Published in final edited form as:

Arch Phys Med Rehabil. 2019 April ; 100(4 Suppl): S58–S64. doi:10.1016/j.apmr.2018.08.193.

Sociocultural Factors Influencing Caregiver Appraisals Following Traumatic Brain Injury

Angelle M. Sander, Ph.D.^{1,2}, Robin A. Hanks, Ph.D.^{3,4}, Phillip A. Ianni, Ph.D.⁵, Nicholas R. Boileau, MPH, Anna L. Kratz, Ph.D.⁵, Elizabeth A. Hahn, M.A.⁶, David S. Tulskey, Ph.D.⁷, and Noelle E. Carlozzi, Ph.D.⁵

¹H. Ben Taub Department of Physical Medicine and Rehabilitation, Baylor College of Medicine & Harris Health System, Houston, TX, USA

²Brain Injury Research Center, TIRR Memorial Hermann, Houston, TX, USA

³Rehabilitation Institute of Michigan, Department of Psychology and Neuropsychology, Detroit, Michigan, USA

⁴Department of Physical Medicine and Rehabilitation, Wayne State University, Detroit, Michigan, USA

⁵Department of Physical Medicine and Rehabilitation, University of Michigan; Ann Arbor, MI, USA

⁶Department of Medical Social Sciences, Northwestern University Feinberg School of Medicine, Chicago, IL, USA

⁷Center for Health Assessment Research and Translation, and the Departments of Physical Therapy and Psychological and Brain Sciences, University of Delaware, Newark, DE, USA

Abstract

Objective: To investigate the association of the sociocultural variables race/ethnicity, education, and poverty level to caregivers' positive and negative appraisals following traumatic brain injury.

Design: Survey.

Setting: Community.

Participants: 344 caregivers (216 White; 69 Black; 39 Hispanic) of persons with complicated mild to severe TBI at least one-year post-injury.

Intervention: Not applicable.

TBI-CareQOL Site Investigators and Coordinators: Noelle Carlozzi, Anna Kratz, Amy Austin, Mitchell Belanger, Micah Warschausky, Siera Goodnight, Jennifer Miner (University of Michigan, Ann Arbor, MI); Angelle Sander (Baylor College of Medicine and TIRR Memorial Hermann, Houston, TX), Curtisa Light (TIRR Memorial Hermann, Houston, TX); Robin Hanks, Daniela Ristova-Trendov (Wayne State University/Rehabilitation Institute of Michigan, Detroit, MI); Nancy Chiaravalloti, Dennis Tirri, Belinda Washington (Kessler Foundation, West Orange, NJ); Tracey Brickell, Rael Lange, Louis French, Rachel Gartner, Megan Wright, Angela Driscoll, Diana Nora, Jamie Sullivan, Nicole Varbedian, Johanna Smith, Lauren Johnson, Heidi Mahatan, Mikelle Mooney, Mallory Frazier, Zoe Li, and Deanna Pruitt (Walter Reed National Military Medical Center/).

Publisher's Disclaimer: This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

Main Outcome Measures: Modified Caregiver Appraisal Scale (M-CAS); Zarit Burden Interview (ZBI).

Results: Black caregivers reported lower levels of perceived burden on both the M-CAS and the ZBI. Black and Hispanic caregivers reported more traditional caregiver ideology (caregiving as a responsibility) than did Whites. Greater poverty was associated with higher burden on the M-CAS, lower caregiver satisfaction, and less mastery. Higher education was associated with higher burden on the ZBI and with lower caregiver mastery.

Conclusions and Implications: Treatment professionals should be culturally sensitive to the different perspectives that caregivers may have based on sociocultural factors. Sociocultural factors should be considered in research investigating caregiver outcomes, including appraisals.

Keywords

Caregivers; Brain Injuries; Traumatic; Outcome Assessment (Health Care); Surveys and Questionnaires; Cultural Competency

TBI often results in substantial long-term distress for caregivers.¹⁻⁸ Managing emotional adjustment is a concern for over 1/3 of caregivers of adults with TBI.⁹ Addressing caregivers' emotional distress is important for their own well-being, but also because their distress significantly impacts outcomes in the person with TBI.^{10,11}

Caregivers' emotional distress can be impacted by their perceptions of the caregiving role. Studies have demonstrated that caregivers experience a high level of perceived burden related to caring for the person with TBI, and that this perception persists over time.¹²⁻¹⁵ Furthermore, these perceptions are associated with greater emotional distress.¹⁶ Perceived burden has been shown to predict caregivers' health-related quality of life (HRQOL) following TBI,¹⁷ although this relationship can be moderated by personal resources and environmental support.^{18,19} While related to emotional distress, caregivers' perceptions of burden are independent from emotional distress and more impacted by the functioning of the person with injury.^{20,21}

