

BRAIN INJURY

vol. 16 issue 3

professional

Brain Injury as a
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Debra Braunling-McMorrow, PhD

from the editor in chief

In their seminal article in 2010, Masel and DeWitt introduced the brain injury world to the concept of Brain Injury (BI) as a Chronic Condition. While this was not a foreign concept for those who experienced brain injury, those who served persons with BI and payers who were accountable for the long term support of those with BI, it was a paradigm shift that allowed all to put into perspective what they were experiencing and seeing. This shift in thinking about brain injury has resulted in a much deeper dive into understanding the long term physical, cognitive, behavioral, degenerative consequences and the healing of injury.

Drs. Kristin Dams-O'Connor and John Corrigan have dedicated their careers to understanding the messiness and complexities in predicting brain injury outcomes. In this Special Edition on Chronic Brain Injury, they have assembled a stellar line up of researchers and clinicians and persons with brain injury and their families. As a result, they have summarized what we know and what we yet do not understand as they explore the persistent variability of outcomes for persons with TBI.

Their lead article concisely reviews the research to date. It is an article that will be often cited by clinicians, researchers and persons with brain injury. In addition, this edition helps bring research to practice with articles on building resilience, self-management, sexual dysfunction and return to work. Most of what this edition does is bring the real issues of living with brain injury into focus. The interviews with persons with brain injury and their families help anchor the issues.

On another note, It has been a pleasure and a challenge serving as Co-Editor-in-Chief since 2014, taking over that role from Dr. Ron Savage. In this past year as the North American Brain Injury Society and The International Brain Injury Associations have merged, Dr. Nathan Zasler joined me as Co-Editor-in-Chief. Moving forward, I am pleased to announce that Dr. Beth Slomine will be assuming my role as the new Co-Editor in Chief along with Dr. Zasler. Many of you know Dr. Slomine's reputation as an expert in pediatric brain injury and an accomplished researcher. She is an Associate Professor of Psychiatry and Behavioral Sciences and Associate Professor of Physical Medicine and Rehabilitation at Johns Hopkins University School of Medicine. She also holds a number of positions at Kennedy Krieger Institute including serving as the Director of Neuropsychological Rehabilitation Services, The Neuropsychology Director of both the Responsiveness Program and the Concussion Clinic, and the Co-Director of the Center for Brain Injury Recovery. Enough said. She is clearly accomplished and eager to take on the role.

They say a sign of a good leader is to be able to hand off a position better than when you arrived so your absence will not be missed (or something like that). While I do hope some will miss me, I am proud of the *Brain Injury Professional*, and I believe it is uniquely poised to continue its expanding influence in the brain injury world. Thank you to everyone who has contributed to the success of this exceptional publication and for allowing me to be a part of it for these past many years.

Editor Bio

Debra Braunling-McMorrow, PhD, is the President and CEO of Learning Services. She serves on the board of the North American Brain Injury Society as Vice Chair. She has served as a chair of the American Academy for the Certification of Brain Injury Specialists (AACBIS), board of executive directors of Brain Injury Association of America, and several national committees, editorial boards, and peer review panels. She is a published author and lecturer in the field of brain injury rehabilitation for over 30 years. To contact Dr. McMorrow, please email conference@nabis.org.

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from the **guest editors**



John D. Corrigan, PhD



Kristen Dams-O'Connor, PhD

Traumatic Brain Injury (TBI) can result in lasting changes in cognition, mood, behavior, and physical functioning. It has long been assumed that after an individual recovers for a year or so, things don't change much – the injury has taken its course. But in recent years, research has begun to quantify something that people living with brain injury, their families, and doctors have suspected for a while: that the effects of a TBI are not static. Some people keep improving for years and years following injury, and sadly others begin to decline after a period of recovery. And for some people, the TBI seems to serve as a catalyst for a wide variety of health problems. Research has highlighted high rates of chronic health conditions experienced by long-term survivors of TBI, drawn associations between TBI and dementia, and consistently found evidence for a shortened lifespan – even among those who survive more than a year following injury.

Ten years ago some of these findings were summarized in a paper published in the *Journal of Neurotrauma*, and the authors wondered: should TBI be considered a chronic disease? This was a provocative question indeed. The TBI community was activated by the dialog that ensued, and researchers across the globe have begun to investigate the myriad questions that arose: How might a TBI initiate or exacerbate diseases of other body systems? What happens in the brain years after injury to allow a neurodegenerative process to unfold? And most importantly: how can we treat it? As these questions continue to be explored, researchers and clinicians and survivors began searching for treatments, tools, tips and tricks – things that can be done now to maximize health, productivity, life quality, and longevity.

