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Impact of TBI on caregivers of veterans with TBI: Burden and interventions

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ABSTRACT

Objectives: Describe State-of-the-Art in practice and research in caregiving with individuals, specifically, Veterans with traumatic brain injury (TBI) and the implications for current practice and future research. **Sources:** Professional literature and personal experience of review panel.

Main Outcomes: Unpaid caregiving for individuals with TBI is most often provided by a spouse, parent or other blood relative; the majority of caregivers are women. Although caregiving can be rewarding, it also may create financial burden and psychological stress. Depression among family caregivers occurs four times more frequently than in the general population. Positive coping can help reduce the impact of stress, and Department of Veterans Affairs (VA) programmes are available to ease financial burden. Group interventions show promise in reinforcing and improving positive coping for both family caregivers and Veterans with TBI.

Conclusions: Identifying the specific needs of caregivers and families of Veterans with TBI and other traumatic injuries, including post-traumatic stress syndrome (PTSD), will require further longitudinal research. Currently available group interventions and programmes appear to benefit injured Veterans and their family caregivers financially and psychologically. Increased understanding of characteristics of quality family caregiving and its long term costs and benefits is likely to lead to additional improvements in these interventions and programmes.

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Introduction

Many individuals with a history of traumatic brain injury (TBI) experience significant problems in resuming full participation in family and community life. Obstacles to community re-integration typically include impaired cognition, physical impairments and pain, impaired emotional and behavioural self-regulation and may accompany TBI at all levels of severity, i.e. mild to severe. The adjustment issues and barriers to community re-integration experienced by individuals with TBI also translate into stressors for their close others. The impact on close others and family caregivers will vary with the severity and extent of challenges experienced by the person with TBI and may range from physical strain and emotional stress of living with a person whose abilities, personality and behaviour have been altered by the TBI to additional demands on the caregiver for on-going monitoring and supervision, physical assistance and assistance in accomplishing both basic (ADL) and instrumental activities of daily living (IADL). A *family caregiver*, sometimes called an *informal caregiver*, is commonly defined as an untrained individual who provides unpaid care and assistance to a relative or friend who is 18 years or older to help them take care of themselves. Seventy-eight per cent of all Americans with disabilities who need long term care in the home only receive assistance from a family member or friend [1]. Since most caregivers of individuals with TBI are family, research on family functioning after TBI is also relevant.

The burden, associated distress and needs of families with TBI has been well-established in previous reviews [2,3]. In this article, we selectively report on studies in areas that have not been a focus of prior reviews (i.e. economic impact and studies specific to military/Veteran caregivers) and more recent family intervention studies selected for scientific rigour and innovation. We consider both traditional families consisting of blood relatives and close others who provide caregiving for the person with TBI as *family*. The overarching goal of this project was to make recommendations for optimal current care and future research of family caregivers of military and Veterans with TBI. Our focus was on family caregivers living with TBI, although we recognize that in a military/Veteran population TBI is not infrequently complicated by post-traumatic stress disorder (PTSD) or other disabling comorbidities. We accessed not only the clinical and scientific literature but also the input of individuals and organizations representing military and Veteran family caregivers in developing this report and recommendations.

Economic impacts

Formal long term care is primarily funded by government programmes and accounts for 1.5% of the Gross Domestic Product (GDP), approximately \$230 billion, annually. The cost of family caregiving can be estimated using a replacement wage approach which assumes 20 hours of caregiving per

week at an hourly wage of \$11. Using this approach, the cost of family caregiving is estimated to cost \$450 billion per year—nearly double that of formal care [4]. Other estimates of the economic costs of family caregiving on the caregiver have mainly considered work impacts. The most comprehensive and rigorous study of caregiving in a traditional elderly population shows that caring for their mothers affects current and future labour market outcomes for daughters age 55–64 through several channels [5]. Specifically, women who become caregivers are less likely to be working; women who leave work have a low probability of returning to work (less than 14%); and those who return to work return to a 13% lower wage. Over an adult daughter's lifetime, importantly, the welfare costs of caregiving were \$164,726. This dwarfs estimates from others that show a snapshot of one year's foregone wages being around \$20K [6,7]. The economic impacts are of course not limited to labour force impacts but can include direct costs of caregiving (e.g. travel to appointments and out of pocket costs) and indirect costs (e.g. work, day-care costs, cost of a caregivers own health care if injured or ill due to caregiving). Considering both short term and long term economic impacts on caregivers is therefore critical to understand the full financial penalty, especially for caregiving in TBI which has a long expected duration.

There has only been one study of the economic impacts of caregivers of Veterans with TBI to our knowledge. Focusing on caregiving of service members who had polytrauma including TBI, this study showed that 62.3% of the caregivers depleted assets and/or accumulated debt and that 41% of the working caregivers left the labour force [8]. If a Veteran needed intensive help, the primary caregiver faced 4.6 higher odds of leaving the labour force, and used \$27,576 more assets and/or debt compared to caregivers of Veterans needing little or no assistance. Beyond this evidence, we have very little empirical information about the economic strain experienced by caregivers of Veterans with TBI but it is likely to be substantial given that Veterans are young when injured and therefore the injury interrupts the economic pathways for security such as schooling, full-time work and other investments in the development of human capital. As mentioned previously, caregivers may also experience these economic interruptions, often reducing work or exiting the labour force. Additionally, the direct costs of care of the Veteran, even though covered well by Department of Veterans Affairs (VA) services, may introduce economic strain. Travel costs to appointments, hiring day care to watch young children due to the injury or due to accompanying the Veteran to appointments are examples of additional out-of-pocket expenses often required in caring for the Veteran with TBI.