Lawton (1989) proposed that the traditional concept of caregiver burden is a subset of a broader category of cognitive and emotional appraisals of a stressor (caregiving) and one's ability to cope with it. As a subjective experience, these appraisals can be impacted by multiple variables. Cultural differences have been found to impact appraisals of caregiver burden following TBI.²² Lower income has been associated with increased caregiver strain or burden.²³ Blacks and Hispanics reported more traditional beliefs about caring for persons after TBI, including feelings of duty/obligation.²⁴ These traditional beliefs about caregiving interacted with race/ethnicity to predict emotional distress, such that traditional beliefs were associated with greater emotional distress for Blacks and Hispanics, but not for Whites. Unfortunately, this study combined Blacks and Hispanics, potentially masking important cultural differences. Additionally, all participants were treated in inpatient rehabilitation, which limits generalizability to those without access to rehabilitation services.

The purpose of the current study was to investigate the contribution of the sociocultural factors of race/ethnicity, education, and poverty to caregiver appraisals in a sample of

caregivers of persons with TBI. The study improves upon prior work by comparing appraisals separately for Whites, Blacks, and Hispanics, by indexing income level to national poverty levels, and by including caregiver education.

Methods

Participants

Participants were 344 caregivers of civilians who had sustained medically documented complicated mild, moderate, or severe TBI at least one year ago and after the age of 15. Full details of the study sample are reported elsewhere.²⁵ Injury severity was defined according to the Traumatic Brain Injury Model Systems (TBIMS) inclusion criteria.²⁶ Recruitment methods included review of databases from former TBI studies and from medical record data capture systems²⁷ at two rehabilitation hospitals in Michigan and one each in Texas and New Jersey. Caregivers were contacted and asked if they provided physical or financial assistance, or emotional support, to the person with TBI.

Measures and Procedures

Data used in this study were collected as part of a larger study on development of a quality of life measure for caregivers of persons with TBI,²⁸ which was approved by the institutional review boards at all participating sites. All participants provided informed consent. Participants completed the measures online using a data capture system hosted by assessmentcenter.net. Demographic and injury severity information was obtained by medical record review and/or by interview with participants.

In the parent study, race was coded as White, Black, American Indian or Alaska Native, Asian, Native Hawaiian, Other Pacific Islander, or Other. Ethnicity was coded as yes or no for Hispanic ancestry. For the current analysis, a race/ethnicity variable was created by categorizing participants into one of three groups: non-Hispanic White, Black, and Hispanic. Individuals were classified as Hispanic if they identified their ethnicity as Hispanic and indicated that their race was White or Other. Individuals identifying as having more than one race or as a member of other racial groups (e.g. Native American, Asian) were excluded from the analyses due to small sample size (N=19).

Data on educational attainment were provided by participants and categorized into one of four levels (Table 1). Poverty status was determined from the income level provided by participants, and was classified as definitely below the poverty line, maybe below the poverty line, or above the poverty line, using the 2016 Federal Government poverty level thresholds based on income and number of people in the household. Number of people in the household was defined as the number of children currently in the household plus two (person with injury and their caregiver). For the parent study, income was assessed by asking participants to select which of several brackets their income fell within (e.g., \$10,000 to \$19,999). For the current analysis, participants whose income bracket included incomes below the poverty line for their household size were categorized as “maybe below the poverty line.” Those whose income brackets were clearly below or above the poverty line were classified accordingly.

Two measures of caregivers' perceptions were administered. The Caregiver Appraisal Scale (CAS) was developed to assess appraisals of the caregiving role among caregivers of persons with dementia.³⁰ Based on a cognitive-behavioral model of stress,³¹ this 47-item questionnaire conceptualizes appraisals as an assessment of the caregiving role, including positive and negative. Items are rated on a scale of 1 (*strongly disagree*) to 5 (*strongly agree*). The validity of the CAS for caregivers of persons with TBI was investigated by Struchen and colleagues,³² who found four components: perceived burden, caregiver relationship satisfaction, caregiving ideology, and caregiving mastery. Items that loaded less than .40 on any component or loaded on two factors were eliminated, leaving 35 items in the final recommended measure. The domain subscales were shown to have good internal consistency, with the exception of caregiving mastery, which has only four items. External validity was supported by a significant relationship between scores on the perceived burden subscale and a measure of emotional distress. Struchen and colleagues' scoring method for this Modified CAS (M-CAS) was used in the current study, with reverse scores used for some items so that higher scores indicating better functioning.

