Diagnosis of the Care Recipient¹

	Total N=158 ²	MCI (n=51)	Dementia (n=102) ³	P Value
	n (%) or Mean (SD)	n (%) or Mean (SD)	n (%) or Mean (SD)	
Type of Caregiver				0.0002
ADRC	58 (36.71)	30 (58.8)	28 (27.5)	
Community	100 (63.29)	21 (41.2)	74 (72.5)	
Caregiver Gender				
Male	20 (12.66)	6 (11.8)	14 (13.7)	0.74
Female	138 (87.34)	45 (88.2)	88 (86.3)	
Caregiver's age (25-95)	65 (11.58)	66.29 (10.14)	65.04 (12.28)	0.53
Care recipient's age (59-104)	83 (8.54)	80.63 (7.89)	83.46 (8.73)	0.05
Marital Status				0.23
Married/ Living with partner	119 (75.32)	9 (17.7)	27 (26.5)	
Divorced/Widowed/ Other	39 (24.68)	42 (82.4)	75 (73.5)	
Race/Ethnicity				0.67
African American/Black	15 (9.8)	7 (14)	8 (8.2)	
Asian/Pacific Islander	13 (8.5)	3 (6)	9 (9.2)	
Hispanic/Latino	24 (15.69)	7 (14)	15 (15.3)	
Non-Hispanic White	101 (66.01)	33 (66)	66 (67.4)	
Educational Attainment				0.95
High school or less	20 (13.16)	6 (12.5)	13 (13.13)	
Some College	49 (32.24)	15 (31.25)	33 (33.33)	
College or higher	83 (54.61)	27 (56.25)	53 (53.54)	
Care recipient relation to caregiver				0.15
Spouse	76 (51.35)	30 (61.2)	46 (48.4)	
Parent/parent-in-law	72 (48.65)	19 (38.8)	49 (51.6)	
Hours caring per week (0-168)	62 (65.61)	53.86 (63.68)	68.16 (67.33)	0.22
Years caring (0-20)	5 (4.69)	6.3 (5.37)	4.7 (4.2)	0.06
Lives with care recipient				0.39
Yes	106 (71.14)	38 (76)	65 (69.2)	
No	43 (28.86)	12 (24)	29 (30.9)	
Primary language				0.21
English	148 (93.67)	46 (90.2)	98 (96.1)	
Spanish	6 (3.8)	4 (7.84)	2 (2)	
Other	4 (2.53)	1 (1.96)	2 (2)	
Early life adversity				
Maximum number of kids living in home (1-12)	4 (2.07)	4.14 (2.64)	3.69 (1.67)	0.27
Number of live births (1-11)	4 (2.17)	3.82 (2.46)	3.83 (1.89)	0.99
Kids die before age 18				0.59
Yes	19 (12.26)	7 (14)	11 (11)	

	Total N=158 ²	MCI (n=51)	Dementia (n=102) ³	P Value
	n (%) or Mean (SD)	n (%) or Mean (SD)	n (%) or Mean (SD)	
No	136 (87.74)	43 (86)	89 (89)	
Go hungry as a child				0.12
Yes	18 (11.92)	8 (15.7)	7 (7.4)	
No	133 (88.08)	43 (84.3)	88 (92.6)	
Depressive symptoms (0-46)	14 (9.16)	12 (8.54)	15.2 (9.35)	0.04
Perceived stress (0-36)	15 (6.96)	13.37 (7.1)	16.03 (6.89)	0.03
Burden (0-76)	33 (15.93)	27.49 (17.52)	35.88 (14.43)	0.002
Self-rated health (1-5)		3.29 (1.06)	3.46 (0.84)	0.35
Familism				
Familial obligations (6-30)	21 (4.15)	20.43 (4.38)	21.09 (4.05)	0.36
Support (3-15)	10 (2.85)	9.7 (2.92)	9.87 (2.86)	0.73
Family as referents (4-25)	12 (3.44)	11.76 (3.94)	11.66 (3.16)	0.86
Positive aspects of caregiving (9 – 45)				
Self-affirmation	22 (6.42)	21.04 (6.51)	22.48 (6.36)	0.19
Outlook on life	11 (3.21)	11.2 (2.85)	11.07 (3.39)	0.82
Social support (4-30)	16 (5.08)	16.8 (5.15)	16.03 (4.9)	0.37
Neighborhood cohesion (0-2)	1 (0.5)	1.13 (0.47)	1.15 (0.52)	0.8
Health literacy (1-4)	4 (0.52)	3.67 (0.65)	3.78 (0.45)	0.27

¹. All statistics refer to the caregiver, unless otherwise stated.

². Data are based on N = 158 participants. Race/ethnicity data were unavailable for 5 participants (1 is missing, and 4 is listed "Other"). Educational attainment was unavailable for 6. Sibling death (kids die before age 18) had 3 missing. Go hungry as a child had 7 missing. Five people reported questionable cognitive impairment

Table 2.