There is also qualitative evidence that costs of caregiving in TBI are high, even with substantial support from VA. Van Houtven and colleagues [9] conducted interviews with 50 caregivers in the VA CARES Evaluation study of the Program of Comprehensive Assistance for Family Caregivers. Their as yet unpublished findings revealed high costs for some family caregivers from reduced caregiver employment, direct care costs and depletion of assets. Unique to TBI, caregivers also detailed costs of caregiving

that have not been commonly considered. These relate to impulsive spending by the Veteran as a result of injury that negatively impacts the family budget. One wife said 'He wanted to buy everything. He didn't understand the concept of money and that we had to pay bills first.' Strategies to handle this included, first, being aware that it could happen given the unique impacts of the injury, and forming separate accounts to protect the family's money.

Although the costs of family caregiving often severely impact individual family budgets, family caregiving may result in cost savings to public funds. One study in a national sample of elderly shows that informal caregiving reduces home health care use and delays nursing home entry [10]. That means that in a Medicare population, informal care can lead to cost savings to the public purse by replacing covered formal care services. No studies have quantified how caregiving of severely injured Veterans replaces or supplements Veterans Health Administration (VHA) paid care. However, caregiving could also lead to higher VHA health care costs if caregivers identify problems that require formal care or medical treatment or if the strain from caregiving leads to seeking more health care and support from VHA, such as, through adult day health care or through acute care (e.g. potentially avoidable trips to an emergency department if the caregiver cannot cope). Thus, it is not clear that the economic costs to caregivers (e.g. leaving work or incurring debt) are accompanied by cost savings to the health care system by reducing Veteran health care use. It is unknown how direct economic hardships on Veterans and family caregivers due to TBI translate to cost implications for the VHA health care system in the care provided. For example, if high financial strain on caregivers leads to lower quality care being provided to Veterans with TBI, there are likely to be negative impacts on Veteran health and the VA health care system in the long term with consequent increased costs.

Emotional impact

In addition to the economic burden of caregiving, there is consistent evidence that providing informal caregiving can cause adverse emotional and physical health effects [11–13]. These adverse emotional and physical effects come with additional burden both to family finances and quality of life. Furthermore, prior reviews consistently conclude that a significant proportion of caregivers of individuals with TBI experience psychological distress as well as family disruption with a substantial majority of caregivers reporting some degree of burden and experiencing a degree of disruption in family functioning [2–3]. Little is known specifically about the health effects of caregiving for Veterans with TBI or other disabling conditions, such as, PTSD. We know from Van Houtven and colleagues recent work [9] that caregivers of Veterans with polytrauma provide intensive and varied care, and that many experience financial strain, especially intensive caregivers. Caregivers provide care not only in activities of daily living, but also in emotion management and navigation of the healthcare, legal and military benefits systems [14]. Additional evidence is emerging. An exploratory analysis provides evidence that caregivers of Veterans with polytrauma,

including TBI, who have not received training endorsed higher anxiety, depression, burden and lower self-esteem than those who received training [15]. In this same sample, investigators found that care recipients' neurobehavioral functioning affected caregiver mental health. Care intensity affected caregiver burden and caregiver burden also affected caregiver mental health. Resources mediated the relationship between neurobehavioral functioning and mental health, and social resources moderated the relationship between intensity of care and burden [16]. Results of these recent studies suggest that caregivers of Veterans with TBI/polytrauma are at risk for burden and poor mental health and that bolstering resources, especially social resources, may reduce these risks. In recent years, there has been an increased emphasis on and interest in caregivers of military veterans with the passage of the 2010 Caregivers and Veterans Omnibus Act. A specific focus on caregivers to Veterans with TBI was also encouraged by the move of the Defense and Veterans Brain Injury Center (DVBIC) to the Defense Center of Excellence (DCoE) for Psychological Health and Traumatic Brain Injury (established in 2007 in response to rising concerns about the rates of PTSD and TBI among returning service members) as well as by research mandated by the National Defense Authorization Act (NDAA). Although the NDAA mandated study is a longitudinal study of caregivers to those individuals within a military related TBI, it only received Institutional Review Board (IRB) approval in 2012 and is still underway. This study promises to offer important new information about the effect of caregiving for military and Veteran survivors of TBI on the overall health and well-being of caregivers and children in families of caregivers as well as the types of health care and social services needed to foster health among caregivers. This new emphasis, coupled with growing interest from the private sector to support returning warriors and their caregivers, has also led to additional epidemiologic studies of the Veteran and military caregiver population that employ large, nationally representative samples.

The RAND 'Hidden Heroes' Study

One of the largest, most recent and most representative studies of caregivers is the RAND Study of Military Caregivers completed in 2014 [17]. This study implemented a national

survey of caregivers that entailed screening a representative sample of US households. Nearly 3,000 caregivers to adults in the US participated in this survey, including over 1,129 military caregivers, nearly 1,828 civilian caregivers and, for comparison purposes, 1,163 non-caregivers. Based on this survey, RAND estimated that 9% of the US population, or 22 million individuals, were caregivers to another adult with a disabling condition or illness. Among all US caregivers, 5.5 million caregivers were providing care and support to a current or former member of the military, 1.1 million of these were supporting post-9/11 veterans. This more recent cohort of military and Veteran caregivers are younger than most other caregivers. Additionally they are more likely to be spouses caring for a partner or parents caring for an adult child rather than adult children caring for an ageing parent. The study also found that 2.5 million military and civilian caregivers are supporting a person with a TBI.

