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Perceived care partner burden at 1-year post-injury and associations with emotional awareness, functioning, and empathy after TBI: A TBI model systems study

Daniel W. Klyce[a,b,c,*], Kritzianel Merced[a,1], Alexander Erickson[a,d,2], Dawn M. Neumann[e,f], Flora M. Hammond[e,f], Angelle M. Sander[g,h], Jennifer A. Bogner[i], Tamara Bushnik[j,k], Joyce S. Chung[l] and Jacob A. Finn[m,n]

[a] *Central Virginia VA Health Care System, Richmond, VA, USA*
[b] *Virginia Commonwealth University Health System, Richmond, VA, USA*
[c] *Sheltering Arms Institute, Richmond, VA, USA*
[d] *Palo Alto University, Palo Alto, CA, USA*
[e] *Indiana University School of Medicine, Indianapolis, IN, USA*
[f] *Rehabilitation Hospital of Indiana, Indianapolis, IN, USA*
[g] *Baylor College of Medicine, Houston, TX, USA*
[h] *TIRR Memorial Hermann, Houston, TX, USA*
[i] *The Ohio State University, Columbus, OH, USA*
[j] *New York University Langone Health, New York, NY, USA*
[k] *Rusk Rehabilitation Center, New York, NY, USA*
[l] *VA Palo Alto Health Care System, Palo Alto, CA, USA*
[m] *Minneapolis VA Health Care System, Minneapolis, MN, USA*
[n] *University of Minnesota, Minneapolis, MN, USA*

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Abstract.

BACKGROUND: People with traumatic brain injury (TBI) can lack awareness of their own emotions and often have problems with emotion dysregulation, affective disorders, and empathy deficits. These impairments are known to impact psychosocial behaviors and may contribute to the burden experienced by care partners of individuals with TBI.

OBJECTIVE: To examine the associations of emotional awareness, emotional functioning, and empathy among participants with TBI with care partner burden.

METHOD: This multisite, cross-sectional, observational study used data from 90 dyads (participants with TBI and their care partner) 1-year post-injury. Participants with TBI completed the Difficulty with Emotional Regulation Scale (DERS; Awareness, Clarity, Goals, Impulse, Nonacceptance, and Strategies subscales); PTSD Checklist-Civilian Version; NIH Toolbox Anger-Affect, Hostility and Aggression Subdomains; PHQ-9; GAD-7; and the Interpersonal Reactivity Index (empathic concern and perspective taking subscales). Care partners completed the Zarit Burden Inventory (ZBI) and provided demographic information.

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[1] Present address: VA Durham Health Care System, Durham, NC, USA.

[2] Present address: VA Greater Los Angeles Health Care System, Los Angeles, CA, USA.

[*] Address for correspondence: Daniel W. Klyce, Ph.D., ABPP, Central Virginia VA Health Care System, 1201 Broad Rock Boulevard (652/151-TBI), Richmond, VA 23249, USA. E-mail: daniel.klyce@va.gov.

RESULTS: Care partners were predominately female (77%), and most were either a spouse/partner (55.2%) or parent (34.4%). In an unadjusted model that included assessments of emotional awareness, emotional functioning, and empathy of the participant with TBI, the DERS-Awareness and NIH-Hostility subscales accounted for a significant amount of variance associated with care partner burden. These findings persisted after adjusting for care partner age, relationship, education, and the functional status of the participant with TBI ($\beta = 0.493$ and $\beta = 0.328$, respectively).
CONCLUSION: These findings suggest that high levels of hostility and low emotional self-awareness can significantly affect the burden felt by TBI care partners.

Keywords: Traumatic brain injury, alexithymia, emotional awareness, caregiving

1. Introduction

Traumatic brain injury (TBI) is a leading cause of mortality and morbidity in young adults and is a major public health problem worldwide (Corrigan et al., 2010; Rodriguez et al., 2006). Prevalence studies have found that 12% of the general population has a history of TBI with varying severity (Frost et al., 2013). Approximately 5.3 million Americans live with long-term disability following TBI (Thompson, 2009), thus requiring ongoing monitoring and care (Centers for Disease Control and Prevention, 2015; Taylor et al., 2017). Persistent effects of TBI can include impaired cognitive, emotional, behavioral, and social functioning, which can result in increased responsibilities and strain on family care partners (Hoofien et al., 2001; Osborn et al., 2016; Rabinowitz & Levin, 2014; Sabaz et al., 2014; Simpson et al., 2013). Caring for an individual who has sustained a TBI may place significant burden on family members and loved ones, influencing their own adjustment to the condition, functioning over time, and the effective development of strategies to alleviate distress (Marsh et al., 2002; Nabors et al., 2002).