In the current issue of *Brain Injury Professional*, we attempt to summarize the current state of knowledge with respect to TBI as a chronic health condition. Evidence has accumulated to support the notion that individuals with TBI have increased risk for a variety of pre-existing and post-injury chronic health conditions, and there appears to be a link between TBI and some types of neurodegenerative processes. But we've also seen clear evidence that a substantial minority of people with TBI continue to recover for years longer than we traditionally believed possible. We don't yet know why outcomes can differ so greatly. In this issue, we have selected topical articles that present evidence-based and clinically-supported answers for those who wonder how they can be in the group that continues to recover, grow, and thrive. Our team of authors discuss the power of resilience and how to build it, strategies for vocational success (not just how to get a job, but how to keep it!), and specific strategies for health self-management. We consider the support needs of care partners, and the importance of sexuality education in post-TBI rehabilitation. We sought input from experts in living with brain injury who graciously shared their wisdom and advice for living well. We hope that the content of this issue encourages ongoing dialogue about healthy living after TBI.

The research summarized here can and should be used to advocate for intensive rehabilitation, long-term health management, and other supports that TBI survivors need and deserve. And the advice contained herein, whether based in empirical science, clinical expertise, or lived experience – is offered with encouragement and admiration for all those who are striving to live well with TBI.

Editors' Bios

John D. Corrigan, PhD, is a Professor in the Department of Physical Medicine and Rehabilitation at Ohio State University and Director of the Ohio Valley Center for Brain Injury Prevention and Rehabilitation, which, among other activities, is the designated lead agency in the state of Ohio for TBI policy and planning.

Kristen Dams-O'Connor, PhD, is Director of the Brain Injury Research Center of Mount Sinai and Associate Professor in the Departments of Rehabilitation Medicine and Neurology at Icahn School of Medicine at Mount Sinai in New York, NY. She leads the Late Effects of TBI (LETBI) Project, a TBI brain donor program focused on characterizing the clinical and pathological signatures of post-traumatic neurodegeneration. She is also Project Director of the New York Traumatic Brain Injury Model System of care at Mount Sinai.



Traumatic Brain Injury as a Chronic Disease Process: Looking Back on a Decade of Research

Eric Watson, PhD • Raj G. Kumar, MPH, PhD • Brent Masel, MD • John D. Corrigan, PhD • Kristen Dams-O'Connor, PhD

A seminal paper published in 2010 argued for the conceptualization of traumatic brain injury (TBI) not as an isolated injury event, but as a disease process that unfolds heterogeneously over many years (Masel & DeWitt, 2010). The purpose of that paper was to summarize the evidence needed to encourage clinicians and, perhaps more importantly, the insurance industry, to recognize TBI as a condition that may require lifelong care. The World Health Organization defines a chronic disease as one that has one or more of the following characteristics: it is permanent, it requires specialized care, and/or it may require a long period of observation, supervision, or care (Pruitt & Epping-Jordan, 2002). The authors summarized scientific evidence that TBI is associated with an increased risk for a broad range of neurological and non-neurological health conditions, which together supported the notion that TBI may initiate and/or accelerate health decline across multiple body systems. Unlike an injury event (such as a broken bone) which has a finite recovery timeline, the sequelae of TBI appear to persist and evolve for years post-injury.

At the time of its publication, this conceptualization was quite novel – and it stimulated a major investment on the part of clinicians, researchers, and the individuals with TBI and their families who have generously participated in research studies, to further investigate whether, and for whom, TBI becomes a chronic disease process. The research conducted in this area over the past decade has led to a better understanding of the heterogeneous long-term outcomes experienced by TBI survivors, and the chronic health burden experienced by some. Here, we will review some of these developments and revisit the ideas first discussed in 2010 in light of new findings, and highlight the pressing questions that remain unanswered.

Physical health

The role of both comorbid and pre-existing physical health conditions in TBI risk, recovery and long-term outcomes has become more widely recognized.

Physical health problems in older adults, such as cerebrovascular diseases and activities of daily living (ADL) limitations, are associated with increased risk for sustaining a TBI in late life (Dams-O'Connor et al., 2016) – which suggests older adults with TBI were already sicker than their uninjured peers. One study reported that among adults over age 50 admitted to inpatient rehabilitation for TBI, 70% had at least one chronic disease diagnosis (Kumar et al., 2018), and the most prevalent conditions were hypertensive disease, musculoskeletal disease, diseases of lipid metabolism, and diabetes. Adults with TBI of all ages have a variety of health problems at 10-year follow-up; the most common are hypertension, fractures, osteoarthritis, high cholesterol, and sleep disorders (Hammond et al., 2019). Not surprisingly, the presence of these conditions influences trajectories of functional outcome and satisfaction with life (Malec et al., 2019).