The RAND survey revealed other characteristics of the current military/Veteran TBI caregiver community in the US. In a large majority of cases, caregivers are blood relatives of the care recipient: 29% are spouses; 24%, parents and 24%, other family. They are mostly female (60%) and live with the care recipient (55%). Two-thirds reported that they had additional support for caregiving and rely on a caregiving network. Most (63%) have served in caregiving role for more than 3 years. Among those who provide caregiving to a military Veteran with TBI, one-third to one-half assist in basic ADLs and approximately 80% assist in IADLs (see Figures 1 and 2). In addition, 79.3% report assisting the individual with TBI in remembering things; 87.4% help in filling out paperwork; and 75.1% help with coping with stress.

As in prior studies, the 2014 RAND survey also documented the burden of caregiving, particularly for the caregivers of military or Veterans with TBI. The prevalence of probable depression (39%) among caregivers of military or Veterans with TBI was nearly double that of civilian caregivers (20%) and four times greater than that among non-caregivers (10%) which is similar to estimates of the prevalence of depression in the general population. Caregivers of military/Veterans with TBI also reported a number of other adverse effects and difficulties described in Figure 3. The RAND study differed from prior studies in how it identified caregivers,

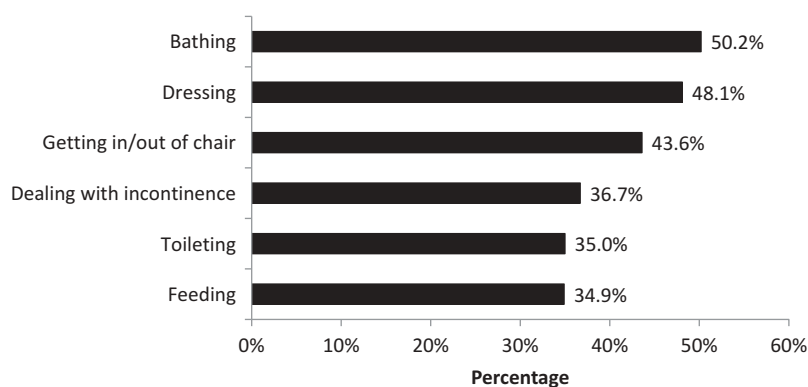


Figure 1. Activities of daily living performed by caregivers of persons with TBI.

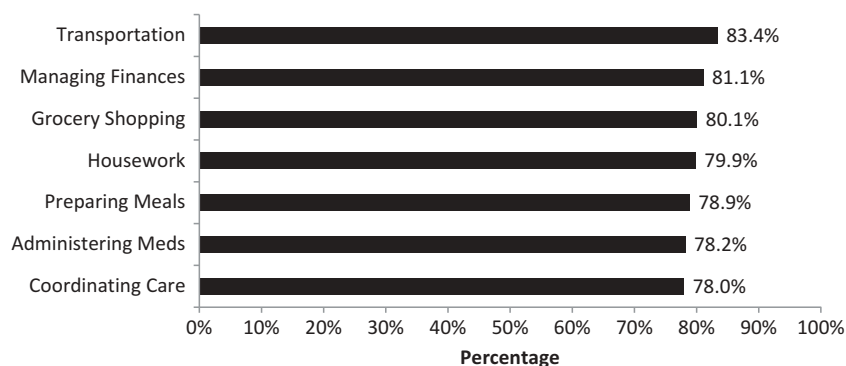


Figure 2. Instrumental activities of daily living performed by caregivers of persons with TBI.

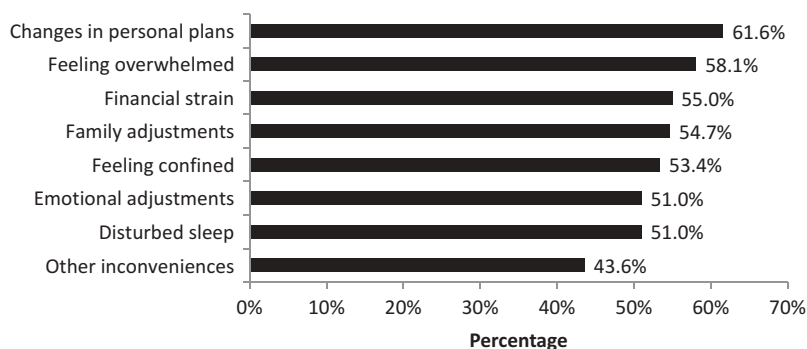


Figure 3. Adverse effects reported by caregivers of persons with TBI.

relying upon a series of screening questions to determine whether or not someone met criteria as a caregiver, as opposed to asking someone to self-identify. The RAND study used cross-sectional methods and also incorporated items used to measure burden at the specific point in time that the survey was completed. These distinctions make it difficult to draw specific comparisons with other studies. However, the general findings are consistent with previous research in indicating increased risk for emotional, relational and financial consequences.

The Department of Veterans Affairs Program of Comprehensive Assistance for Family Caregivers (PFAFC)

In response to the needs of disabled Veterans and their caregivers, support for caregivers has evolved in the VA system. Recent milestones in the development of support for caregivers within the VA are outlined in Table 1. Of critical importance is Public Law 111-163, the Caregivers and Veterans Omnibus Health Services Act, signed by President Obama on 5 May 2010, in an effort to aid family caregivers of eligible post-9/11 Veterans by requiring VA to establish a comprehensive assistance programme and general support services for caregivers. A Veteran is eligible for comprehensive caregiving support through the VA if they are enrolled in the VA health care system and have a severe injury, including both TBI and PTSD, incurred or aggravated during military service on or after 11 September 2001. The injury must render them unable to perform

one or more activities of daily living and/or need supervision or protection based on symptoms or residuals of neurological impairment or injury leaving them in need of personal care services. The VA has been administering medical, travel, training and a monthly stipend under this law since 5 May 2011. The support services offered include a toll-free caregiver support line, expanded education and training on caring for Veterans at home, counselling and support groups.