Univariate Analyses for Outcomes of Depressive Symptoms and Self-Rated Health

Variable	Depressive Symptoms		Self-Rated Health	
	Standardized beta (β)	P-Value	Standardized beta (β)	P-Value
Type of Caregiver (ref=community)				
ADRC	0.157	0.05	0.038	0.64
Perceived stress	0.722	<.001	-0.312	<.001
Early life adversity variables				
Number of live births	-0.084	0.34	0.036	0.10
Go hungry as a child				
Yes	-0.106	0.22	0.246	0.03
No (Reference)				
Kids die before age 18				
Yes	-0.056	0.51	0.11	0.19
No (Reference)				
Maximum number of kids living in home (1-12)	0.020	0.81	0.088	0.28
Health literacy	-0.19	0.02	0.127	0.11
Familism variables				
Family obligations	0.093	0.31	0.03	0.74
Familial support	-0.176	0.04	0.168	0.05
Family as referents	-0.022	0.81	-0.084	0.35
Co-residence with care recipient (ref=no)				
Yes	0.063	0.57	-0.13	0.25
Diagnosis				
MCI	0.089	0.32	0.078	0.39
Dementia (Reference)				
Number of hours caregiving	0.067	0.51	-0.003	0.97
Years caring	-0.133	0.12	0.017	0.84
Relationship to care recipient (ref=parent/parent-in-law)				
Spouse	0.007	0.95	-0.09	0.37
Caregiver age	-0.227	0.01	0.023	0.80
Care recipient age	-0.107	0.18	-0.024	0.77
Lives with care recipient (ref=no)				
Yes	0.058	0.49	-0.092	0.26
Caregiver gender (ref=female)				
Male	-0.096	0.27	0.036	0.68
Caregiver Primary Language (ref=other)				
English	-0.076	0.54	0.1045	0.40
Spanish	0.0368	0.77	0.104	0.41
Caregiver Race (ref=minority)				
Non-Hispanic White	-0.174	0.06	0.056	0.54
Caregiver Marital Status				

Variable	Depressive Symptoms		Self-Rated Health	
	Standardized beta (β)	P-Value	Standardized beta (β)	P-Value
Married/ Living with partner	-0.07	0.38	0.146	0.07
Divorced/ Widowed/ Other (Reference)				
Caregiver Education (ref=HS or less)				
Some College	-0.058	0.66	0.191	0.14
College or higher	-0.163	0.22	0.298	0.02
Neighborhood cohesion	-0.121	0.13	0.217	0.01
Social Support	-0.305	<.001	0.11	0.17
Positive aspects of caregiving				
Self-affirmation	0.135	0.17	-0.006	0.95
Outlook on life	-0.285	0.004	0.119	0.23
Burden	0.401	<.001	-0.092	0.25

Table 3.

Multivariate Regression Analysis of Variables Associated with Depressive Symptoms and Self-Rated Health

Variable	Depressive Symptoms	Self-Reported Health
	Standardized beta (β) (95% CI)	Standardized beta (β) (95% CI)
Type of Caregiver (ref=community)	-0.56 (-3.35, 2.24)	0.23 (-0.14, 0.6)
Perceived stress	0.92 (0.72, 1.11)***	-0.05 (-0.08, -0.02)***
Early life adversity variables		
Number of live births	0.18 (-0.39, 0.75)	0.03 (-0.04, 0.11)
Go hungry as a child (ref=No)	1.93 (-1.93, 5.79)	-0.55 (-1.06, -0.04)*
Kids die before age 18 (ref=No)	0.34 (-3.49, 4.18)	-0.34 (-0.85, 0.16)
Health literacy	-0.23 (-2.9, 2.44)	-0.31 (-0.67, 0.04)
Familism variables		
Familial Support	-0.15 (-0.63, 0.32)	0.05 (-0.01, 0.11)
Caregiver age	-0.09 (-0.21, 0.03)	0.004 (-0.01, 0.02)
Race (ref=minority)		
Non-Hispanic White	-0.83 (-3.68, 2.03)	0.18 (-0.2, 0.56)
Education (ref=high school or less)		
Some College	-2.07 (-6.12, 1.99)	0.23 (-0.31, 0.77)
College or higher	-2.35 (-6.26, 1.56)	0.58 (0.06, 1.1)*
Neighborhood cohesion	2.01 (-0.57, 4.58)	0.26 (-0.08, 0.61)
Social Support	-0.2 (-0.44, 0.05)	0.001 (-0.03, 0.03)
Positive aspects of caregiving		
Outlook on life	-0.13 (-0.53, 0.26)	-0.01 (-0.06, 0.05)
Burden	0.01 (-0.08, 0.1)	0.01 (-0.01, 0.02)
Caregiver Marital Status (ref=Divorced/Widowed/ Other)		
Married/ Living with partner	-1.51 (-4.17, 1.15)	0.34 (-0.01, 0.69)

* p < .05,

** if p < .01,

*** if p < .001. Model does not include interaction terms (shown in text).