Additional studies have highlighted particular health conditions, such as post-traumatic headache which affects over 70% of individuals with moderate-to-severe in the first year after injury (Hoffman et al., 2011). Post-traumatic epilepsy is also a major concern for adults with moderate-to-severe TBI, the incidence rate of new-onset seizure disorder (9.2%) is greatest in the first year post-injury (Ritter et al., 2016). A meta-analysis (Mathias & Alvaro, 2012) of 21 studies found 50% of individuals report some form of sleep disturbance after TBI, and between 25-29% have a diagnosed sleep disorder (insomnia, hypersomnia, or apnea). As discussed further below, chronic pain is among the most commonly reported health problems following TBI in both military and civilian settings (Nampiaparampil, 2008). Finally, several studies have reiterated a link between TBI and hypopituitarism, which can result in a number of downstream clinical consequences (Tanriverdi & Kelestimur, 2015).

For a TBI to be considered disease causative and/or disease accelerative, one would expect the overall burden of disease to be greater in those with TBI as compared to those without. Very few studies have directly compared those with and without a TBI, though a few studies comparing dementia risk in those with and without TBI report higher rates of diabetes, cerebrovascular and cardiovascular disease in the TBI groups (Barnes et al., 2014; Gardner et al., 2014).

Behavioral health

Research over the last decade has extended and expanded upon the associations identified by Masel and DeWitt (2010) between TBI and depression, anxiety, suicide, and substance use disorder. An exhaustive review observed that the incidence of major depressive disorder and post-traumatic stress disorder following TBI exceeded population rates, commonly emerging in the first year, though onset may be delayed with more severe injuries (Ponsford et al., 2018). However, they also concluded that the frequency of psychotic spectrum, eating and somatoform disorders did not exceed rates observed in the general population. Substance use disorders were more frequent prior to injury among adults who incur TBIs, but may decline post-injury due to both spontaneous behavior change and more severe injuries limiting safety and/or access (Bogner et al., 2019). There is some suggestion that childhood TBI may predispose individuals to adult substance misuse (Cannella et al., 2019; Weil, et al., 2019).

There has been some progress in identifying efficacious treatments for post-TBI behavioral health challenges. There is evidence that SSRI's generally, and sertraline specifically, can mitigate depression after TBI (Jorge, et al., 2016). Research examining the non-pharmacological interventions, such as cognitive behavioral therapy

(CBT), have demonstrated effectiveness in reducing symptoms of depression (Fann et al., 2015), anxiety (Ponsford et al., 2016), and emotion dysregulation (Neumann et al., 2017). However, given the heterogeneity among research designs, psychotherapeutic approaches and population characteristics, comprehensive practice recommendations are not yet possible. Emerging areas of concern include the intersection between opioid use disorder and TBI (Corrigan & Adams, 2018). In suicide prevention, there is growing recognition that among persons with brain injury, risk assessment must focus more on opportunity for self-harm and less on emotional distress (Simpson & Brenner, 2019).

Neurodegenerative disease

The associations between TBI, post-traumatic neurodegeneration and Alzheimer's Disease and related disorders (ADRDs) has received unprecedented attention in the last decade. Just prior to the publication of the 2010 Masel & Dewitt paper, chronic traumatic encephalopathy (CTE) was discovered post-mortem in the brains of several former professional football players (Omalu et al., 2005), suggesting that this apparently unique pathological disease appears to be associated with repetitive head trauma (McKee et al., 2009). Since then, hundreds more CTE cases have been diagnosed postmortem (McKee et al., 2016), which has resulted in renewed interest in the association between TBI and dementia. Masel and Dewitt (2010) report findings from the Institute of Medicine report (IOM (US), 2008) which concluded that there is sufficient evidence of an association between moderate-severe TBI and Alzheimer's disease (AD). Research over the past decade, however, has highlighted the complexity of these associations a link between TBI and AD in particular has not been consistently replicated. One review determined that among 11 studies assessing the relationship between TBI and dementia, two studies found no association, and four studies observed an association only in specific subgroups (Dams-O'Connor et al., 2016). The preponderance of evidence does suggest an association between TBI and neurodegenerative disease, but post-traumatic neurodegeneration may be distinct from AD-like clinical symptoms (Crane et al., 2016; Dams-O'Connor et al., 2013; Nordström & Nordström, 2018; Sayed et al., 2013).