The 22-item Zarit Burden Interview (ZBI)³³ was developed to assess perceived burden in caregivers of persons with dementia. Items are rated on a scale ranging from never to nearly always, with a total score of 0 (low burden) to 88 (high burden). The ZBI has demonstrated good reliability and validity in caregivers of persons with dementia,³⁴ with an average internal consistency of .86 across studies.³⁵ The ZBI has been used to assess perceived burden in caregivers of persons with TBI.^{36,37}

Caregivers also completed the caregiver version of the Mayo-Portland Adaptability Inventory (MPAI)-4,³⁸ a 35-item measure that assesses caregivers' perceptions of the physical, cognitive, emotional, behavioral, and social role functioning of the person with injury. The measure has good reliability and validity.³⁹ Each item is rated on a scale of 0 to 5, and the total score is on a T-distribution (mean of 50; standard deviation of 10). Higher scores indicate worse functioning.

Data Analysis

Data were normally distributed according to Bulmer's criteria;⁴⁰ therefore, parametric analyses were used. Caregiver demographic information was compared between the three race/ethnicity groups, with Fisher's Exact Test used for categorical variables with less than five respondents per cell.^{41,42} One-way Analysis of Variance (ANOVA) was used to compare continuous variables between groups.

Regressions.

Five separate multiple linear regression models were tested using four subscales of the CAS and the total ZBI score as dependent variables. Dummy variables representing Hispanic ethnicity, Black race, education (4 levels) and poverty level (3 levels), were entered simultaneously into the model as predictors. Due to limited prior investigation of the relationship of race, poverty, and education to caregiver appraisals after TBI, our analyses were exploratory in nature. We decided against correcting for multiple comparisons in order to reduce risk of dismissing a variable that warrants further research. Instead, we provide

effect sized so that readers can determine the value of individual variables. Partial eta-squared (η^2) effect sizes were calculated, with effect sizes of .01 considered small, .06 medium, and .14 large.^{43,44} The Variance Inflation Factor (VIF) was used to assess collinearity, with a VIF value ≤ 5 as the cutoff.⁴⁵

Missing Data.

Expectation maximization (EM) was utilized to impute data for participants who were missing <10% of items on any particular scale (n=15 for the M-CAS).⁴⁶ This is a relatively unbiased method compared to regression and mean substitution.⁴⁷ Participants were excluded from analyses if they had >10% missing data (n=2). In the linear regression models, participants who had missing poverty information (n=13) were excluded.

Results

Sample Demographics

Demographics for the caregivers, by racial/ethnic group, are shown in Table 1. Black participants (15%) were less likely to have a bachelor's degree than White (44%) or Hispanic (33%) participants (Fisher's Exact $p < .001$). White participants (80%) were more likely to be above the poverty line than Black (29%) or Hispanic (49%) participants (Fisher's Exact $p < .001$). White participants were more likely to be the spouse (43%) of the injured person, while Black (28%) and Hispanic (26%) participants had a sizable number of "other family member" caregivers (Fisher's Exact $p < .001$). There were no group differences with regard to age of the caregiver or years in the caregiving role. There was no difference in MPAI scores between Whites, Blacks, and Hispanics, indicating that they were caring for persons with equivalent levels of functioning.

Prediction of Modified Caregiver Appraisal Scale (M-CAS) Scores

Across all models, the highest value for the Variance Inflation Factor was for poverty (VIF=1.5), which indicated that multicollinearity was not a concern. As shown in Table 2, the sociodemographic variables jointly accounted for 4% of the variance in the M-CAS Perceived Burden scale. There was a significant association between race/ethnicity and burden scores, with Blacks reporting less burden compared to Whites, $\beta = .18$, $t = 2.58$, $\eta^2 = .02$, $p = .01$. There was no difference in perceived burden between Whites and Hispanics. Greater poverty was associated with more burden, $\beta = .15$, $t = 2.15$, $\eta^2 = .02$, $p = .03$. The sociodemographic variables accounted for 3% of the variance in scores on the M-CAS Satisfaction Scale. There was no difference between racial/ethnic groups or education groups. Greater poverty was associated with lower caregiver satisfaction, $\beta = .18$, $t = 2.59$, $\eta^2 = .02$, $p = .01$. The entire model accounted for 5% of the variance on the M-CAS Caregiver Ideology scale. Compared to Whites, Blacks, $\beta = .15$, $t = 2.28$, $\eta^2 = .02$, $p = .02$, and Hispanics, $\beta = .17$, $t = 2.85$, $\eta^2 = .03$, $p = .005$, reported more traditional beliefs about the caregiving role. Neither education nor poverty level was associated with Caregiver Ideology scores. The sociodemographic variables accounted for 7% of the variance in M-CAS Caregiver Mastery scores. Greater poverty, $\beta = .23$, $t = 3.33$, $\eta^2 = .04$, $p = .001$, and greater education, $\beta = -.14$, $t = -2.15$, $\eta^2 = .01$, $p = .03$, were

associated with lower perceived mastery. Race/ethnicity was not associated with feelings of mastery.

