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## Health Literacy, Health Outcomes, and the Caregiver Role in Traumatic Brain Injury

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### Abstract

**Purpose/Objective:** The purpose of this study is to estimate the occurrence of low health literacy among caregivers of people with traumatic brain injury (TBI), and to evaluate associations of health literacy with caregiver health-related quality of life (HRQOL) and perceptions of the caregiving role.

**Research Method/Design:** The TBI-CareQOL measurement system assesses important self-reported outcomes for caregivers of civilians or service members/veterans (SMVs) with TBI. The validation phase included the Health Literacy Assessment Using Talking Touchscreen Technology (Health LiTT) measure. Multivariable regression evaluated the impact of low health literacy on generic and TBI-specific HRQOL and appraisals of the caregiving role, adjusted for caregiver gender, race/ethnicity and education, and the functional status of the TBI care recipient.

**Results:** Among 131 caregivers, 28 (21%) had low health literacy. Compared with the high health literacy group, the group with low health literacy had fewer women, more racial/ethnic

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minorities, and lower education (all  $p < .05$ ). The low health literacy group reported more subjective caregiving burden, less satisfaction with their relationship with the TBI recipient, less caregiving mastery, and poorer physical health (all  $p < .05$ ). There were no differences between health literacy groups in caregiving ideology, caregiver-specific HRQOL or general mental health.

**Conclusions/Implications:** A better understanding of the links between health literacy and caregiver HRQOL and the caregiving role can help identify strategies to meet the needs of this underserved population. Tailored interventions for caregivers with low health literacy could improve outcomes for both the caregiver and the care recipient.

### Keywords

caregivers; health literacy; caregiver appraisal; health-related quality of life; traumatic brain injury

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### Introduction

More than half of unpaid family or informal caregivers are performing medical/nursing tasks without training, and these caregivers report high levels of physical strain and emotional stress (National Alliance for Caregiving & AARP Public Policy Institute, 2015). In particular, caregivers of people with traumatic brain injury (TBI) have many unmet needs related to caregiving and coping (Adams & Dahdah, 2016; Moore, Kiatchai, Ayyagari, & Vavilala, 2017) and are at risk for poor health-related quality life (HRQOL; Carozzi et al., 2015, 2016, 2018; Chan, Parmenter, & Stancliffe, 2009; Chronister, Chan, Sasson-Gelman, & Chiu, 2010; Griffin et al., 2017; Keatley et al., 2018; Kratz, Carozzi, Brickell, & Sander, 2014; Lester et al., 2010; Mansfield et al., 2010; Phelan et al., 2011; Ruff, Ruff, & Wang, 2009; Saban et al., 2016; Taft, Schumm, Panuzio, & Proctor, 2008; Verhaeghe, Defloor, & Grypdonck, 2005). HRQOL is a multidimensional concept that includes physical, mental and social well-being (Fayers & Machin, 2007). Negative HRQOL outcomes for these caregivers may be related to feelings of being overwhelmed with managing medical and health issues for the person with TBI. This explanation would be consistent with research findings that a substantial portion of persons with moderate to severe TBI require supervision up to nine years postinjury, which frequently includes assistance with obtaining needed health care, making medical appointments and managing health issues (Bailey et al., 2017; Griffin et al., 2012; Hall, Bushnik, Lakisic-Kazazic, Wright, & Cantagallo, 2001; Hart et al., 2003).

Inadequate health literacy also may contribute to caregivers feeling overwhelmed by the demands of assisting the person with TBI with health management tasks. Health literacy is a multidimensional concept referring to “the degree to which individuals can obtain, process, and understand the basic health information and services they need to make appropriate health decisions” (Nielsen-Bohlman, Panzer, & Kindig, 2004). It represents a constellation of skills to perform health-related tasks, including the ability to read and write (print literacy), use quantitative information (numeracy), speak and listen effectively (oral literacy), and obtain information (navigation skills; Berkman et al., 2011; Nielsen-Bohlman et al., 2004). Health literacy may be significantly worse than functional (day-to-day) literacy because of the unfamiliar context and vocabulary of the health care system (Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, American Medical

Association (1999); DeWalt & Pignone, 2005). Health literacy is particularly relevant for the tasks and knowledge required of caregivers in general (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014; Yuen, Knight, Ricciardelli, & Burney, 2018). In addition, inadequate health literacy in caregivers may be associated with poorer health behaviors and outcomes in the person receiving care (Yuen et al., 2018). Health literacy may be even more relevant for caregivers of persons with moderate to severe TBI because the cognitive impairments associated with this condition may preclude persons with TBI from adequately managing their health. In spite of this relevance, only limited research has been conducted on the health literacy of caregivers in general, or caregivers of persons with TBI, in particular, or the health literacy of both the caregiver and the care recipient (Yuen et al., 2018). A systematic review identified only 12 papers from 2003 to 2015 (Yuen et al., 2018), with only a few single studies reporting positive associations between low caregiver health literacy and (a) poorer care recipient health outcomes and (b) increased caregiver burden. None of these studies was conducted in people with TBI.

The Behavioral Model for Vulnerable Populations (BMVP; Andersen, 1968, 1995; Gelberg, Andersen, & Leake, 2000) served as the conceptual framework for the analyses in this report. This model specifies that predisposing characteristics (e.g., sociodemographics), needs (e.g., functional ability), and enabling resources (e.g., health literacy) influence health outcomes (e.g., HRQOL and caregiving role). The purpose of this article was to estimate the occurrence of low health literacy among TBI caregivers, and to evaluate associations of health literacy with caregiver HRQOL and perceptions of the caregiving role. It was hypothesized that low health literacy would be associated with poorer HRQOL and perceptions that are more negative.