For benefits purposes, the VA distinguishes between three types of caregivers:

- *General family caregiver*: Caregivers of Veterans under the programme who provide personal care services, but do not meet the criteria for a Primary or Secondary Family Caregiver. They have access to online and in-person caregiver education and training, VA's Caregiver Support line (1-855-260-3274), telehealth, counselling and respite care. In addition to this programme being available to post-9/11 caregivers, it is available to caregivers of Veterans from any era of service.
- *Secondary family caregiver*: An individual who provides personal care services for the Veteran who is generally a back-up to the Primary Family Caregiver. They have access to all benefits and services available to General Caregivers plus monitoring, Veteran-specific instruction and training, beneficiary travel and on-going technical support.
- *Primary family caregiver*: An individual who the Veteran specifies on the joint application and is approved by VA as a primary provider of personal care services. They

Table 1. Recent milestones in VA caregiver support.

2007: VA Advisory Committee on Operation Iraqi Freedom/Operation Enduring Freedom Veterans and Families established.	<ul style="list-style-type: none"> Responsible for reviewing VA services and benefits; providing advice to the Secretary on health care, benefits and family support issues; and making recommendations for tailoring VA services and benefits to meet the needs of OEF/OIF veterans and their families.
2007: Resources for Enhancing Alzheimer's Caregiver Health (REACH-VA) program introduced [40].	<ul style="list-style-type: none"> The first national clinical translation of a proven dementia behavioural intervention covering multiple states and facilities.
2007: Eight caregiver assistance pilot programs at selected VA medical centres nationwide, to examine ways to improve education and provide training and resources for caregivers assisting veterans. One of these eight pilot programs focuses on providing education, skills training and resources to caregivers of veterans with TBI, including both OEF/OIF and non-OEF/OIF veterans.	
2008: Caregiver Advisory Board established.	<ul style="list-style-type: none"> Charged with developing a caregiver assistance program that addresses caregiver issues across VA's health care disciplines and programs. The board is to identify core caregiver needs system-wide, the development of initial recommendations for VA caregiver support services, and the oversight of eight caregiver assistance pilot programs to assess the feasibility and advisability of various mechanisms to expand and improve VA caregiver assistance services.
2009: VA FACES study began, to help researchers understand more about the needs of caregivers for Veterans with TBI and polytrauma.	<ul style="list-style-type: none"> 79 per cent of those who provide care to polytrauma patients are women; 62 per cent of those women are parents and 32 per cent are spouses. Nearly 25 per cent of all caregivers reported that they provide more than 40 hours per week of care [14].
2009: VA Family Care Map piloted at VA's four Polytrauma Rehabilitation Centers (PRC) to ensure family members are fully involved in the care of veterans with polytrauma.	<ul style="list-style-type: none"> A uniform approach to involve and integrate the family, through education and collaboration, into the centre of the Veterans care for polytraumatic injuries [41].
2010: Caregivers and Veterans Omnibus Health Services Act becomes law	<ul style="list-style-type: none"> On 5 May 2010, President Obama signed Public Law 111-163, in an effort to aid family caregivers of eligible post-9/11 veterans by requiring VA to establish a comprehensive assistance program and general support services for caregivers.
2011: VA's National Caregiver Support Line established	<ul style="list-style-type: none"> Caregivers for Veterans can access a toll-free caregiver support line (1-855-260-3274), expanded education and training on caring for Veterans at home, and other support services such as counselling and support groups.
2014: Research in caregiving advances [42]	<ul style="list-style-type: none"> Shows caregivers continue to provide care and support even after their loved ones have been placed in long-term care facilities, and this experience also takes a toll on family members involved in this process.

have access to comprehensive services and supports with all benefits and services available to General and Secondary Family Caregivers plus a monthly stipend, respite care for at least 30 days per year which can increase if clinically appropriate, and health care coverage if eligible.

The monthly stipend provided only to Primary Family Caregivers is an acknowledgment of their sacrifices in caring for a seriously injured Veteran. It is not intended to replace career earnings or create an employment relationship. Caregivers report that the stipend is an important component of VA's Family Caregiver Program and helps alleviate financial distress [18]. The benefits offered through VA's Program of Comprehensive Assistance for Family Caregivers are significantly different from nearly all other VA benefits programmes since they are delivered to the caregiver directly. Moreover, this integrated approach to health and support services is fundamentally different from the supports for caregivers available elsewhere. If properly managed, this approach could deliver substantial health benefits for Veterans and their caregivers in terms of better care access, continuity, coordination, effectiveness, safety and satisfaction.

Interventions to assist families and caregivers

As documented in early studies and the more recent RAND study, a substantial proportion of caregivers will experience distress, depression or family disruption in reaction to the stress associated with living with a person with TBI. Underscoring the complexity of family assessment, Sander and colleagues [19], in a multi-site study that included a sample representing a relatively broad range of socio-economic and ethnic groups, discovered that 25–33% of families are already in significant distress when a family member sustains a TBI. The Sander study used the General Functioning Index (GFI) of the Family Assessment Device (FAD) as a primary measure. The FAD [20] is a 60-item inventory that comprehensively assesses family functioning through self-report of one or more family members. The 12-item GFI of the FAD provides a shorter measure that may be more practical for screening purposes. While the RAND study did not employ the FAD, there was an indication of lower relationship quality among military and Veteran caregivers when compared to other caregiver groups. Future studies of this population should consider using this measure which has been used in a number of other studies of families with TBI to screen family caregivers.