Prediction of Zarit Burden Interview (ZBI) Scores

Jointly, the sociodemographic variables accounted for 6% of the variance in ZBI scores. Caregivers who are Black reported lower burden on the ZBI, $\beta = -.22$, $t = -3.22$, $\eta^2 = .03$, $p = .001$. Higher education was associated with higher burden, $\beta = .15$, $t = 2.35$, $\eta^2 = .02$, $p = .02$. There was no association between poverty levels and ZBI scores.

Discussion

The current study investigated the impact of three sociocultural variables on different aspects of caregiver appraisals following TBI. Perceived burden is the dimension of caregiver appraisal that has received the most attention in prior research. We found that Black caregivers reported less perceived burden, which is consistent with prior studies that have documented lower perceived burden in Black informal caregivers of elderly adults,⁴⁸ of persons with serious mental illness,⁴⁹ and of persons with dementia.^{50–52} These findings may be attributable to cultural differences in expectations or beliefs about caring for family members who are not able to care for themselves. For example, Blacks and Hispanics are less likely to place family members with dementia in nursing homes.⁵³ Potential differences in social support may also explain these results, as Black caregivers of persons with dementia have been found to rely more on support from extended family.^{54–55} We did not find a difference in perceived burden between Hispanic and White caregivers of persons with TBI. This is consistent with findings from a study of perceived burden in caregivers of persons with serious mental illness.⁴⁹ Prior research assessing caregiver burden following TBI has not investigated burden separately for Hispanics and Blacks. Our results indicate that combining Hispanics and Blacks and comparing them to Whites can mask important differences.

Our finding that Black and Hispanic caregivers endorsed more traditional beliefs about the caregiving role extends previous findings of more traditional caregiver ideology among a combined sample of Blacks and Hispanics compared to Whites.²⁴ Similar to perceived burden, the greater traditional caregiver ideology among Blacks and Hispanics may be due to cultural differences. Studies conducted with caregivers of persons with dementia have found a stronger sense of familial obligation for Blacks and Hispanics.^{54,56} It is interesting that Blacks in our study also appraised the caregiving role as less burdensome, suggesting that traditional ideology may moderate the impact of TBI-related stressors on perceived burden. Conversely, one study found an association between more traditional caregiver ideology and emotional distress in a combined sample of Black and Hispanic caregivers, but not for White caregivers. Again, combining Blacks and Hispanics does not allow for clear interpretation of findings. Future research should focus on determining the impact of traditional caregiver ideology on appraisals of burden and emotional distress.

Greater poverty was associated with lower caregiver satisfaction, lower mastery, and greater perceived burden. Minimal prior research has investigated the association between socioeconomic characteristics and caregivers' appraisals following TBI. Mazlan and

colleagues²³ found that lower income was associated with greater burden, while Sander et al.²⁴ found that household income category did not contribute to scores on the M-CAS. These prior studies were limited by not accounting for contribution of household size to income, lack of indexing to U.S. poverty levels, and not simultaneously accounting for income, race/ethnicity, and education. The current findings indicate that caregivers living near or below the poverty line are at risk of experiencing greater caregiver-related burden and have decreased satisfaction with the caregiver role. It is tempting to conclude that this is related to lack of access to resources; however, the relationship is likely to be complex and could be moderated by other factors, such as attitudes, rural versus urban living, and trust in institutions, including health care. Nevertheless, poverty level should be considered when targeting caregivers who may require extra assistance.

To our knowledge, no prior study has directly investigated the association between education level and caregiver appraisals following TBI. Our finding that greater education was associated with higher burden on the ZBI and with lower perceived mastery may seem counterintuitive; however, clinical observations suggest that well-educated persons often set unrealistic expectations for themselves regarding caregiver goals. They often express beliefs that they should be able to handle everything and show reluctance to reach out for support. A recent study of non-TBI caregivers in Germany found that higher education was associated with increased feelings of mental burden. The authors attributed this to concerns over loss of autonomy that may be greater in persons with more education. This is a hypothesis that requires further research to validate.

Current results emphasize the importance of including multiple sociocultural variables in research on caregivers' appraisals following TBI. Inclusion of only one variable, such as race/ethnicity, may result in misattribution of variance that could be attributable to other related sociocultural factors. This is particularly important since racial/ethnic groups are often not equivalent with respect to other sociocultural variables, such as education and poverty levels. While the overall amount of variance accounted for in this study was small, it provides some information that can be used to target caregivers at risk for poor outcomes due to negative appraisals of the caregiving role. Targeting these groups with additional education and resources may be helpful. The findings also dispel some myths that could impact interactions between health providers and caregivers, such as the belief that persons with higher education have an easier time adjusting to the caregiving role. Our findings indicate that caregivers with higher education may, in some cases, require greater reassurance and support.