## Method

This article is based on the original data collected in the validation testing phase for the TBI-CareQOL study, which took place November 2016 through August, 2017. TBI-CareQOL is a self-reported outcome measurement system that captures multiple aspects of HRQOL significant to caregivers of civilians or service members/veterans with TBI (Carlozzi et al., 2015, 2016; Carlozzi, Kallen, Hanks, Hahn, et al., 2019; Carlozzi, Kallen, Hanks, Kratz, et al., 2019; Carlozzi, Kallen, Ianni, Hahn, et al., 2019; Carlozzi, Kallen, Ianni, Sander, et al., 2019; Carlozzi, Kallen, Sander, et al., 2019). The final phase of the TBI-CareQOL study was to validate the new HRQOL measures and to conduct additional validation on existing instruments. Health literacy was identified as an important concept to measure in this phase.

## Participants

Caregivers of civilians with TBI were recruited from the Rehabilitation Institute of Michigan (RIM), TIRR Memorial Hermann Rehabilitation Hospital in Texas, and the University of Michigan Medical School. Caregivers of service members/veterans (SMVs) with TBI were recruited primarily through military caregiver support organizations, for example, Hearts of Valor. Multiple recruitment strategies for convenience sampling were implemented, including existing TBI caregiver databases, medical record data capture systems (Hanauer, Mei, Law, Khanna, & Zheng, 2015), and hospital-based and community outreach efforts.

Potential study participants were contacted by a study coordinator who described the study and evaluated them for eligibility. Caregivers were at least 18 years old, English-speaking, and were caring for an individual who sustained a medically documented TBI after age 16. TBI Model Systems criteria were used to classify the TBI as complicated mild, moderate, or severe (Dijkers, Marwitz, & Harrison-Felix, 2018). Caregivers of SMVs with mild TBI were included in the sample if they also indicated that they provided at least a minimal level of physical assistance, financial assistance, or emotional support to an individual with a TBI. Only one person with mild TBI was included in this analysis; thus, mild TBI was combined with complicated mild TBI. TBI severity data were not available for the military participants recruited through community outreach at the University of Michigan (57% of the military sample). The individual with the TBI had to be at least one year postinjury. Any caregiver who was recruited through the community was required to provide medical record documentation of a TBI injury. The TIRR Institutional Review Board (IRB) approved a waiver of consent because this research was considered low risk. The University of Michigan Medical School IRB approved both a waiver of written informed consent (to allow for telephone consent) as well as in-person written consent. All RIM participants provided written informed consent. Some participants in the validation phase completed two assessments, approximately two weeks apart, to evaluate test-retest reliability of selected instruments. To reduce respondent burden, the instruments administered during the retest were split into four sets and each participant completed only one set. Each participant received \$60 for the first assessment and \$70 for the second assessment. Health literacy was measured at the second assessment in two of the sets, and only those data were used for this article.

### Measures and Method of Administration

Sociodemographic data were obtained by self-report, and information about the person with TBI was obtained by medical record review and/or by caregiver report. Caregivers also completed the Mayo-Portland Adaptability Inventory-Fourth Edition (MPAI-4) as a measure of the functional ability of the person with TBI (Malec et al., 2003). MPAI-4 items represent the range of physical, cognitive, emotional, behavioral, and social problems that people may encounter after an acquired brain injury. MPAI-4 scores were dichotomized to indicate low functioning/more impairment (score  $\geq 60$ ) versus high functioning/less impairment (score  $< 60$ ) as determined by the developers of this measure (Malec, 2005). The other measures used in this article are described below. A full list of measures from the validation phase is available from the authors. Participants were asked to complete surveys through the PROMIS Assessment Center online platform (<http://www.assessmentcenter.net>), either at a designated computer at the site or on their own computer.

Health Literacy Assessment Using Talking Touchscreen Technology (Health LiTT) is a novel, self-administered multimedia test that meets psychometric standards for measurement of individual respondents, especially in the low to middle range of health literacy (Hahn, Choi, Griffith, Yost, & Baker, 2011; Hahn et al., 2014; Yost et al., 2009, 2010). Participants respond to three item types covering a range of health-related topics and reading levels: prose (reading comprehension), document (identify and interpret information presented in charts, graphs or tables), and quantitative (perform arithmetic operations). A 14-item short

form was used in this study (Hahn et al., 2014). Health LiTT is scored on a *t* score scale (mean of 50 and standard deviation of 10). Health LiTT scores were dichotomized to create two groups: low (inadequate) health literacy (<55) versus high (adequate) health literacy (≥ 55). This dichotomization provided the best cutoff to maximize sensitivity and specificity for distinguishing between inadequate and adequate health literacy (Slesinger, Yost, Choi, & Hahn, in press).

The 37-item Caregiver Appraisal Scale assesses both positive and negative perceptions of the caregiving role in terms of burden, satisfaction with the relationship with the patient, caregiving ideology (beliefs or ideologies regarding caregiving), and caregiving mastery (one's capability for coping with stressors; Lawton, Kleban, Moss, Rovine, & Glicksman, 1989; Struchen, Atchison, Roebuck, Caroselli, & Sander, 2002). The Caregiver Appraisal Scale is scored so that high values reflect positive feelings and low values reflect negative feelings.

The TBI-CareQOL measures were Caregiver Strain (feelings of being overwhelmed, stressed, self-defeated, downtrodden, and “beat-down” related to the caregiver role); Caregiver-Specific Anxiety (feelings of worry and anxiety specific to general safety, health, and future well-being of the person with the injury); Feeling Trapped (feelings of being unable to go places or do things due to caregiving responsibilities); and Feelings of Loss-Self (feelings of loss for the caregivers themselves, including loss of self, relationships, activities and future plans; Carlozzi, Kallen, Hanks, Hahn, et al., 2019; Carlozzi, Kallen, Hanks, Kratz, et al., 2019; Carlozzi, Kallen, Ianni, Hahn, et al., 2019; Carlozzi, Kallen, Ianni, Sander, et al., 2019; Carlozzi, Kallen, Sander, et al., 2019). Each TBI-CareQOL measure was administered as a computer-adaptive test. TBI-CareQOL measures are scored on a *t* score scale, with higher values representing poorer outcomes.