Significant levels of distress have been documented among care partners of people with TBI (Anderson et al., 2002; Ergh et al., 2003; Kreutzer et al., 2009; Marsh et al., 1998a, 2002; Verhaeghe et al., 2005). For example, a substantial portion of care partners of individuals with TBI report unhealthy family functioning or dissatisfaction with life (Kreutzer et al., 2009; Verhaeghe et al., 2005). Care partners also report higher levels of depression, anxiety, and social isolation (Anderson et al., 2002; Ergh et al., 2003; Kreutzer et al., 2009; Manskow et al., 2015; Marsh et al., 1998a, 2002; Verhaeghe et al., 2005), which can subsequently influence the quality of life and functioning for the patients with TBI (Lehan et al., 2012; Vogler et al., 2014). Hence, care partner adjustment to TBI is a concern across the continuum of care (Liu et al., 2020; Manskow et al., 2015). Although definitions vary, care partner burden is typically defined as the level of multifaceted strain perceived by the care partner from caring for a family member and/or loved one over time (Liu et al., 2020). As such, caregiving burden becomes the individual's subjective assessment of the caregiving situation and the degree of difficulties or stressors impacting their experience (Chou, 2000). To this end, an important area of rehabilitation research involves understanding how factors related to individuals with TBI can contribute to caregiving burden (Everhart et al., 2020; Uphold et al., 2014).

Research has found that emotion dysregulation and behavioral difficulties experienced by a person with TBI can be linked to higher burden experienced by care partners (Kreutzer et al., 2009; Marsh et al., 1998a, 2002). For instance, a study conducted with sixty-nine primary care partners of adults with severe TBI assessed at 1-year post-injury found that emotional difficulties—in particular anger, apathy, and dependency—were associated with higher levels of perceived distress by care partners (Marsh et al., 1998b). Similarly, a study following these care partners at 6-months and 1-year after TBI suggested that care partners tend to adapt faster to physical impairments, but that cognitive and behavioral (including depressed mood, anger, aggression, and irritability) problems tend to pose greater challenges to adjustment, possibly influencing the level of care partner burden (Marsh et al., 2002). A potential explanation for these findings is that post-TBI emotional and behavioral changes negatively impacts their interpersonal interactions (how they interact with their care partner and others), which in turn, can contribute to relationship strain and loneliness, and likely exacerbates care partner burden (Anderson et al., 2002; Ergh et al., 2003; Sander et al., 2012; Vangel et al., 2011).

Impairments with emotional self-awareness and empathy are also common TBI sequelae that impact socio-emotional functioning and therefore likely influence care partner burden (Fynn et al., 2021; Neumann et al., 2014; Neumann & Zupan, 2020; Williams & Wood, 2007, 2008, 2010). Emotional self-awareness pertains to an individual's ability to recognize their own emotional response and states, and is considered a pillar of emotion regulation (Gratz & Roemer, 2004). Poor emotional self-awareness, sometimes referred to as alexithymia (Bermond, 2000), has been associated with avoidance coping; anger, anxiety and depression; diminished empathy; low relationship quality (as perceived by the uninjured partner), and care partner burnout in the TBI population (Caplan et al., 2017; Katsifaraki & Wood, 2014; Williams et al., 2019; Williams & Wood, 2010, 2013; Wood et al., 2014; Wood & Doughty, 2013). Low empathy after TBI has been associated with poor social behaviors and outcomes (Milders, 2019). Empathic behaviors signal caring and interpersonal connectedness through attempts to understand the other person's situation and experience (perspective taking); demonstration of concern about a loved one's emotional state; or a mutual sharing in their emotional feelings. Empathy is important for providing loved ones with emotional support. Difficulty conveying empathy and understanding for other's feelings has clear implications for the social functioning of individuals with TBI and their primary care partners (Williams & Wood, 2010; Wood & Williams, 2008). Given the emotional distress often experienced by care partners of people with TBI, there is probably a strong need for empathy and emotional support, which if lacking, could exacerbate care partners' perceived burden. Despite the potential impact, no work has directly examined the impact of impaired emotional self-awareness or empathy on care partner burden.