Screening with the FAD is based on the assumption that more severe family turmoil recorded on screening is likely to require more intensive intervention. However, a thorough assessment of family functioning for those families that indicate significant distress on the FAD will require further evaluation in order to determine the appropriate level of family intervention. Godwin, Schaaf and Kreutzer's excellent review [3] provides a number of measures in addition to the FAD that may be useful in conducting more in-depth family assessments following initial screening. A thorough evaluation of families suspected of severe pathology may also require consultation with a family mental health specialist.

Virtually all families will be in some degree of distress initially after one of their members sustains a TBI. The critical question for the screening clinician is whether (1) the distress represents a normal reaction in a family that was functioning well before the injury, (2) is complicated by pre-existing mild

disturbance in family dynamics or (3) is associated with more longstanding and pathological family dysfunction. Families in the first category will benefit from education about TBI, assistance in beginning to consider the longer term consequences, and reinforcement of their existing coping strategies. In our experience, a significant trauma like a TBI typically pulls a well-functioning family closer together and the most effective intervention is to support their characteristic ways of coping and supporting each other. Families in the second category often need more intensive counselling and assistance in developing mutually supportive coping skills in addition to education about TBI and assistance in developing longer term contingency plans. Families in the third group will likely require very intensive family therapy (that was most likely needed prior to the injury) in addition to standard TBI education, support and long term planning. In some families in which the dynamics were abusive or destructive, the person with TBI may need protection from family members and assistance, including legal assistance, in removing him/herself from the pathological family structure. Examples of cases in this latter category include child or spousal abuse, family-wide substance abuse and co-dependency and chaotic or pathologically enmeshed families. Conversely, in some cases, the family may need to take steps to protect themselves from harm due to the person with TBI's severe behavioural disturbance. Fortunately cases in which there is significant risk of harm to the person with TBI or family are rare.

Initial research in family functioning after TBI demonstrated that active coping strategies and perceived social support were associated with better caregiver adjustment than avoidant coping strategies [21,22]. Examples of active coping strategies include problem-solving, optimism and working toward positive outcomes. Maladaptive coping strategies include denial and minimization, substance use, wishful thinking, self-blame and unconstructive worry. Early uncontrolled studies demonstrated that most families (i.e. those in categories 1 and 2 above) benefit from interventions that combine TBI and community resource education with cognitive-behavioural therapy (CBT) including stress management and goal management training [3,23]. In these studies, interventions were typically provided in groups that included only family members and not the person with TBI. These studies also raised the possibility that early intervention may prevent or reduce the longer term impact of the TBI on caregivers. Such findings are consistent with clinical experience and support the potentially cost-effective use of group interventions to address caregiver and family issues early after TBI.

More recently, Backhaus and colleagues have further developed and tested a group programme, the Brain Injury Coping Skills group (BICS), to assist families in coping with TBI. BICS includes both identified individuals with TBI and their close others in 16 two-hour group sessions. Reflecting recommendations from earlier studies, BICS combines TBI education, CBT coping skills training and support. A detailed treatment manual is available [24]. An initial randomized controlled trial (RCT) showed improvement in coping skills and self-efficacy for BICS participants compared to a no treatment control group [25], and a subsequent comparative effectiveness trial showed benefit for both professionally-

directed and peer-directed BICS groups [26]. The latter trial randomized 11 participants to the BICS condition and 11 to a peer-directed support group. Possible key ingredients included in both groups were: (1) a supportive environment promoting high levels of engagement and low conflict between group participants, (2) opportunities to frequently meet with the same individuals and (3) an organized structure supported by a facilitator. In both studies, participants were generally not in a pathological level of psychological distress.

Kreutzer and colleagues [27] tested their Brain Injury Family Intervention (BIFI) programme in a RCT. BIFI has similar components to BICS and was delivered in groups that included both individuals with TBI and their family members in 5 two-hour sessions. The RCT was conducted over a period of 10 years and included 108 participants in the active treatment group and 46 in a wait-list control group. The primary dependent measure was the Family Needs Questionnaire (FNQ). From pre- to post-treatment, the BIFI group showed significant improvement on 4 of the 6 subscales of the FNQ; whereas, the control group showed no significant change on any FNQ subscale. However, there was a significant difference between control and treatment group only on the Professional Support subscale. The investigators felt that, despite the relatively large number of participants, their study may have been underpowered. Compared to the BICS study, the BIFI study included fewer sessions (5 compared to 16 in BICS) and the dependent measure possibly represented a more distal, indirect and complex impact of the intervention (i.e. reduction in perceived family needs compared to improvement in self-efficacy for BICS).

Backhaus and associates further developed their BICS group process to more specifically address the needs of couples in which one member had a TBI. Their Couples CARE (Caring and Relating) group [28] includes CBT interventions as well as elements of Dialectical Behavior Therapy (DBT) methods to address severe behaviour problems subsequent to TBI and Gottman-style relationship counselling. Initial evaluation of the group indicated improved satisfaction and quality of relationship. Winter, Moriarty and others [29,30] at the Veterans Affairs Medical Center in Philadelphia developed the Veterans' In-home Program (VIP) and evaluated its impact on 81 dyads consisting of a Veteran with TBI and a family member compared to standard care in a RCT. VIP involved 6 in-home visits by an occupational therapist and 2 telephone contacts over a 3–4 month period. In-home visits aimed to help the Veteran develop cognitive compensation and emotional regulation strategies and to recommend environmental modifications. Family members received education and support and were actively involved in the intervention. After programme completion, VIP family members reported less depression and lower perceived burden [29], and Veterans had better community re-integration and less difficulty managing everyday problems related to TBI [30] compared to the standard of care controls. Perlick and colleagues [31] developed a Veterans Multi-Family Group offered in three phases: (1) *joining* in which clinicians met with individual families for two or three sessions to evaluate on-going problems and define treatment goals, (2) two three-hour *educational workshops* about TBI for Veterans with TBI and