The 12-Item Medical Outcomes Study Short Form Health Survey (SF-12) was administered as a generic measure of health status (Hays, Sherbourne, & Mazel, 1995; Stewart, Ware, Stewart, & Ware, 1991). The SF-12 yields overall physical health and mental health scores, each scored on a *t* score scale with higher values representing better health.

### Statistical Analysis

Chi-square tests, Fisher's exact tests, and analysis of variance methods were used to compare the two health literacy groups on sociodemographic and clinical characteristics. Separate multivariable linear regression models were estimated to evaluate the effect of health literacy on each outcome (Caregiver Appraisal, TBI-CareQOL and General Health Status scales), adjusted for gender, race/ethnicity (Non-Hispanic White vs. others), education (three categories), and MPAI-4 (low vs. high functioning). Only participants with complete data were included in the regressions; a small number ( $n = 16$ ) were excluded. A nominal significance level of 0.05 was used to interpret results. Least squares means and standard errors were reported for the health literacy groups. Health literacy effect sizes were estimated and interpreted using Cohen's *d* (difference between means divided by the overall standard deviation in this sample;  $d = 0.2$ , small effect size;  $d = 0.5$ , medium effect size;  $d = 0.8$ , large effect size; Cohen, 1988).

## Results

Among 131 caregivers who participated in this study, 28 (21%) had low (inadequate) health literacy (see Table 1). Compared with the high health literacy group, the group with low health literacy had fewer women, more racial/ethnic minorities, and lower education (all  $p < .05$ ). The low health literacy caregivers were also more likely to be caring for a child/other family member, whereas the high health literacy caregivers were more likely to be spouses of service members/veterans.

Least squares means, mean differences, and effect sizes for the self-reported outcomes are shown in Table 2. The low health literacy group reported more subjective caregiving burden, less satisfaction with their relationship with the patient, and less caregiving mastery (capability for coping with stressors; all  $p < .05$ ; medium effect sizes; Appraisal of the Caregiving Role). There were no differences between health literacy groups, and small effect sizes, in caregiving ideology, caregiver-specific HRQOL (TBI-CareQOL), and general mental health. The low health literacy group did report poorer physical health ( $p < .05$ ; medium effect size).

## Discussion

This study provides new information on the health literacy of caregivers of people with TBI, and finds support for the hypothesis that low health literacy would be associated with negative perceptions of the caregiver role. Only one HRQOL measure (physical health) was associated with health literacy, whereas the other HRQOL measures were not, contrary to the hypothesis. The occurrence of low health literacy was 21% in this sample. Low health literacy in other types of caregivers ranged from 0% to 52% depending on the measure and cut-off criteria used (Yuen et al., 2018). Because of inconsistencies in the definition and measurement of health literacy (Jordan, Osborne, & Buchbinder, 2011), it is difficult to compare results across studies. Health literacy in this study was measured with Health LiTT, which represents an individual's capacity to process and understand health-related information and the ability to apply that information in health situations (Yost et al., 2009). Scores were dichotomized to distinguish between adequate and inadequate health literacy. Health LiTT is unique in that it is self-administered rather than interviewer-administered which is used in other measures.

Compared with the high health literacy group, those with low health literacy in this study had more racial/ethnic minorities and lower education. These results are consistent with previous findings in diverse populations that race, ethnicity, and educational attainment have strong relationships with health literacy (Berkman et al., 2011). As hypothesized, the low health literacy group in this study reported more subjective caregiving burden, less satisfaction with their relationship with the patient, and less caregiving mastery (one's capability for coping with stressors), even after adjusting for gender, race/ethnicity, and education. In terms of HRQOL, there were no differences between health literacy groups in caregiver-specific HRQOL or general mental health, but the low health literacy group reported poorer physical health.



In other caregiver groups, low health literacy was associated with more burden among caregivers caring for people with chronic diseases (Demir Barutcu, 2019) and those caring for people with diabetes (Gibson, 2012). In terms of HRQOL, two systematic reviews identified only four studies that measured both HRQOL and health literacy, with some reporting associations between health literacy and HRQOL, and others not finding such associations (Berkman et al., 2004, 2011). As the field of health literacy has advanced, more studies in diverse populations are emerging to investigate the associations between health literacy and HRQOL; these results have also been mixed (Hahn et al., 2015, 2017; Montbleau, King, Henault, & Magnani, 2017; Stollefson et al., 2019; Wang, Kane, Xu, & Meng, 2015; Zhang, Li, Fong, & Thumboo, 2009). Because HRQOL is a multidimensional concept, with dozens of disease-specific and generic domains, more research is needed to identify patterns of associations between health literacy and various HRQOL domains. In addition, research is needed to evaluate potential moderators and mediators of the relationship between health literacy and health outcomes (Berkman et al., 2011).