Although some research to-date has begun to examine associations of post-TBI emotional and behavioral functioning with care partner burden, more advanced and comprehensive models of socio-emotional functioning are needed to better understand how these factors contribute to the burden of care partners for individuals with TBI. As such, the objective of this study is to examine the degree to which emotional awareness and other aspects of emotion regulation, emotional functioning, and empathy among people with TBI account for caregiving burden using a multiple regression framework. The findings from this study will contribute to the current knowledge of important care partner burden risk factors, and support development or refinement of interventions to address the emotional and behavioral functioning of people with TBI and the adjustment of their informal care partners.

2. Method

2.1. Study design and setting

The study is a secondary analysis of data collected during an observational, multi-site collaborative investigation of the incidence and correlates of alexithymia among people with a history of TBI. Data were collected at four TBI Model Systems (TBIMS) centers between January 2019 and June 2021.

2.2. Participants

Participants included people with a history of moderate-to-severe TBI who were enrolled in the longitudinal TBIMS national database and their care partners. To be eligible for inclusion in the TBIMS national database (NDB), participants must have a moderate-to-severe TBI as defined by: (a) posttraumatic amnesia > 24 hours, (b) loss of consciousness > 30 minutes, (c) an initial Glasgow Coma Scale score < 13, and/or (d) abnormal findings on neuroimaging consistent with a TBI. Participants must also be admitted to a TBIMS affiliated hospital within 72 hours of initial injury, complete acute and inpatient rehabilitation within a designated TBIMS center, and be 16 years or older at the time of injury. Participants provide informed consent or assent when consented by a legal authorized representative. To be eligible for the current study, participants were approximately 1-year post-injury (+/- 2 months), able to understand and communicate effectively to participate in data collection, and they had a self-identified care partner who was willing to participate. For this study, an informal care partner was defined as an intimate partner or family member who shares a residence with the person who has a TBI, irrespective of the objective level of supervision or functional assistance that person provides.

2.3. Ethical considerations

All study procedures were approved by the Institutional Review Boards at the local TBI Model System sites (protocol numbers: 1211010085, 1993H0142, H-42997, s13-00056). All participants (or their proxy) provided informed consent prior to any study procedures.

2.4. Procedures

Participants who were already consented into the TBIMD NDB were invited to take part in the current study at the time of their 1-year follow-up interview. Data were collected primarily through participant interviews conducted by telephone, with some data collected through a combination of mail, phone or in-person assessments. Data collected for the current study were added to the follow-up data collection that occurs through the TBIMS longitudinal study. All participants were compensated following assessment.

2.5. Measures

Participants with a history of TBI completed measures of emotional regulation, anger, empathy, and symptoms of emotional distress. Their care partners completed a measure of subjective care partner burden. Demographic and injury-related information were collected through combination of interviews, questionnaires, and chart reviews.

2.5.1. Difficulty with Emotional Regulation Scale (DERS)

The DERS (Gratz & Roemer, 2004) is a 36-item measure of emotional regulation that uses six subscales to assess the frequency with which respondents use specific self-regulation strategies in response to general emotional distress: (1) Lack of Emotional Awareness, (2) Lack of Emotional Clarity, (3) Difficulties Controlling Impulsive Behaviors When Distressed, (4) Difficulties Engaging in Goal-Directed Behavior When Distressed, (5) Non-acceptance of Negative Emotional Responses, and (6) Limited Access to Effective Emotion Regulation Strategies. Respondents are prompted to rate how frequently they engage in each regulation behavior on a scale of “1 – Almost Never” to “5 – Almost Always.” Responses to items within a subscale are summed to create subscale scores and total emotional dysregulation scores. The possible ranges for each subscale score vary—i.e., Awareness (6–30), Clarity (5–25), Impulse (6–30), Goals (5–25), Non-acceptance (6–30), and Strategies (8–40). Higher scores indicate higher levels of emotional dysregulation. As we are interested in understanding how different components of self-regulation are associated with care partner burden, especially emotional awareness, we use subscale scores in our models instead of total emotional dysregulation scores. The DERS has high internal consistency, test-retest reliability, and good construct validity (Gratz & Roemer, 2004).