Limitations

Our available data for calculating household size included only number of children in the household, to which we added the person with injury and caregiver. It is possible that there were other adults living in the household that were not accounted for in this calculation. Household income was reported as a categorical variable with categories that did not map exactly onto existing thresholds for poverty levels. In addition, household income was based on self-report rather than objective data. Although racial/ethnic makeup and poverty rates in

this sample were similar to the U.S. average, educational attainment for this sample was higher than the U.S. average.⁵⁸

This study focused on three sociocultural variables that could impact caregivers' appraisals; however, the amount of variance accounted for was small. As much of the variance was not accounted for, future studies should investigate other factors that could impact appraisals, including level of acculturation, neighborhood characteristics, financial resources, social support, and non-injury-related stressors. Acculturation may be particularly worthy of consideration, as findings from a recent study of Latino caregivers of persons with dementia found that acculturation moderated the effectiveness of a caregiver intervention, such that those with higher acculturation benefitted more.⁵⁹ Clinically, caregiver interventions should be individualized, taking sociocultural variables into consideration, but also including other caregiver needs.

Conclusions

Our findings highlight the importance of considering sociocultural factors when working with caregivers of persons with TBI and their families. Findings also emphasize the importance of a more comprehensive examination of sociocultural factors rather than focusing on a single aspect such as race. Interventions can be designed to integrate cultural norms and beliefs to maximize caregiver satisfaction and emotional well-being.

Acknowledgements:

Work on this manuscript was supported by the National Institutes of Health (NIH)- National Institute of Nursing Research (R01NR013658), and the National Center for Advancing Translational Sciences (UL1TR000433). We thank the investigators, coordinators, and research associates/assistants who worked on this study, the study participants, and organizations who supported recruitment efforts. The University of Michigan Research Team would also like to thank the Hearts of Valor and the Brain Injury Association of Michigan for assistance with community outreach for recruitment efforts at this site.

We certify that no party having a direct interest in the results of the research supporting this article has or will confer a benefit on us or on any organization with which we are associated. We also certify that all financial and material support for this research and work are clearly identified in the title page of the manuscript.

List of Abbreviations:

HRQOL	Health-Related Quality of Life
IRB	Institutional Review Board
M-CAS	Modified Caregiver Appraisal Scale
NIH	National Institutes of Health
TBI	Traumatic Brain Injury
ZBI	Zarit Burden Interview
MPAI	Mayo Portland Adaptability Inventory