Caregiving mastery is closely related to the concept of self-efficacy, which is the belief or confidence in one's ability to have influence over events in one's life (Bandura & Schwarzer, 1992). Self-efficacy may be especially important in racial/ethnic minority populations, given the disproportionate barriers they experience, including health care access, financial barriers (Karter, Ferrara, Darbinian, Ackerson, & Selby, 2000; Piette, Wagner, Potter, & Schillinger, 2004), and cultural beliefs (Schorling & Saunders, 2000), all of which may contribute to lower self-efficacy (Sarkar, Fisher, & Schillinger, 2006). Self-efficacy may also be an important causal link between health literacy and health outcomes (Berkman et al., 2011). There is growing consensus that clinicians should play a greater role in assessment and improvement of caregiver knowledge and skills, including health literacy (Adelman et al., 2014; Family Caregiver Alliance, 2006a, 2006b; Moore et al., 2017). Increasing health-related self-efficacy and/or health literacy in caregivers of people with TBI might be a critical clinical strategy for improving coping and health outcomes in the caregivers themselves, with possible transfer of benefits to the health of the person with TBI. Education studies in other caregiver groups demonstrated improvement in self-efficacy (Hendrix et al., 2016) or burden and the ability to find health information (Cianfrocca et al., 2018). Preparedness may influence the HRQOL of both patients and their caregivers (Magasi, Buono, Yancy, Ramirez, & Grady, 2019; Stone, 2014). Thus, it would likely follow that increased health literacy would be associated with improved preparedness and outcomes.

There are some limitations to this study. Because convenience sampling was used, generalizability is limited with regard to racial/ethnic minorities, male caregivers, and caregivers who are parents or relations other than spouses. More than one third (36%) of caregivers in the United States have a high school education or less (National Alliance for Caregiving & AARP Public Policy Institute, 2015), yet this study enrolled only 20% with low education. Caregivers of service members/veterans were primarily recruited through support organizations, and so results may not be representative of those who care for a person with a military-related TBI. It will be important to recruit caregivers through military medical centers in future studies.

In this study many individuals with low health literacy also had lower education and were from racial/ethnic minority groups. This suggests that resources for accessing health information may be limited. Health care providers in the rehabilitation setting may need to think more broadly about how to provide access for such persons. For example, useful strategies might include multimedia platforms, including phone apps and Internet websites, or nontraditional avenues of information dissemination such presentations at local churches or community centers. Among infant caregivers, many of whom had low health literacy, text messaging as an educational tool was effective in reducing the number of visits to the emergency department (Ladley, Hieger, Arthur, & Broom, 2018) The efficacy of novel strategies could be studied via research with regard to helping clinicians plan the best strategies for assessing HRQOL in TBI caregivers.

In conclusion, knowing more about the people who are at risk for not having access to health information allows treating professionals to target health literacy interventions. For those who provide care to those with TBI, it will be important to think about the type of information to be presented, the reading level of those who will be exposed to this information, and methods of dissemination that need to be expanded. For example, a multidisciplinary family home care management course for caregivers of people with chronic diseases included a focus on diverse levels of health literacy (Cianfrocca et al., 2018). In this way, more caregivers can be reached and provided with appropriate health care information.

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## References

- Adams D, & Dahdah M (2016). Coping and adaptive strategies of traumatic brain injury survivors and primary caregivers. *NeuroRehabilitation*, 39, 223–237. 10.3233/NRE-161353 [PubMed: 27372358]
- Adelman RD, Tmanova LL, Delgado D, Dion S, & Lachs MS (2014). Caregiver burden: A clinical review. *Journal of the American Medical Association*, 311, 1052–1060. 10.1001/jama.2014.304 [PubMed: 24618967]
- Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, American Medical Association. (1999). Health literacy: Report of the Council on Scientific Affairs. *Journal of the American Medical Association*, 281, 552–557. [PubMed: 10022112]
- Andersen RM (1968). Behavioral model of families' use of health services. Chicago, IL: University of Chicago.
- Andersen RM (1995). Revisiting the behavioral model and access to medical care: Does it matter? *Journal of Health and Social Behavior*, 36, 1–10. [PubMed: 7738325]
- Bailey EK, Nakase-Richardson R, Patel N, Dillahunt-Aspillaga C, Ropacki SA, Sander AM, ... Tang X (2017). Supervision needs following veteran and service member moderate to severe traumatic brain injury: A VA TBI model systems study. *The Journal of Head Trauma Rehabilitation*, 32, 245–254. 10.1097/HTR.0000000000000317 [PubMed: 28520667]
- Bandura A, & Schwarzer R (1992). Self-efficacy mechanism in psychobiologic functioning In Schwarzer R (Ed.), *Self-efficacy: Thought control of action* (pp. 355–394). Washington, DC: Hemisphere Publishing.
- Berkman ND, DeWalt DA, Pignone MP, Sheridan SL, Lohr KN, Lux L, ... Bonito AJ (2004). Literacy and health outcomes Evidence report/technology assessment no. 87 (AHRQ Publication No. 04-