2.5.2. NIH toolbox emotional battery – anger subdomain

The NIH Anger Scales (Pilkonis et al., 2013; Salsman et al., 2013) are comprised of three components: anger as an emotion (Anger-Affect), aggression as a behavior (Anger-Aggression), and hostility as a cynical or mistrustful attitude (Anger-Hostility). Each scale contains 5 items, and respondents are to rate each on a scale of “1 – Extremely Untrue of Me” to “7 – Extremely True of Me.” Raw subscale scores are converted to T-scores, with higher scores indicating higher levels of anger. These scales are part of the NIH TBI Common Data Elements and have strong psychometric properties (Pilkonis et al., 2013; Salsman et al., 2013).

2.5.3. PTSD Checklist Civilian (PCL-C)

The PCL-C (Blanchard et al., 1996; Weathers et al., 1993) is a 17-item self-report measure that assesses symptoms of posttraumatic stress based on DSM-IV symptom criteria. Respondents are asked to rate how much they have been bothered by each symptom over the past month as it relates to a stressful experience from the past on a scale of “1 – Not at All” to “5 – Extremely.” The PCL can be used algorithmically to indicate a probable diagnosis of PTSD; however, for the current study items were summed to create a total score. Psychometric testing of the PCL indicates it is a valid assessment of PTSD symptoms (Blevins et al., 2015).

2.5.4. Generalized Anxiety Disorder-7 (GAD-7)

The GAD-7 (Spitzer et al., 2006) is a 7-item self-report screening measure of anxiety based on DSM-IV criteria for GAD. Respondents rate how frequently they have experienced each symptom over the past two weeks on a scale of “0 – Not at All” to “3 – Nearly Every Day.” Items are summed to create a total score, with higher scores indicating more problematic levels of anxiety.

2.5.5. Patient Health Questionnaire-9 (PHQ-9)

The PHQ-9 (Kroenke et al., 2001) is a 9-item self-report screening measure of depression based on DSM-IV criteria for major depressive episode. Respondents rate how frequently they have experienced each symptom over the past two weeks on a scale of “0 – Not at All” to “3 – Nearly Every

Day." Items are summed to create a total score, with higher scores indicating more problematic levels of depression (range 0–27). This measure has sound psychometric properties and has been validated in the TBI population (Fann et al., 2005).

2.5.6. Interpersonal Reactivity Index (IRI)

The IRI (M. Davis, 1980; M. H. Davis, 1983) is a 28-item measure of empathy that assesses domains of (1) perspective-taking, (2) empathic concern, (3) fantasy, and (4) personal distress. Respondents are prompted to rate how representative each statement is of their experience on a scale of "0 – Does Not Describe Me Well" to "4 – Describes Me Very Well." Items are summed to create subscale scores, with higher scores indicating higher levels of empathic concern. For the current study, only the 14 items comprising the empathic concern and perspective-taking domains were administered (score range for each subscale: 0–28). The IRI has good test-retest and internal reliability (M. Davis, 1980; M. H. Davis, 1983).

2.5.7. Zarit Burden Inventory (ZBI)

The ZBI (Bédard et al., 2001; Higginson et al., 2010) is a 22-item, validated, self-report measure of subjective burden associated with caregiving. Respondents are asked to rate their perceptions of changes in their emotional functioning, physical health, and social participation as it relates to the experience of caregiving. Items are rated on a scale of "0 – Never" to "4 – Nearly Always." Items are summed to create a total score, with higher scores indicating higher levels of subjective burden. For the current study, respondents completed the 12-item version of the ZBI (score range: 0–48). The ZBI-12 has demonstrated good internal consistency and concurrent validity with measures of perceived stress (Bédard et al., 2001; Gratão et al., 2019). Previous investigation of the ZBI-12 have suggested a clinical cut-off score of 13 for screening problematic levels of burden (Gratão et al., 2019), with a score > 17 suggestive of severe/high burden (Bédard et al., 2001).