References

1. Brooks N, Campsie L, Symington C, Beattie A, McKinlay W. The five year outcome of severe blunt head injury: a relative's view. *J Neurol Neurosurg Psychiatry*. 1986;49(7):764–770. [PubMed: 3746307]
2. Brooks N, Campsie L, Symington C, Beattie A, McKinlay W. The effects of severe head injury on patient and relatives within seven years of injury. *J Head Trauma Rehab*. 1987;2:1–13.
3. Gillen R, Tennen H, Affleck G, Steinpreis R. Distress, depressive symptoms, and depressive disorder among caregivers of patients with brain injury. *J Head Trauma Rehabil*. 1998;13(3):31–43. [PubMed: 9582177]
4. Kreutzer JS, Gervasio AH, Camplair PS. Primary caregivers' psychological status and family functioning after traumatic brain injury. *Brain Inj*. 1994;8(3):197–210. [PubMed: 8004079]
5. Kreutzer JS, Rapport LJ, Marwitz JH, et al. Caregivers' well-being after traumatic brain injury: a multicenter prospective investigation. *Arch Phys Med Rehabil*. 2009;90(6):939–946. [PubMed: 19480869]
6. Ponsford J, Olver J, Ponsford M, Nelms R. Long-term adjustment of families following traumatic brain injury where comprehensive rehabilitation has been provided. *Brain Injury*. 2003;17(6):453–468. [PubMed: 12745702]
7. Ponsford J, Schonberger M. Family functioning and emotional state two and five years after traumatic brain injury. *J Int Neuropsychol Soc*. 2010;16(2):306–317. [PubMed: 20128950]
8. Malec JF, Van Houtven CH, Tanielian T, Atizado A, Dorn mC. Impact of TBI on caregivers of veterans with TBI: Burden and interventions. *Brain Inj* 2017;31:1235–1245. [PubMed: 28981343]
9. Powell JM, Wise EK, Brockway JA, Fraser R, Temkin N, Bell KR. Characteristics and concerns of caregivers of adults with traumatic brain injury. *J Head Trauma Rehabil* 2017;32:E33–E41. [PubMed: 27022956]
10. Sady MD, Sander AM, Clark AN, Sherer M, Nakase-Richardson R, Malec JF. Relationship of preinjury caregiver and family functioning to community integration in adults with traumatic brain injury. *Arch Phys Med Rehabil* 2010;91:1542–1550.
11. Sander AM, Maestas KL, Sherer M, Malec JF, and Nakase-Richardson R. Relationship of caregiver and family functioning to participation outcomes after postacute rehabilitation for traumatic brain injury: A multicenter investigation. *Arch Phys Med Rehabil* 2012;93:842–848.
12. Manskow US, Sigurdardottir S, Roe C, Andelic N, Skandsen T, Damsgard E, Elmstahl S, Anke A. Factors affecting caregiver burden 1 year after severe traumatic brain injury: A prospective nationwide multicenter study. *J Head Trauma Rehabil* 2015;30:411–423. [PubMed: 25119652]
13. Doser K, Norup A. Caregiver burden in Danish family members of patients with severe brain injury: The chronic phase. *Brain Inj* 2016;30:334–342. [PubMed: 26829640]
14. Bayen E, Jourdan C, Ghout I, Darnoux E, Azerad S, Vallat-Azouvi C, Weiss JJ, Aegerter P, Pradat-Diehl P, Joel ME, Azouvi P. Objective and subjective burden of informal caregivers 4 years after a severe traumatic brain injury: Results from the Paris-TBI study. *J Head Trauma Rehabil* 2016;31:E59–67.
15. Manskow US, Friberg O, Roe C, Braine M, Damsgard E, Anke A. Patterns of change and stability in caregiver burden and life satisfaction from 1 to 2 years after severe traumatic brain injury: A Norwegian longitudinal study. *NeuroRehabilitation* 2017;40:211–222. [PubMed: 27935561]
16. Sander AM, High WM, Jr, Hannay HJ, Sherer M. Predictors of psychological health in caregivers of patients with closed head injury. *Brain Injury* 1997;11(4):235–249. [PubMed: 9134198]
17. Saban KL, Griffin JM, Urban A, Janusek MA, Pape TL, Collins E. Perceived health, caregiver burden, and quality of life in women partners providing care to Veterans with traumatic brain injury. *J Rehabil Res Dev* 2016;53:681–692. [PubMed: 27997670]
18. Chronister J, Johnson ET, Chan F, Tu W, Chung Y, Lee GK. Positive personenvironment factors as mediators of the relationship between perceived burden and quality of life in caregivers of individuals with traumatic brain injuries. *Rehabilitation Counseling Bulletin* 2016;59(4):235–246.
19. Griffin JM, Lee MK, Bangerter LR, Van Houten CH, Friedmann-Sanchez G, Phelan SM, Carlson KF, Meis LA. Burden and mental health among caregivers of veterans with traumatic brain injury/polytrauma. *Am J Orthopsychiatry* 2017;87:139–148. [PubMed: 28206801]