- E007-2). Rockville, MD: U.S. Department of Health and Human Services Retrieved from <http://purl.access.gpo.gov/GPO/LPS47971>
- Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Viera A, Crotty K, ... Viswanathan M (2011). Health literacy interventions and outcomes: An updated systematic review, executive summary, evidence report/technology assessment no.199 (Publication Number 11-E006-1). Rockville, MD: U.S. Department of Health and Human Services Retrieved from <http://www.ahrq.gov/clinic/eptsups/litupsum.htm>
- Carlozzi NE, Brickell TA, Psych D, French LM, Sander A, Kratz AL, ... Lange RT (2016). Caring for our wounded warriors: A qualitative examination of health-related quality of life in caregivers of individuals with military-related traumatic brain injury. *Journal of Rehabilitation Research and Development*, 53, 669–680. [PubMed: 27997672]
- Carlozzi NE, Kallen MA, Hanks R, Hahn EA, Brickell TA, Lange RT, ... Sander AM (2019). The TBI-CareQOL measurement system: Development and 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*, 100, S1–S12. [PubMed: 30195987]
- Carlozzi NE, Kallen MA, Hanks R, Kratz AL, Hahn EA, Brickell TA, ... Sander AM (2019). The development of a new computer adaptive test to evaluate feelings of being trapped in caregivers of individuals with traumatic brain injury: TBI-CareQOL feeling trapped item bank. *Archives of Physical Medicine and Rehabilitation*, 100, S43–S51. [PubMed: 30075146]
- Carlozzi NE, Kallen MA, Ianni PA, Hahn EA, French LM, Lange RT, ... Sander AM (2019). The development of a new computer-adaptive test to evaluate strain in caregivers of individuals with traumatic brain injury: TBI-CareQOL caregiver strain. *Archives of Physical Medicine and Rehabilitation*, 100, S13–S21. [PubMed: 29966647]
- Carlozzi NE, Kallen MA, Ianni PA, Sander AM, Hahn EA, Lange RT, ... Hanks R (2019). The development of a two new computer adaptive tests to evaluate feelings of loss in caregivers of individuals with traumatic brain injury: TBI-CareQOL feelings of loss-self and feelings of loss-person with traumatic brain injury. *Archives of Physical Medicine and Rehabilitation*, 100, S31–S42. [PubMed: 29958904]
- Carlozzi NE, Kallen MA, Sander AM, Brickell TA, Lange RT, French LM, ... Hanks R (2019). The development of a new computer adaptive test to evaluate anxiety in caregivers of individuals with traumatic brain injury: TBI-CareQOL Caregiver-Specific Anxiety. *Archives of Physical Medicine and Rehabilitation*, 100, S22–S30. [PubMed: 29958902]
- Carlozzi NE, Kratz AL, Sander AM, Chiaravalloti ND, Brickell TA, Lange RT, ... Tulskey DS (2015). Health-related quality of life in caregivers of individuals with traumatic brain injury: Development of a conceptual model. *Archives of Physical Medicine and Rehabilitation*, 96, 105–113. 10.1016/j.apmr.2014.08.021 [PubMed: 25239281]
- Carlozzi NE, Lange RT, French LM, Sander AM, Freedman J, & Brickell TA (2018). A latent content analysis of barriers and supports to healthcare: Perspectives from caregivers of service members and veterans with military-related traumatic brain injury. *The Journal of Head Trauma Rehabilitation*, 33, 342–353. 10.1097/HTR.0000000000000373 [PubMed: 29385014]
- Chan J, Parmenter T, & Stancliffe R (2009). The impact of traumatic brain injury on the mental health outcomes of individuals and their family carers. *Australian e-Journal for the Advancement of Mental Health*, 8, 155–164. 10.5172/jamh.8.2.155
- Chronister J, Chan F, Sasson-Gelman EJ, & Chiu C-Y (2010). The association of stress-coping variables to quality of life among caregivers of individuals with traumatic brain injury. *NeuroRehabilitation*, 27, 49–62. 10.3233/NRE-2010-0580 [PubMed: 20634600]
- Cianfrocca C, Caponnetto V, Donati D, Lancia L, Tartaglino D, & Di Stasio E (2018). The effects of a multidisciplinary education course on the burden, health literacy and needs of family caregivers. *Applied Nursing Research*, 44, 100–106. 10.1016/j.apnr.2018.10.004 [PubMed: 30389053]
- Cohen J (1988). *Statistical power analysis for the behavioral sciences* (2nd ed.). Hillsdale, NJ: Erlbaum.
- Demir Barutcu C (2019). Relationship between caregiver health literacy and caregiver burden. *Puerto Rico Health Sciences Journal*, 38, 163–169. [PubMed: 31536629]
- DeWalt DA, & Pignone MP (2005). Reading is fundamental: The relationship between literacy and health. *Archives of Internal Medicine*, 165, 1943–1944. [PubMed: 16186462]

- Dijkers MP, Marwitz JH, & Harrison-Felix C (2018). Thirty years of national institute on disability, independent living, and rehabilitation research traumatic brain injury model systems center research: An update. *The Journal of Head Trauma Rehabilitation*, 33, 363–374. 10.1097/HTR.0000000000000454 [PubMed: 30395041]
- Family Caregiver Alliance. (2006a). *Caregiver assessment: Principles, guidelines and strategies for change: Report from a National Consensus Development Conference (Vol. I)*. San Francisco, CA: Author.
- Family Caregiver Alliance. (2006b). *Caregiver assessment: Voices and views from the field: Report from a national consensus development conference (Vol. II)*. San Francisco, CA: Author.
- Fayers PM, & Machin D (2007). *Quality of life: The assessment, analysis and interpretation of patient-reported outcomes (2nd ed.)*. Chichester, UK: Wiley 10.1002/9780470024522
- Gelberg L, Andersen RM, & Leake BD (2000). The Behavioral Model for Vulnerable Populations: Application to medical care use and outcomes for homeless people. *Health Services Research*, 34, 1273–1302. [PubMed: 10654830]
- Gibson JT (2012). *Correlation of health literacy to the stress level of informal caregivers for people with type 2 diabetes*. Minneapolis, MN: Walden University.
- Griffin JM, Friedemann-Sánchez G, Jensen AC, Taylor BC, Gravely A, Clothier B, ... van Ryn M (2012). The invisible side of war: Families caring for U.S. service members with traumatic brain injuries and polytrauma. *The Journal of Head Trauma Rehabilitation*, 27, 3–13. 10.1097/HTR.0b013e3182274260 [PubMed: 21873883]
- Griffin JM, Lee MK, Bangerter LR, Van Houtven CH, Friedemann-Sanchez G, Phelan SM, ... Meis LA (2017). Burden and mental health among caregivers of veterans with traumatic brain injury/polytrauma. *American Journal of Orthopsychiatry*, 87, 139–148. 10.1037/ort0000207 [PubMed: 28206801]
- Hahn EA, Burns JL, Jacobs EA, Ganschow PS, Garcia SF, Rutsohn JP, & Baker DW (2015). Health literacy and patient-reported outcomes: A cross-sectional study of underserved English- and Spanish-speaking patients with type 2 diabetes. *Journal of Health Communication*, 20, 4–15. 10.1080/10810730.2015.1061071
- Hahn EA, Choi SW, Griffith JW, Yost KJ, & Baker DW (2011). Health literacy assessment using talking touchscreen technology (Health LiTT): A new item response theory-based measure of health literacy. *Journal of Health Communication*, 16, 150–162. 10.1080/10810730.2011.605434 [PubMed: 21951249]
- Hahn EA, Kallen MA, Jacobs EA, Ganschow PS, Garcia SF, & Burns JL (2014). English-Spanish equivalence of the health literacy assessment using talking touchscreen technology (Health LiTT). *Journal of Health Communication*, 19, 285–301. 10.1080/10810730.2014.936567 [PubMed: 25315599]
- Hahn EA, Magasi SR, Carlozzi NE, Tulsy DS, Wong A, Garcia SF, ... Heinemann AW (2017). Health and functional literacy in physical rehabilitation patients. *Health Literacy Research and Practice*, 1, e71–e85. 10.3928/24748307-20170427-02 [PubMed: 31294252]
- Hall KM, Bushnik T, Lakisic-Kazacic B, Wright J, & Cantagallo A (2001). Assessing traumatic brain injury outcome measures for longterm follow-up of community-based individuals. *Archives of Physical Medicine and Rehabilitation*, 82, 367–374. 10.1053/apmr.2001.21525 [PubMed: 11245760]
- Hanauer DA, Mei Q, Law J, Khanna R, & Zheng K (2015). 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*, 55, 290–300. 10.1016/j.jbi.2015.05.003 [PubMed: 25979153]
- Hart T, Millis S, Novack T, Englander J, Fidler-Sheppard R, & Bell KR (2003). The relationship between neuropsychologic function and level of caregiver supervision at 1 year after traumatic brain injury. *Archives of Physical Medicine and Rehabilitation*, 84, 221–230. 10.1053/apmr.2003.50023 [PubMed: 12601653]
- Hays RD, Sherbourne CD, & Mazel R (1995). *User's manual for the Medical Outcomes Study (MOS) core measures of health-related quality of life*. Santa Monica, CA: Rand Corporation.