Importantly, several studies have begun to identify potentially modifiable factors that may be associated with increased risk for dementia following TBI, such as sleep fragmentation and intermittent hypoxia (Lim et al., 2013; Osorio et al., 2015), increased immune response and neuroinflammation (Zhu et al., 2012), and overall burden of chronic health conditions that may at least partially mediate the relationship between TBI and dementia (Wilson et al., 2017). This research is promising as increasing physical activity (Blondell et al., 2014), treating disordered sleep (Cedernaes et al., 2017), and managing physical and psychiatric comorbidities (Diniz et al., 2013; Wilson et al., 2017) could potentially stave off cognitive decline and the development of dementia process in late life.

Mortality

The age-adjusted mortality rates following TBI have not meaningfully changed since 2010 (Brooks et al., 2013). Individuals who survive at least one year following TBI are 2.33X more likely to die than their uninjured counterparts, with a reduced life expectancy of up to 9 years (Brooks et al., 2013; Harrison-Felix et al., 2015). We have learned that the absolute incidence of TBI is increasing in the elderly population due to increased life expectancy and mobility in the aging population (Rozenbeek, et al., 2013), and the rate of TBI hospitalization in adults over 75 is exceeding population growth in this age group (Kristen Dams-O'Connor et al., 2013).

The changes in the demographic landscape of TBI have implications for mortality, as older age at TBI is associated with increased risk for acute mortality, greater acute care complications, comorbidities, use of anti-platelet/anti-coagulants, and conservative acute care (McIntyre et al., 2013). Still, relative to general population, individuals with moderate-severe TBI from all age strata are at increased relative risk for mortality, with the exception of adults over 85 (Harrison-Felix et al., 2012). Teenagers and middle-aged adults are at particularly increased relative risk for mortality compared to their counterparts in the general population.

The association between mild TBI and mortality is much more tenuous, with little new evidence in the last decade. A study from the European Union counter-intuitively found a lower 6-month all-cause death rate (5%) in the lower income countries than in higher income countries (8%) (De Silva et al., 2009). An American study found an all-cause in-hospital mortality rate of 1.4% in a large sample of patients with mTBI (Selassie et al., 2011). Across both of these mTBI studies, it was not clear that deaths were directly related to the mTBI, extra-cranial concurrent injuries, or other causes.

Conclusion

The study of TBI as a chronic condition has garnered unprecedented support in the past decade, with findings largely confirming the evidence compiled in the 2010 paper by Masel and Dewitt. Still, there are many more questions than answers. Due to scarcity of studies designed to directly compare the physical and behavioral health of those with and without TBI, it remains unclear whether, when and how a TBI leads to the onset or exacerbation of many of these health challenges relative to uninjured adults. More research is needed to distinguish post-TBI cognitive dysfunction from neurodegenerative disease processes and to elucidate the underlying mechanisms driving post-traumatic neurodegeneration. It will be particularly important to characterize the subgroup(s) of TBI survivors who are at elevated risk for long-term evolving sequelae of TBI so that preventative care efforts can be dispatched accordingly. It will also be important to investigate how the sequelae of TBI interact with one another to alter a person's health and wellbeing. Post-TBI cognitive impairment, for example, may limit a person's ability to self-manage his/her health and contribute directly to health decline. It may be the case that certain medical conditions contribute to or exacerbate cognitive impairment and behavioral health disorders. For example, other fields studying trauma suggest that underlying biological abnormalities like persistent autonomic dysregulation (Brod et al., 2014), metabolic function (Brenner et al., 2018) and hyperinflammation (Bollen et al., 2017; Kiecolt-Glaser et al., 2015) may cause executive dysfunction that increases the likelihood of behavioral health disorders. This information might guide the development of treatments to maximize post-TBI health. Even as research progresses and knowledge accumulates, current long-term care for TBI survivors can be improved considerably by bringing together leading experts to develop consensus guidelines for treatment of the most common post-TBI conditions and comorbidities. The most valuable clinical practice guidelines will be specific to key subgroups (e.g., older vs younger adults; mild vs severe TBI). The implications of TBI as a chronic disease process on long-term health care needs and health care costs have not yet been fully realized. It is clear that research, advocacy, and policy efforts need to continue at unprecedented levels so that individuals with TBI can more universally gain access to the care they need, when they need it – even decades following the initial event.