20. Marsh NV, Kersel DA, Havill JH, Sleigh JW. Caregiver burden during the year following severe traumatic brain injury. *J Clin Exp Neuropsych* 2002;24(4):434–447.
21. Davis LC, Sander AM, Struchen MA, Sherer M, Nakase-Richardson R, Malec JF. Medical and psychosocial predictors of caregiver distress and perceived burden following traumatic brain injury. *J Head Trauma Rehab* 2009;24(3):145–154.
22. Mbakile-Mahlanza L, Manderson L, Downing M, Ponsford J. Family caregiving of individuals with traumatic brain injury in Botswana. *Disabil Rehabil* 2017;39:559–567. [PubMed: 26972548]
23. Mazlan M, Ghani SZ, Tan KF, Subramanian P. Life satisfaction and strain among informal caregivers of patients with traumatic brain injury in Malaysia. *Disabil Rehabil* 2016;5:1–8.
24. Sander AM, Davis LC, Struchen MA, Atchison T, Sherer M, Malec JF, Nakase- Richardson R. Relationship of race/ethnicity to caregivers' coping, appraisals, and distress after traumatic brain injury. *NeuroRehabilitation* 2007;22:9–17. [PubMed: 17379945]
25. Carlozzi NE, Kallen MA, Hanks R, et al. The TBI-CareQOL Measurement System: Development and validation of health-related quality of life measures for caregivers of individuals with civilian- and military-related traumatic brain injury Under Review.
26. Corrigan JD, Cuthbert JP, Whiteneck GG, et al. Representativeness of the Traumatic Brain Injury Model Systems National Database. *J Head Trauma Rehabil*. 2012;27(6):391–403. [PubMed: 21897288]
27. Hanauer DA, Mei Q, Law J, Khanna R, Zheng K. Supporting information retrieval from electronic health records: A report of University of Michigan's nine-year experience in developing and using the Electronic Medical Record Search Engine (EMERSE). *Journal of Biomedical Informatics*. 2015;55:290–300. [PubMed: 25979153]
28. Carlozzi NE, Kallen MA, Hanks R, Hahn EA, Brickell TA, Lange RT, French LM, Kratz AL, Tulskey DS, Cella D, Miner JA, Ianni PA, Sander AM. The TBI CareQOL Measurement System: Development and preliminary validation of health-related quality of life measures for caregivers of civilians and service members/veterans with traumatic brain injury. *Archives of Physical Medicine and Rehabilitation*, under review.
29. U.S. Department of Health & Human Services. (2016). Computations for the 2016 Annual Update of the HHS Poverty Guidelines for the 48 Contiguous States and the District of Columbia. Washington, D.C.: U.S. Government Printing Office.
30. Lawton MP, Kleban MH, Moss M, Rovine M, Glicksman A. Measuring caregiving appraisal. *J Gerontol*. 1989;44(3):P61–71. [PubMed: 2715587]
31. Lazarus RS, Folkman S. Stress, Appraisal, and Coping. New York: Springer, 1984.
32. Struchen MA, Atchison TB, Roebuck TM, Caroselli JS, Sander AM. A multidimensional measure of caregiving appraisal: validation of the Caregiver Appraisal Scale in traumatic brain injury. *J Head Trauma Rehabil*. 2002;17(2):132–154. [PubMed: 11909511]
33. Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist*. 1980;20(6):649–655. [PubMed: 7203086]
34. Hebert R, Bravo G, Preville M. Reliability, validity and reference values of the Zarit Burden Interview for assessing informal caregivers of community-dwelling older persons with dementia. *Can J Aging*. 2000;19(4):494–507.
35. Bachner YG, O'Rourke N. Reliability generalization of responses by care providers to the Zarit Burden Interview. *Aging and Mental Health* 2007;11:678–685. [PubMed: 18074255]
36. Machamer J, Temkin N, Dikmen S. Significant other burden and factors related to it in traumatic brain injury. *J Clin and Exp Neuropsychol* 2002;24:420–433. [PubMed: 12187456]
37. Kreutzer JS, Marwitz JH, Sima AP, Godwin EE. Efficacy of the brain injury family intervention: Impact on family members. *J Head Trauma Rehabil* 2015;30:249–260. [PubMed: 26147315]
38. Malec JF, Kragness M, Evans RW, Finlay KL, Kent A, Lezak MD. Further psychometric evaluation and revision of the Mayo-Portland Adaptability Inventory in a national sample. *J Head Trauma Rehabil* 2003;18:479–492. [PubMed: 14707878]
39. Malec JF, Lezak MD. Manual for the Mayo-Portland Adaptability Inventory. 2nd edition. 2008 from www.tbims.org/combi/mpai.
40. Bulmer MG. Principles of Statistics. New York: Dover Publications, 1979.

41. Fisher RA. Frequency distribution of the values of the correlation coefficient in samples of an indefinitely large population. *Biometrika*. 1915; 10(4):507–521.
42. Freeman GH and Halton JH Note on exact treatment of contingency, goodness of fit and other problems of significance. *Biometrika*. 1951; 38:141–149. [PubMed: 14848119]
43. Cohen J Statistical power analysis for the behavioral sciences. New York: Academic Press, 1969.
44. Richardson JTE. Eta squared and partial eta squared as measures of effect size in educational research. *Educational Research Review*. 2010; 6(2): 135–147.
45. Sheather SJ. A Modern Approach to Regression with R. New York: Springer, 2009.
46. Dempster AP, Laird NM, Rubin DB. Maximum Likelihood from Incomplete Data Via Em Algorithm. *J Roy Stat Soc B Met*. 1977;39(1):1–38.
47. Musil CM, Warner CB, Yobas PK, Jones SL. A comparison of imputation techniques for handling missing data. *Western journal of nursing research*. 2002;24(7):815–829. [PubMed: 12428897]
48. Wajnberg A, Soones TN, Smith KL, Russell D, Ross JS, Federman A. Identifying sociodemographic characteristics associated with burden among caregivers of the urban homebound: The importance of racial and relationship differences. *Gerontology & Geriatric Medicine* 2016;2:1–7.
49. Stueve A, Vine P, Struening EL. Perceived burden among caregivers of adults with serious mental illness: Comparison of Black, Hispanic, and White families. *American Journal of Orthopsychiatry* 1997;67:199–209. [PubMed: 9142353]
50. Hinrichsen GA, Ramirez M. Black and white dementia caregivers: A comparison of their adaptation, adjustment, and services utilization. *The Gerontologist* 1992;32:375–381. [PubMed: 1500003]
51. Lawton MP, Rajagopal D, Brody E, Kleban MH. The dynamics of caregiving for a demented elder among black and white families. *Journal of Gerontology: Social Sciences* 1992;27:S156–S164.
52. Knight BG, Silverstein M, McCallum TJ, Fox LS. A sociocultural stress and coping model for mental health outcomes among African American caregivers in Southern California. *Journal of Gerontology: Psychological Sciences* 2000;55B:142–150.
53. Yaffe K, Fox P, Newcomer R, Sands L, Lindquist K, Dane K, Covinsky KE. Patient and caregiver characteristics and nursing home placement in patients with dementia. *JAMA* 2002;287:2090–2097. [PubMed: 11966383]
54. Wood JB, Parham IA. Coping with perceived burden: Ethnic and cultural differences in Alzheimer's family caregiving. *Journal of Applied Gerontology* 1990;9:325–339.
55. Cox C Service needs and interests: A comparison of African American and white caregivers seeking Alzheimer assistance. *American Journal of Alzheimer's Disease* 1993;5/6:33–40.
56. Cox C, Monk A. Minority caregivers of dementia victims: A comparison of Black and Hispanic families. *Journal of Applied Gerontology* 1990;9:340–354.
57. Schnitzer S, Oedekoven M, Amin-Kotb K, Gellert P, Balke K, Kuhlmeier A. Caregivers' burden and education level: Does subjective health mediate the association? *Innovation in Aging* 2017; 1 suppl 1:447.
58. United States Census Bureau. Educational Attainment in the United States: 2016. 2016; <https://www.census.gov/data/tables/2016/demo/education-attainment/cps-detailed-tables.html> Accessed 5/19/2017.
59. Meyer OL, Liu XL, Tancredi D, Ramirez AS, Schulz R, Hinton L. Acculturation level and caregiver outcomes from a randomized intervention trial to enhance caregivers' health: Evidence from REACH IN. *Aging and Mental Health* 2018;22:730–737. [PubMed: 28436694]