their caregivers and (3) *bimonthly problem-solving multifamily group meetings* attended by Veterans and their families for 6 months. Their initial uncontrolled evaluation of this programme documented decreased anger expression as well as increased perceived social support and occupational activity on the part of the Veteran with TBI. Caregivers reported decreased burden and increased empowerment. In a qualitative analysis of participant impressions of the group, Straits-Troster and associates [32] found themes suggesting that the most helpful components included opportunities: (1) to explore common struggles and reduce isolation, (2) to build skills to cope with TBI and related problems, (3) to restore relationships through communication and understanding and (4) to increase understanding of the interconnection between TBI and PTSD. In a systematic review, Rietdijk and colleagues [33] reported generally positive outcomes and long term benefits for a variety of telehealth and web-based interventions that provided training and support to caregivers of individuals with TBI. Seven RCTs, 4 non-RCTs and 5 case series were reviewed. Various studies included either adults or children with TBI and targeted education and support, improved functioning of the person with TBI and improved family problem-solving and psychological well-being. In a RCT including 201 participants, McLaughlin and colleagues [34] reported the efficacy of a web-based intervention to help families with TBI develop advocacy skills.

Filling the gaps in understanding caregiver costs, burden and interventions

Available research documents the significant emotional, physical and financial impact of disabling illness and injury on caregivers and families. However, more detailed and specific examination of the structure and special needs of Veteran families with TBI will be required in order to more effectively address their needs. Longitudinal studies are needed to determine the impacts of caregiving over time and whether these impacts are episodic or chronic and cumulative. The impact on children of providing care or being part of a family that provides care for a Veteran with TBI merits specific examination. Objective or well-validated self-report measures of caregiver health, well-being and productivity as well as that of the Veteran will increase the precision of such research and long term forecasting. Ultimately the characteristics of high quality family caregiving need to be clearly identified and the effects of high quality caregiving on the long term outcome for the Veteran with TBI need to be evaluated.

In order to fill the evidence gap on impacts of TBI caregiving, several domains will be important to consider. The first step is to get a very basic understanding of prevalence of caregivers of Veterans with TBI. Anecdotally we know that younger caregivers as well as male caregivers do not think of themselves as 'caregivers,' so even terminology is a challenge to determine prevalence. Next, we need to better understand how to capture data on tasks provided for TBI veterans by caregivers. This will require a shift from a focus on ADLs to IADLs and emotional support, and a focus on measuring hours of active caregiving or quantity. In estimating the financial impact, prevalence and quantity are necessary,

along with wage, to calculate the *replacement value* of TBI caregiving, which is a common way to measure its value. Finally, the time horizon in caregiving should be carefully considered. Most studies to-date have taken a short-term view, given that the average caregiving episode for elderly parents is 3–5 years. For TBI, caregiving may be a 40–70 year endeavour.

Relatedly, the long time horizon and age at injury of the Veteran means that caregivers face differential challenges that also affect their economic well-being over time. These are sometimes called *spillover costs to family*. The majority of caregivers are parents or spouses. However, each will face different challenges. Spousal caregivers are likely to be new to parenthood, early in their own careers or pursuing education. Thus, any work interruptions will impact retirement savings and economic security in old age. Parent caregivers may be at peak earnings potential at the time caregiving occurs, and consequently early retirement will also reduce their Social Security earnings in old age. There may be economic spillovers to children of spousal caregivers that should be considered. If caregivers cannot afford day care there may be missed early childhood education that will reduce human capital accumulation over the long term, for example, if it leads to lower educational attainment of these children. Other impacts on children could include housing instability, family fracture and stress impacts that are likely associated with poor economic and health outcomes of the younger generation.

Considering the economic impacts on caregivers of TBI Veterans overall requires an expanded view. One needs to consider direct and indirect economic impacts and spillovers to other family members. In addition, whereas the economic research in caregiving has focused on leaving the labour force, for TBI caregiving in particular, it is critical to quantify other economic losses. Even within the realm of work behaviour, considering work productivity, lost promotions, temporary leaves without pay, diminished earnings growth and pension losses are critical due to the long time horizon in caregiving of Veterans with TBI. For those who remain working, there may be lost opportunities due to *job lock* [35], whereby a parent caregiver has to remain near the Veteran and loses out on other employment opportunities. An expanded view will also be required to understand the impact of caregiving with Veterans with TBI on quality of life and family functioning.

As mentioned previously, since TBI is a chronic condition that will persist throughout the Veteran's lifetime, longitudinal studies will be required to fully understand the long term and dynamic impact of caregiving with Veterans with TBI on family functioning and quality of life. Most studies of family functioning are cross-sectional and few longitudinal studies are currently available [36]. Schönberger et al. [37] assessed family functioning and emotional status in individuals and families with TBI at 2 and 5 years post-injury. Family functioning as measured by the FAD was in the unhealthy range for about a third of these families at both 2 and 5 years post-injury, with no change over time. Almost half of relative respondents reported elevated anxiety and about 20% reported significant depression at both follow-ups with no significant change over time. These researchers constructed a structural equation model demonstrating the close

relationships between the emotional and behavioural status of the individual with TBI, family functioning and the emotional status of other family members.

There has been increasing focus in recent years on considering TBI as a lifelong, chronic condition in providing health care for individuals with this condition [38,39]. The close associations between the emotional and behavioural status of the individual with TBI and that of other family members identified by Schonberger and colleagues underscores the importance of working with the entire family in providing such long term care.