2.6. Data analysis

2.6.1. Regression

A multiple regression framework was used to examine the associations between care partner burden and emotional awareness and functioning among people with TBI. Listwise deletion was used to handle missing data. To avoid bias from multicollinearity within the regression model, we examined the variance inflation factors (VIF) and correlations among the independent variables. To identify problematic variables for removal from the unadjusted model, we used a VIF threshold >5 and a $r>0.7$. Based on an initial unadjusted model including all the dependent variables, the DERS-Strategies subscale was removed from subsequent analyses (VIV = 6.79). Likewise, both the PCL and GAD-7 were removed from subsequent analyses given their strong correlations with the PHQ-9 ($r=0.74$ and $r=0.81$, respectively).

2.6.2. Covariates

Care partner age, relationship to the person with TBI, and education level were used as covariates in an adjusted model, along with functional independence of the person with TBI at 1-year post-injury (FIM Total). The care partners' relationship to the person with TBI was aggregated into two categories: "Spouse or Partner" and "Other Family Member." Care partner level of education was aggregated into three categories: "High School Graduate," "Associates Degree or Some College," and "Bachelors Degree or Higher."

2.6.3. Statistical power

There were complete data for 90 dyads, using the care partner responses to the ZBI as the dependent variable in the multiple regression model, which provided adequate power to detect a large effect size ($f^2=0.35$).

3. Results

Care partners were predominately female (77%), and most were either a spouse/partner (55.2%) or parent (34.4%). On average, care partners were 53.8 years old (SD = 14.7), and the average amount of time they had known the person with TBI was 28.6 years (SD = 15.3). A summary of care partner and person with TBI characteristics is provided in Table 1.

A multiple regression model examined the association between measures of empathy, emotional awareness, and emotional functioning among participants with TBI (independent variables) and care partner burden (dependent variable). An initial, unadjusted model was significant ($F_{(11,81)}=2.007$, $p=0.038$), and the effects for the DERS – Awareness subscale and the NIH – Anger/Hostility subscale were significant. After adjusting for care partner characteristics and the functional independence of the

Table 1
Characteristics of study sample ($n = 96$)

Care partners	Mean (SD) or count (%)
Demographic variables	
Age (years)	53.8 (14.7)
Education level	
High school graduate	29 (30.2%)
Associate degree or some college	31 (32.3%)
Bachelor degree or higher	36 (37.5%)
Caregiving variables	
Years known person with TBI	28.6 (15.3)
Hours per day providing care	7.8 (7.8)
Days per week with person with TBI	6.9 (0.6)
Relationship to person with TBI	
Spouse or romantic partner	54 (55.2%)
Other family member	40 (41.7%)
Persons with TBI	
Demographic variables	
Age (years)	43.0 (19.9)
Sex	
Male	75 (18.1%)
Female	21 (21.9%)
Race	
Black	14 (14.6%)
Hispanic origin	13 (13.5%)
White	68 (70.8%)
Other	1 (1.0%)
Education	
Less than high school	21 (21.9%)
High school graduate	28 (29.2%)
Associates or some college	22 (22.9%)
Bachelors or higher	25 (26.0%)
Injury variables	
Mechanism of injury	
Motor vehicle collision	29 (30.2%)
Fall	32 (33.3%)
Motorcycle collision	11 (11.5%)
Other vehicle-related	8 (8.3%)
Gunshot wound	5 (5.2%)
Other violence-related	4 (4.1%)
Other	7 (7.2%)
Initial GCS total scores	
Mild (13-15)	25 (26.0%)
Moderate (9-12)	7 (7.3%)
Severe (3-8)	29 (30.2%)
Chemically sedated	33 (34.4%)
Intubated	1 (1.0%)
Missing or unknown	1 (1.0%)
Functional Independence Measure	
Admission to IRF	51.7 (22.8)
Discharge from IRF	91.2 (16.2)
One-year follow-up	116.1 (8.6)

GCS = Glasgow Coma Scale; IRF = Inpatient Rehabilitation Facility.