Table 1

Caregiver Demographics by Race/Ethnicity

	White	Black	Hispanic	Total	Sig.
N (%)	216 (67)	69 (21)	39 (12)	324 (100)	
Education n (%)					
Less than high school/GED	11 (5)	16 (23)	16 (41)	43 (13)	FET* = p < .001
High school	32 (15)	12 (18)	3 (8)	47 (15)	
Some college	78 (36)	30 (44)	7 (18)	115 (36)	
Bachelor's or higher	95 (44)	10 (15)	13 (33)	118 (36)	
Poverty level n (%)					
Definitely below poverty line	12 (6)	33 (48)	8 (20)	53 (16)	FET = p < .001
Maybe below poverty line	22 (10)	13 (19)	11 (28)	46 (14)	
Above poverty line	173 (80)	20 (29)	19 (49)	212 (65)	
Missing	9 (4)	3 (4)	1 (3)	13 (4)	
Age (M, SD, range)	52.7 (13.6, 18–81)	48.9 (14.3, 21–83)	50.3 (14.4, 22–78)	51.6 (13.9, 18–83)	F = 2.23, p = .11
Relationship to person with TBI n (%)					
Parent	83 (38)	17 (25)	14 (36)	114 (35)	FET = p < .001.
Spouse/Partner	92 (43)	16 (23)	11 (28)	119 (36)	
Child	14 (6)	5 (7)	3 (8)	22 (7)	
Other family member	13 (6)	19 (28)	10 (26)	42 (13)	
Other (e.g., friend)	14 (6)	12 (17)	1 (3)	27 (8)	
Years caring for person with TBI (M, SD, range)	5.6 (5.6, <1-59)	7.2 (9.1, <1-67)	5.2 (4.7, 1-21)	5.8 (6.4, <1-67)	F = 1.90, p = .15
MPAI scores (M, SD, range)	47.4 (13.1, -9 – 72)	46.4 (12.5, -9 – 76)	47.0 (15.1, -9 – 65)	47.1 (13.2, -9 – 76)	F = .15, p = .86

MPAI = Mayo-Portland Adaptability Inventory-4

* Fisher's Exact Test

Table 2.

Results of Multiple Linear Regression Models

	R ²	Hispanic beta (ηp^2)	Black beta (ηp^2)	Education beta (ηp^2)	Poverty level beta (ηp^2)
CAS Burden ^a	.04	-.02 (.00)	.18 (.02) [*]	-.11 (.01)	.15 (.02) [*]
CAS Satisfaction ^a	.03	-.05 (.00)	.09 (.01)	-.07 (.00)	.18 (.02) ^{**}
CAS Mastery ^a	.05	-.10 (.01)	.04 (.00)	-.14 (.01) [*]	.23 (.04) ^{**}
CAS Ideology ^a	.07	.17 (.03) ^{**}	.15 (.02) [*]	.05 (.00)	-.13 (.01)
Zarit Burden Interview ^b	.06	-.05 (.00)	-.22 (.03) ^{**}	.15 (.02) [*]	-.12 (.01)

* p < .05

** p < .01; ηp^2 = partial eta-squared effect size

^a = higher scores indicate positive aspects of caregiving

^b = higher scores indicate less positive aspects of caregiving. Reference groups were White for both dummy variables, less than high school education, and below the poverty line status.