Importantly, with comprehensive support for eligible caregivers of Veterans with TBI now in place since 2011 in the VA Caregiver Support Program, it is also vital that we continue to evaluate how support through training and a financial stipend can compensate for the negative economic consequences to caregivers over time, and the channels by which compensation occurs. Comprehensive support affects the caregiver directly through the stipend feature but it could also enhance recovery of the Veteran with TBI and ability to work, and thereby help minimize the negative impacts on the family unit. Results of this evaluation were not available at the time this article was being written but will be available and disseminated in policy and academic fora in late 2016.

Currently available research in interventions to assist caregivers and families of Veterans with TBI offers are very promising in demonstrating the benefit of education, support and coping skills training. Programmes like BICS, BIFI and the Veterans Multi-Family Group provide exemplars for clinical services development as research continues to more clearly identify effective components and formats of these interventions. More focused interventions, for example, for couples, children involved in caregiving and financial planning, merit further development and evaluation. More definitive determination of what types of interventions are most helpful to caregivers and families with specific characteristics will make these interventions more targeted and cost-effective. The effectiveness of

such programmes in the long term in improving the quality of life of both caregivers and Veterans with TBI needs to be confirmed through studies with larger more representative samples. Interventional research in this area is plagued by the same challenges that confront rehabilitation research generally: identifying precision measurement tools that are sensitive to the most immediate effect of the intervention, specifying the optimal frequency and duration (dose) of the intervention, and recruiting and engaging research participants for the typically extended periods of time for intervention. Resolving such issues will require programmes of systematic research that use a variety of experimental and quasi-experimental designs. Outcome measurement will be improved by the use of modern measurement development techniques (i.e. item-response theory) and rigorous identification of the Minimal Clinically Important Difference (MCID) of these measures. Comparative effectiveness trials using adaptive experimental designs may be most useful in identifying the active ingredients of studied interventions. Further identification of the active ingredients of these interventions would inform determination of the type training and expertise required to effectively deliver specific interventions (e.g. doctoral level, other professional and paraprofessional provider) and contribute to cost-effective implementation. Further evaluation of interventions delivered by telephone or over the internet may also improve cost-effectiveness and accessibility of these interventions.

While there are differences in needs between pre-9/11 and post-9/11 (see Figure 4), the development of VA's Caregiver Program provides a unique opportunity for experts to study the benefits and services offered, and to create a prototype to serve a larger population of caregivers in need. But serious gaps remain, especially for caregivers of pre-9/11 Veterans. Such is the case for Jason Courneen (<http://www.militarytimes.com/story/military/benefits/health-care/2015/04/27/va-veterans-caregivers-murray/26312053/>) and Pauline King (<http://www.rand.org/pubs/periodicals/rand-review/issues/2014/spring/caregivers.html>). Another personal story that

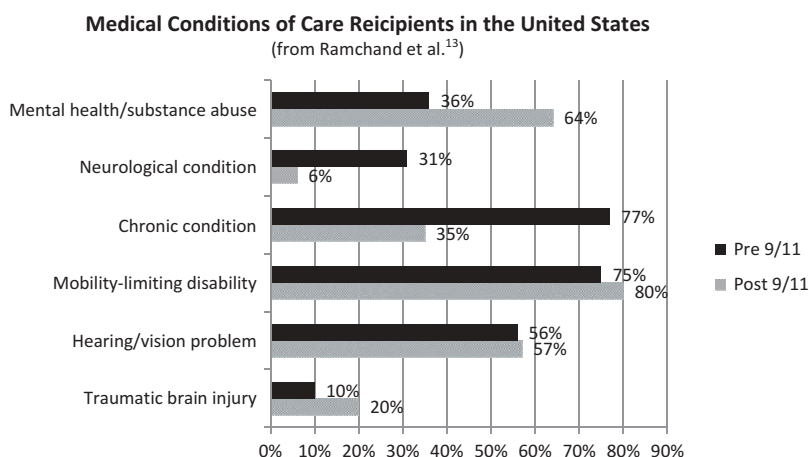


Figure 4. Comparison of Pre-9/11 and Post-9/11 Veterans and caregivers across medical diagnoses.

highlights the available resources as well as the gaps of currently available caregiver support is that of Barrett Dorn as described here by his father, Michael.

Suddenly, in the blink of an eye...

Early afternoon on Monday, 1 August 2011, my wife, Carolyn and I were thrust into a new and unexpected role for our youngest son, Barrett, who had been hit broadside by a twenty-four foot plumbing supply truck which had run a red-light. We suddenly and without warning or any training found ourselves with a new job as Barrett's parents: the role of Caregiver.

Of course, at that very moment we were no more thinking about this new responsibility but rather we were devastated, we were stunned and we were unsure of what the future was going to be. Although surrounded by people rushing around doing their jobs and the utter chaos inside Ryder Trauma Center in Miami at Jackson Memorial Hospital, we felt totally alone and somewhat lost.

Barrett suffered a severe TBI that day which has changed his life and our family's lives, too. Naturally, the person who was impacted the most was Barrett. He will forever live with this injury and will never be the same as he was before it happened. The story, this journey, is really about him; however, what is being written here is a somewhat combined, intertwined summary from our perspective as newly minted Caregivers.

Barrett was home in Miami Shores after the U. S. Marine Corps transferred him to the Temporary Retired Disabled List after he suffered a fractured hip and spent 3 months in the hospital. Although he had studied theatre immediately after high school and had received an A.S. degree from Florida School of the Arts (2001), Barrett enrolled and earned his A. A. from Miami-Dade College while waiting for his PEB (Physical Evaluation Board) to occur. Barrett had been accepted as a transfer student to F.I.U. (Florida International University) as a junior and was planning on earning his Bachelor's degree when the Fall Term began a few weeks later in August 2011.