- Hendrix CC, Bailey DE Jr., Steinhauser KE, Olsen MK, Stechuchak KM, Lowman SG, ... Tulsy JA (2016). Effects of enhanced caregiver training program on cancer caregiver's self-efficacy, preparedness, and psychological well-being. *Supportive Care in Cancer*, 24, 327–336. 10.1007/s00520-015-2797-3 [PubMed: 26062925]
- Jordan JE, Osborne RH, & Buchbinder R (2011). Critical appraisal of health literacy indices revealed variable underlying constructs, narrow content and psychometric weaknesses. *Journal of Clinical Epidemiology*, 64, 366–379. 10.1016/j.jclinepi.2010.04.005 [PubMed: 20638235]
- Karter AJ, Ferrara A, Darbinian JA, Ackerson LM, & Selby JV (2000). Self-monitoring of blood glucose: Language and financial barriers in a managed care population with diabetes. *Diabetes Care*, 23, 477–483. 10.2337/diacare.23.4.477 [PubMed: 10857938]
- Keatley E, Hanks R, Sander AM, Kratz AL, Tulsy DS, Ianni P, ... Carlozzi NE (2018). Predictors of outcomes among caregivers of civilians and service members or veterans with traumatic brain injury. (Manuscript in review).
- Kratz A, Carlozzi N, Brickell TA, & Sander AM (2014). "I Want ME as a Caregiver": Perspectives from Caregivers of Individuals with Traumatic Brain Injury. *Archives of Physical Medicine and Rehabilitation*, 95, e50 10.1016/j.apmr.2014.07.155
- Ladley A, Hieger AW, Arthur J, & Broom M (2018). Educational text messages decreased emergency department utilization among infant caregivers: A randomized trial. *Academic Pediatrics*, 18, 636–641. 10.1016/j.acap.2018.02.003 [PubMed: 29432907]
- Lawton MP, Kleban MH, Moss M, Rovine M, & Glicksman A (1989). Measuring caregiving appraisal. *Journal of Gerontology*, 44, 61–71. 10.1093/geronj/44.3.P61
- Lester P, Peterson K, Reeves J, Knauss L, Glover D, Mogil C, ... Beardslee W (2010). The long war and parental combat deployment: Effects on military children and at-home spouses. *Journal of the American Academy of Child & Adolescent Psychiatry*, 49, 310–320. 10.1097/00004583-201004000-00006 [PubMed: 20410724]
- Magasi S, Buono S, Yancy CW, Ramirez RD, & Grady KL (2019). Preparedness and mutuality affect quality of life for patients with mechanical circulatory support and their caregivers. *Circulation: Cardiovascular Quality and Outcomes*, 12, e004414 10.1161/CIRCOUTCOMES.117.004414 [PubMed: 30636480]
- Malec J (2005). The Mayo-Portland Adaptability Inventory. Santa Clara, CA: The Center for Outcome Measurement in Brain Injury Retrieved from <http://www.tbims.org/combi/mpai>
- Malec JF, Kragness M, Evans RW, Finlay KL, Kent A, & Lezak MD (2003). Further psychometric evaluation and revision of the Mayo-Portland Adaptability Inventory in a national sample. *The Journal of Head Trauma Rehabilitation*, 18, 479–492. 10.1097/00001199-200311000-00002 [PubMed: 14707878]
- Mansfield AJ, Kaufman JS, Marshall SW, Gaynes BN, Morrissey JP, & Engel CC (2010). Deployment and the use of mental health services among U.S. Army wives. *The New England Journal of Medicine*, 362, 101–109. 10.1056/NEJMoa0900177 [PubMed: 20071699]
- Montbleau KE, King D, Henault L, & Magnani JW (2017). Health literacy, health-related quality of life, and atrial fibrillation. *Cogent Medicine*, 4, 1412121 10.1080/2331205X.2017.1412121 [PubMed: 29276719]
- Moore M, Kiatchai T, Ayyagari RC, & Vavilala MS (2017). Targeted areas for improving health literacy after traumatic brain injury. *Brain Injury*, 31, 1876–1881. 10.1080/02699052.2017.1346291 [PubMed: 28816517]
- National Alliance for Caregiving, & AARP Public Policy Institute. (2015). Caregiving in the U.S. 2015. Retrieved from <https://www.aarp.org/ppi/info-2015/caregiving-in-the-united-states-2015.html>
- Nielsen-Bohlman L, Panzer AM, & Kindig DA (2004). Health literacy: A prescription to end confusion. Washington, DC: National Academies Press.
- Phelan SM, Griffin JM, Hellerstedt WL, Sayer NA, Jensen AC, Burgess DJ, & van Ryn M (2011). Perceived stigma, strain, and mental health among caregivers of veterans with traumatic brain injury. *Disability and Health Journal*, 4, 177–184. 10.1016/j.dhjo.2011.03.003 [PubMed: 21723524]