Table 2
Descriptive statistics of measures used in final model ($n = 90$)

Care partner measure (DV)	Mean	SD
Zarit Burden Inventory	9.3	8.6
Person with TBI measures (IV)		
DERS – Nonacceptance	13.1	5.8
DERS – Goals	12.6	5.2
DERS – Impulse	10.8	5.1
DERS – Awareness	14.0	4.9
DERS – Clarity	10.1	4.7
IRI – Perspective taking	18.8	5.6
IRI – Empathic concern	19.9	3.9
NIH – Anger/affect (T-score)	51.0	14.3
NIH – Anger/aggression (T-score)	52.5	10.5
NIH – Anger/hostility (T-score)	50.1	11.5
Patient Health Questionnaire – 9	5.4	6.1

Note. DERS = Difficult with Emotional Regulation Scale; IRI = Interpersonal Reactivity Index; NIH = National Institute of Health.

person with TBI at 1-year post-injury, the model remained significant ($F_{(15,89)} = 1.894$, $p = 0.038$) and accounted for approximately 28% of the variance in care partner burden ($R^2 = 0.277$). The emotional awareness of the person with TBI remained significantly associated with care partner burden ($\beta = 0.493$, SE = 0.218, $p = 0.027$), such that care partner burden increased with lower levels of emotional awareness. The NIH – Anger/Hostility also remained significant and had a positive association with care partner burden ($\beta = 0.328$, SE = 0.121, $p = 0.008$), with higher levels of hostility being associated with higher care partner burden. No other associations were found between predictors or covariates of interest (e.g., age, depression, other areas of emotional awareness/functioning) and care partner burden. A summary of the descriptive statistics for the scales/subscales and the results from the linear regression can be found in Tables 2 and 3, respectively.

4. Discussion

This study assessed the association between socio-emotional functioning in persons with TBI and subjective burden in intimate partners or family members living with individuals who were one-year post-TBI. Our model examined the contribution of emotional awareness along with other aspects of emotion regulation, affect, and empathy to perceived care partner burden. Together, these factors accounted for 28% of the burden reported by care partners. For both unadjusted and adjusted models, patient emotional self-awareness and anger-hostility were the two factors that significantly contributed to care partner burden. Lower emotional self-awareness and greater hostility in the individual with TBI were associated with higher care partner burden. Somewhat unexpectedly, other emotion regulation strategies

Table 3

Results from linear regression to predict subjective care partner burden at 1-year

	Unadjusted model		Adjusted model	
	Std. β	*p*	Std. β	*p*
Variables				
DERS – Nonacceptance	0.123	0.361	0.120	0.388
DERS – Goals	–0.073	0.659	–0.114	0.495
DERS – Impulse	–0.059	0.710	–0.111	0.491
DERS – Awareness	**0.267**	**0.036**	**0.278**	**0.027**
DERS – Clarity	–0.094	0.609	–0.087	0.644
IRI – Perspective taking	0.187	0.149	0.153	0.270
IRI – Empathic concern	0.072	0.568	0.082	0.524
NIH – Anger/affect (T-score)	0.058	0.668	0.022	0.877
NIH – Anger/aggression (T-score)	–0.041	0.742	–0.020	0.886
NIH – Anger/hostility (T-score)	**0.381**	**0.015**	**0.439**	**0.008**
Patient Health Questionnaire – 9	–0.002	0.988	–0.071	0.658
Covariates				
Care partner Age			0.012	0.909
Care partner Relationship			0.078	0.542
Care partner Education			–0.028	0.812
FIM total score			**–0.239**	**0.039**

Note. DERS = Difficult with Emotional Regulation Scale; IRI = Interpersonal Reactivity Index; NIH = National Institute of Health; FIM = Functional Independence Measure; Bolded values indicate significance < 0.05.

(nonacceptance, clarity, goals, and impulse), depression, anger-affect, anger-aggression, and empathic concern and perspective-taking did not significantly contribute to care partner burden.

Individuals who lack insight into their emotions have trouble processing and sharing emotional experiences (Caplan et al., 2017; Williams et al., 2019), as well as have difficulty controlling their emotions (especially anger), but can also be emotionally blunted (Hesse & Floyd, 2008), particularly with expression of positive emotions (e.g., happiness, affection, gratitude). These factors can negatively impact social behaviors and interpersonal interactions, which may be particularly daunting for a care partner who is unlikely to feel appreciated by the person they are caring for who has these traits and/or feel emotionally disconnected from the person. Consistent with our findings, a prior study in TBI found that alexithymia was associated with lower partner-rated relationship quality (Williams & Wood, 2013). Also, prior research by Katsifaraki and Wood found that components of care partner burnout (emotional exhaustion and reduced personal accomplishment) and depression were significantly higher in care partners of participants with TBI who were classified as alexithymic (Katsifaraki & Wood, 2014). On a positive note, there is some preliminary evidence to suggest that emotional self-awareness can be improved with treatment in individuals with TBI (Neumann et al., 2017a). It is unclear at this time why other emotion regulation strategies were not related to care partner burden. It is possible that the consequences of these other forms of emotion dysregulation just have less of an effect on others. However, there is likely overlap between these various aspects of emotion regulation, and our results suggest that emotional awareness accounts for the most variance in care partner burden relative to other aspects of emotional regulation.