All of this happened so quickly that there really isn't any way to have been prepared. In fact, as parents, we are not only living our own lives but we also have a shadow life, a parallel life along with each of our children. In truth, no one is totally prepared to become a parent—we learn as we go, with each child, perhaps a little differently from the preceding child, but we pull from our memories of our own upbringing, our memories of how things were with an earlier child in the family, things we learn from books, people, friends, etc. We help our children through their own growing up and the various stages partly because, we, too, lived those same stages and, although different, many of these stages are quite similar. But, nowhere is there a training for the unexpected, that accident, that event that in the blink of an eye not only alters their life forever but you suddenly realize that the parallel life, the shadow life, that you might have thought was no longer because they had become fully functioning adults and living their life on their own is still there.

The majority of my caregiving journey has been spent helping Barrett although I have on several occasions been able to function at a different, perhaps higher level and, hopefully, help or impact others who are dealing with a similar event in their lives:

- During 2013, I was asked by a woman who had been very instrumental in introducing us to NeuroRestorative in Orlando, where Barrett is currently a participant, to speak with a woman whose husband had just suffered a TBI. I was honoured to be asked, I was ready to help someone else.
- March is the Brain Injury Awareness month and I was asked to speak at a Luncheon at NeuroRestorative in March 2014. I, again, realized that this was a stepping stone in my journey because I was able to tell others about Barrett's experience and how our family was helping and dealing with his recovery and progress.
- This past August I was part of a team of presenters who spoke on the broad subject of caregiving at the VA TBI State-of-the-Art Conference in Washington D.C. leading to this article.

These opportunities have allowed me to progress through my own recovery from Barrett's accident. The very sharing of not only the factual events but also the emotional side of this caregiver role has made me realize that there is so much more than just being there to help but it is about being committed and doing it from your heart. Perspective is an interesting concept and plays a huge role in being successful or not when thrust into something like this. Carolyn and I realized early on that as horrible as the accident was and despite the uncertainty of not knowing how Barrett's physical injuries would present themselves in his life going forward as either physical or cognitive deficits, we were surrounded by 'little blessings'.

These little blessings popped up on day one and every step of the way from Barrett being in Neuro Intensive Care Unit (ICU) to an intermediate medical wing and finally to the rehab centre where our neighbour from around the corner is the head of the Occupational Therapy unit. Through an introduction by the Brain Injury of Florida Coordinator, we were able to get the VA to allow NeuroRestorative to come interview Barrett. Barrett was accepted into the VA's TBI AL-Pilot Program, a programme which they partnered with NeuroRestorative. Since being a participant in this Pilot Program, it is my opinion that Barrett has improved tremendously. Although his TBI is categorized as being severe and there are going to be limits to his ultimate progress, I still think he has always shown progress. Barrett is now doing Yoga (one to two times a week), has Voice lessons once a week, has Music lessons once a week, had Hippo Therapy (horseback riding) and then graduated to Therapeutic Riding once a week, bowls once a week with a group from NeuroRestorative, goes to the local YMCA rather than needing Physical Therapy at the Facility and has volunteered at Habitat for Humanity at their Re-Store and is involved in the local BIAF-Central Florida Support Group meetings.

However, we were recently told that Barrett would be discharged from the VA TBI AL-Pilot Program after he was examined by a newly hired physiatrist at the Orlando VA and a second chart review performed by a team of people from the Orlando VA. That final decree has left us stunned and nearly speechless. Yes, we understand that a severe TBI has built-in deficits and we also realize that Barrett will probably never live independently again but we also remember all the words about TBI not being a dash and being more a marathon, that it is a journey, that it is about slow progress.

So, on one hand, we have been supremely fortunate for all the little blessings that we have had and we are forever grateful to all of those we have met along the way who have helped us. I'd like to think that we may have been some help to others, too. For the most part, we've had good experiences with the VA all along although my son who received much of his post-acute care outside of the Orlando VA. This highlights the question raised at the 2015 VA TBI SOTA Conference regarding what to do with Vets who are seen by two or more VA facilities or in the community and with the VA's computer system not easily allowing these very different facilities to access the full chart of a Veteran.

Nevertheless, the perspective that has stuck with me is that one can approach something like Barrett's accident and his severe TBI with a 'glass is half empty' attitude or you can be positive and think that the 'glass is half full'. I have chosen 'half full' and I made a commitment to my son that I'll be there every step of the way, as best as I can, to help him recover to his potential.

Conclusions

Most encouraging is the increased recognition of and attention to the needs of caregivers of Veterans with TBI and other disabilities. Additional research directed at understanding the quality of family caregiving and the economic and health impacts of being a caregiver over long episodes of care (e.g. Veterans with TBI) is vital to better understand the impacts on both caregivers and Veteran care recipients. In addition, implementation of effective interventions based on this research has significant potential to further improve the lives of caregivers and the Veterans they support. Critical to this mission is to continue to seek input from caregivers of Veterans with TBI, such as Mr. Dorn and Veterans with TBI themselves, in order to tailor effective interventions to meet the needs of Veterans and their families. VA Secretary Bob McDonald recently stated that, 'the VA has been taking steps to make its systems easier for Veterans as well as caregivers. If we're going to be Veteran-centric, we're going to be caregiver-centric, too.' Perhaps Secretary McDonald has given hope for all military and Veteran caregivers, and lessons that can be learned from VA's comprehensive caregiver programme will inform national policy.

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The authors have no conflicts of interest.

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