- Piette JD, Wagner TH, Potter MB, & Schillinger D (2004). Health insurance status, cost-related medication underuse, and outcomes among diabetes patients in three systems of care. *Medical Care*, 42, 102–109. 10.1097/01.mlr.0000108742.26446.17 [PubMed: 14734946]
- Ruff RL, Ruff SS, & Wang XF (2009). Improving sleep: Initial headache treatment in OIF/OEF veterans with blast-induced mild traumatic brain injury. *Journal of Rehabilitation Research and Development*, 46, 1071–1084. 10.1682/JRRD.2009.05.0062 [PubMed: 20437313]
- Saban KL, Griffin JM, Urban A, Janusek MA, Pape TL, & Collins E (2016). Perceived health, caregiver burden, and quality of life in women partners providing care to veterans with traumatic brain injury. *Journal of Rehabilitation Research and Development*, 53, 681–692. 10.1682/JRRD.2015.07.0143 [PubMed: 27997670]
- Sarkar U, Fisher L, & Schillinger D (2006). Is self-efficacy associated with diabetes self-management across race/ethnicity and health literacy? *Diabetes Care*, 29, 823–829. 10.2337/diacare.29.04.06.dc05-1615 [PubMed: 16567822]
- Schorling JB, & Saunders JT (2000). Is “sugar” the same as diabetes? A community-based study among rural African-Americans. *Diabetes Care*, 23, 330–334. [PubMed: 10868860]
- Slesinger NC, Yost KJ, Choi SW, & Hahn EA (in press). Validation of a short form for health LiTT. *Health Literacy Research and Practice*.
- Stellefson M, Paige SR, Alber JM, Chaney BH, Chaney D, Apperson A, & Mohan A (2019). Association between health literacy, electronic health literacy, disease-specific knowledge, and health-related quality of life among adults with chronic obstructive pulmonary disease: Cross-sectional study. *Journal of Medical Internet Research*, 21, e12165 10.2196/12165 [PubMed: 31172962]
- Stewart AL, Ware JE, Stewart AL, & Ware JE (1991). *Measuring functioning and well-being: The medical outcomes study approach*. Durham, NC: Duke University Press.
- Stone K (2014). Enhancing preparedness and satisfaction of caregivers of patients discharged from an inpatient rehabilitation facility using an interactive website. *Rehabilitation Nursing*, 39, 76–85. 10.1002/rnj.123 [PubMed: 24038541]
- Struchen MA, Atchison TB, Roebuck TM, Caroselli JS, & Sander AM (2002). A multidimensional measure of caregiving appraisal: Validation of the Caregiver Appraisal Scale in traumatic brain injury. *Journal of Head Trauma Rehabilitation*, 17, 132–154. [PubMed: 11909511]
- Taft CT, Schumm JA, Panuzio J, & Proctor SP (2008). An examination of family adjustment among Operation Desert Storm veterans. *Journal of Consulting and Clinical Psychology*, 76, 648–656. 10.1037/a0012576 [PubMed: 18665692]
- Verhaeghe S, Defloor T, & Grypdonck M (2005). Stress and coping among families of patients with traumatic brain injury: A review of the literature. *Journal of Clinical Nursing*, 14, 1004–1012. 10.1111/j.1365-2702.2005.01126.x [PubMed: 16102152]
- Wang C, Kane RL, Xu D, & Meng Q (2015). Health literacy as a moderator of health-related quality of life responses to chronic disease among Chinese rural women. *BMC Women’s Health*, 15, 34 10.1186/s12905-015-0190-5 [PubMed: 25887361]
- Yost KJ, Webster K, Baker DW, Choi SW, Bode RK, & Hahn EA (2009). Bilingual health literacy assessment using the Talking Touchscreen/la Pantalla Parlanchina: Development and pilot testing. *Patient Education and Counseling*, 75, 295–301. 10.1016/j.pec.2009.02.020 [PubMed: 19386462]
- Yost KJ, Webster K, Baker DW, Jacobs EA, Anderson A, & Hahn EA (2010). Acceptability of the talking touchscreen for health literacy assessment. *Journal of Health Communication*, 15, 80–92. 10.1080/10810730.2010.500713 [PubMed: 20845195]
- Yuen EYN, Knight T, Ricciardelli LA, & Burney S (2018). Health literacy of caregivers of adult care recipients: A systematic scoping review. *Health & Social Care in the Community*, 26, e191–e206. 10.1111/hsc.12368 [PubMed: 27426731]
- Zhang XH, Li SC, Fong KY, & Thumboo J (2009). The impact of health literacy on health-related quality of life (HRQoL) and utility assessment among patients with rheumatic diseases. *Value in Health*, 12, S106–S109. 10.1111/j.1524-4733.2009.00640.x [PubMed: 20586970]

### **Impact and Implications**

Health literacy is particularly relevant for the tasks and knowledge required of caregivers. Improving health literacy and health-related self-efficacy might be a critical clinical strategy for improving coping and health outcomes in caregivers of persons with traumatic brain injury.