Patient hostility, which was the other variable significantly associated with care partner burden, was an anticipated finding. It is logical that caring for a hostile individual would contribute to perceived burden. However, the fact that our other affect variables (anger, aggression, and depression) did not show significant relationships with care partner burden was unexpected, especially since prior research found care partner distress was associated with emotional functioning of care-recipients with TBI, including anger and depression (Marsh et al., 1998b, 2002). Anger and aggression may differ from hostility in important ways when it comes to perceived burden of a care partner. Anger is a personal emotional experience, which may or may not be expressed through behaviors, and therefore might not always impact the care partner. Physical aggression is a behavioral expression of anger aimed to hurt or harm others (instrumental/motor component). While this might be distressing to a care partner in the moment, acts of physical aggression are likely to be transient and reactionary to isolated events, and thus not contribute to overall "burden." In contrast, hostility, which is considered the cognitive component of behavior (Buss & Perry, 1992), may be a persistent attitude consisting of lingering feelings of ill will, resentment, suspicion, and injustice that leads to ongoing hostile behaviors. The distinction between hostility, anger, and aggression is an important one in terms of their contribution to care partner burden and helping to identify potentially modifiable treatment targets. Notably, some research has found that individuals with TBI are prone to hostility bias (Neumann et al., 2017b, 2021), and a preliminary study suggests hostile thinking can be reduced with an intervention that trains perspective-taking skills (Neumann et al., in press).

Another surprising finding of this study is that empathy was not associated with care partner burden. Our participants' self-ratings of their own empathy suggested they did not have empathy deficits. On average, self-ratings from our sample fell within normal range of standard scores for empathic concern and perspective taking (M. Davis, 1980; M. H. Davis, 1983). Because these were self-ratings and not ratings by the care partner, it is unclear how empathic the care partner perceived the person with TBI to be. Care partner ratings may have yielded a different result, as overall impaired awareness of emotional functioning is likely to impact self-ratings of empathy.

4.1. Clinical implications

Assessment of emotional awareness and hostility following TBI can help to identify individuals who might benefit for treatment. Effective interventions could reduce burden on family care partners and possibly improve broader social relationships and integration for the person with injury and their care partners. As noted earlier in this discussion, treatments targeting socio-emotional functioning, such as training in emotional awareness and in perspective taking, have shown promise in research studies. Unfortunately, these treatments are not commonly carried out in clinical settings. Training of rehabilitation clinicians in these interventions, and in identification of individuals with TBI who could benefit from the interventions, may help to reduce care partner burden and improve social integration. Care partners themselves may benefit from training in how to interact with their loved ones with TBI in ways that may facilitate emotional awareness, such as providing verbal feedback on how they perceive emotional expressions and expressions of hostility. Such training may help care partners feel more empowered to cope with socio-emotional changes in the person for whom they provide care.

4.2. Limitations

This study has some limitations to consider. The study examined adults with moderate-to-severe TBI admitted to the hospital followed by acute inpatient rehabilitation for TBI. As such, the findings may not represent those who do not receive acute inpatient rehabilitation or who are not hospitalized for TBI. Although the participant with the TBI identified the person as a care partner, this role or label of care partner was applied irrespective of the objective level of supervision or functional assistance that person provides. As is the case in most studies of emotional awareness and care partner burden, the study required the use of self-report, raising the possibility of bias. Some variables that may contribute to care partner burden were not collected and were unavailable to be studied (e.g., family functioning, family support, religion, finances, care partner emotional function).

5. Conclusion

In conclusion, at one-year post-TBI, low emotional self-awareness and hostility in people with TBI appear to be important socio-emotional factors that contribute to the perceived burden of their care partners (i.e., intimate partners and/or family members). Increased screening and treatment for these problems along with patient and family education may help to minimize the negative impact of these factors on individuals with TBI and their care partners.

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Conflict of interest

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