**Table 1**

**Sociodemographic and Clinical Characteristics by Health Literacy Group**

<b>Sociodemographic and clinical characteristics</b>	<b>Low health literacy (n = 28)</b>	<b>High health literacy (n = 103)</b>	<b>Full sample (n = 131)</b>	<b>p value</b>
<b>Caregiver</b>				
Female gender	17 (61%)	88 (85%)	103 (80%)	.0034*
Age in years	47.7 (17.9)	45.8 (14.7)	46.2 (15.4)	.561
<b>Ethnicity, race</b>				
Non-Hispanic, White	10 (36%)	80 (78%)	90 (69%)	<.001*
Other	18 (64%)	23 (22%)	41 (31%)	
<b>Highest education</b>				
Less than HS	3 (11%)	4 (4%)	7 (5%)	<.001*
HS/GED	10 (36%)	9 (9%)	19 (15%)	
More than HS	15 (54%)	90 (87%)	105 (80%)	
<b>Relationship to person with TBI</b>				
Spouse	5 (18%)	57 (55%)	62 (47%)	<.001*
Parent	5 (18%)	26 (25%)	31 (24%)	
Child/other family member	11 (39%)	14 (14%)	25 (19%)	
Other	7 (25%)	6 (6%)	13 (10%)	
Years in caregiver role	8.6 (5.8)	6.9 (4.8)	7.2 (5.1)	.120
<b>Person with TBI</b>				
Female gender	7 (25%)	22 (21%)	29 (22%)	.681
Age in years	41.7 (13.6)	40.3 (12.7)	40.6 (12.9)	.621
Time since injury in years	11.2 (6.9)	8.4 (6.8)	9.1 (6.9)	.072
Low level of functioning/high impairment (MPAI-4)	4 (15%)	25 (28%)	29 (24%)	.199
<b>TBI severity</b>				
Mild/complicated mild	8 (32%)	15 (22%)	23 (25%)	.582
Moderate	5 (20%)	18 (26%)	23 (25%)	
Severe	12 (48%)	35 (52%)	47 (50%)	
Service member/veteran	3 (11%)	36 (30%)	39 (30%)	.013*



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*Note.* Entries in the table represent the number of participants (percentage) or the mean (standard deviation). GED = General Educational Development Test (high school equivalency diploma); HS = high school; MPAL-4 = Mayo-Portland Adaptability Inventory, fourth edition; TBI = traumatic brain injury. *p* value: chi-square test, Fisher's exact test, or *t* test for comparison of the health literacy groups, excluding missing data.

\*  $p < .05$ .

**Table 2**

Self-Reported Outcomes by Health Literacy Group

Measure	Least-squares mean (standard error) <sup>c</sup>			p value	Absolute mean difference	Overall SD	Effect size <sup>d</sup>
	Low health literacy (n = 26)	High health literacy (n = 89)	High health literacy (n = 89)				
Appraisal of the caregiving role (Caregiver Appraisal Scale [CAS]) <sup>b</sup>							
Burden	45.2 (3.0)	51.5 (2.7)	51.5 (2.7)	.041*	6.3	14.3	0.44
Relationship satisfaction	40.8 (1.5)	44.1 (1.3)	44.1 (1.3)	.028*	3.3	5.9	0.57
Ideology/beliefs	15.6 (1.0)	14.8 (0.9)	14.8 (0.9)	.443	0.8	4.0	0.20
Mastery	12.6 (0.7)	14.2 (0.6)	14.2 (0.6)	.030*	1.6	3.0	0.53
Caregiver health-related quality of life (TBI-CareQOL) <sup>d</sup>							
Caregiver strain	46.5 (2.5)	45.1 (2.2)	45.1 (2.2)	.578	1.4	11.2	0.13
Caregiver-specific anxiety	49.4 (2.6)	46.6 (2.3)	46.6 (2.3)	.280	2.8	11.4	0.25
Feeling trapped	50.0 (2.2)	47.1 (2.0)	47.1 (2.0)	.199	2.9	10.1	0.29
Feelings of loss-self	47.4 (2.4)	44.2 (2.2)	44.2 (2.2)	.190	3.2	11.2	0.29
General health status (SF-12) <sup>b</sup>							
Physical health	42.9 (1.7)	46.3 (1.5)	46.3 (1.5)	.047*	3.4	7.7	0.44
Mental health	40.2 (1.5)	42.2 (1.3)	42.2 (1.3)	.181	2.0	6.1	0.33

Note. SF-12 = 12-Item Medical Outcomes Study Short Form Health Survey.

<sup>a</sup>Effect size: absolute difference between least-squares means divided by the overall standard deviation (SD).

<sup>b</sup>All CAS and SF-12 domains are scored so that higher values represent better outcomes (e.g., a high Burden score represents less burden, a high Satisfaction score represents more satisfaction, a high Physical Health score represents better health, etc.).

<sup>c</sup>Least squares mean (standard error), adjusted for gender, race (Non-Hispanic White versus others), education (Less than high school, high school/General Educational Development Test (high school equivalency diploma), More than high school), and Mayo-Portland Adaptability Inventory (fourth edition) functioning (low versus high functioning).

<sup>d</sup>All TBI-CareQOL domains are scored so that higher values represent poorer outcomes (e.g., a high Caregiver Strain score represents more strain, etc.).

\*  $p < .05$ .