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Resilience and Chronic Brain Injury Outcomes: Behavioral and Social Pathways for Promoting Well-Being



Amanda R. Rabinowitz, PhD • Grace S. Griesbach, PhD
Shanti M. Pinto, MD • Lenore A. Hawley, MSSW

Outcomes after a moderate-to-severe TBI are quite variable, with some individuals exhibiting impressive recovery and others facing severe disability (Thornhill et al., 2000). Deleterious effects on mental health and well-being are among the most common and troubling long-term effects of TBI. Most research on psychological functioning after TBI has focused on the first year after the injury; however, a growing body of work suggests that higher rates of psychiatric diagnoses and poorer subjective well-being and quality of life persist well into the chronic post-injury phase (Corrigan et al., 2014; Hart et al., 2011; Hart et al., 2012). Predicting who will struggle and who will thrive is a challenge. Even with advanced neuroimaging methods for quantifying neuropathology, a large proportion of the variance in TBI outcomes remains unexplained (Betz et al., 2012; Corrigan et al., 2015; Davis et al., 2012; Forslund et al., 2013). In this article, we discuss how personal and lifestyle factors can improve long-term well-being following TBI.

Resilience

There is a growing appreciation that the personal qualities that individuals bring to their injuries may influence their recovery, a notion referred to as resilience (Rabinowitz & Arnett, 2018; Richardson, 2002). For example, individuals employing a coping style focused on actively addressing stressors and using humor and enjoyable activities to promote well-being have better psychosocial outcomes (Anson & Ponsford, 2006). Higher resilience has been associated with decreased rates of depression and anxiety and increased life satisfaction following TBI (Marwitz et al., 2018). Resilience has also been associated with increased community participation (Marwitz et al., 2018; Wardlaw et al., 2018), perhaps via direct effects on reducing depression (Wardlaw et al., 2018). Incorporating a focus on resilience into brain injury rehabilitation may be a promising approach for improving long-term functioning. There is evidence that behavioral interventions can boost resilience after TBI. For example, Kreutzer and colleagues investigated the role of Resilience and Adjustment Intervention (RAI) on outcomes after TBI in a group of 160 individuals roughly 19 months following TBI. They found that those who completed RAI had improved resilience and lower psychological distress compared with waitlist controls (Kreutzer et al., 2018).

Quality sleep promotes well-being after brain injury

Engaging in emotional and physical health-promoting behaviors is one likely avenue by which resilience may confer its benefits.

For example, quality sleep is associated with better cognitive and emotional functioning after TBI. Animal studies have shown that sleep promotes critical neural functions for learning and memory. For example, sleep spindles, which are activity bursts in the thalamus during non-rapid eye movement (REM) sleep, have been linked with neural plasticity (Andrade et al., 2011). Given the impact that sleep has on cognitive function, it is not surprising that attention and memory deficits are greater in TBI patients with concurrent sleep disorders (Mahmood et al., 2004; Wilde et al., 2007). Sleep has been observed to play a critical role in emotional processing as well. Decades of research have established a strong bi-directional link between disturbed sleep and emotional disorders like depression and anxiety (Alvaro, Roberts, & Harris, 2013; Riemann, Berger, & Voderholzer, 2001). Persons with TBI show altered-sleep architecture, characterized by reduced time in REM sleep (Grima et al., 2016), which is particularly critical for processing emotional stimuli and regulating emotional reactivity (Baran et al., 2012; Jones et al., 2016; Wilde et al., 2007).

Unfortunately, sleep disturbances are a common complaint after TBI (Gardani et al., 2015; Ouellet, Beaulieu-Bonneau, & Morin, 2015). Multiple studies utilizing polysomnography, the “gold standard” for objectively evaluating sleep, have shown that individuals with a TBI have significantly more sleep disorders compared to healthy controls (Grima et al., 2016). Over half of people living with TBI report difficulty initiating or maintaining sleep (Ouellet et al., 2015; Sandsmark, Elliott, & Lim, 2017). Hypersomnia and fatigue are also common complaints that can result from an array of sleep disturbances stemming from TBI (Imbach et al., 2015; Masel et al., 2001). Untreated TBI-related sleep disturbances are likely to worsen with age (Copinschi & Caufriez, 2013; Griesbach et al., 2018).

Although the research on interventions for sleep disturbance after TBI is somewhat limited, there are multiple empirically supported interventions for sleep in the general population that may be considered for treating sleep disorders in the context of TBI. In order to avoid undesirable medication side effects, non-pharmacological interventions for improving sleep are appealing. Common interventions include psychoeducation on sleep hygiene, cognitive behavioral therapy, light therapy and continuous positive airway pressure (CPAP) therapy for sleep apnea. Physical exercise has been gaining attention as a treatment for sleep disturbance (Guilleminault et al., 1995; Reid et al., 2010), and evidence suggests that this may be a particularly promising intervention for persons with sleep disorders related to TBI.

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Physical activity and resilience after brain injury

In addition to improving sleep, exercise is associated with a host of emotional, cognitive, and physical health benefits that may improve functioning after TBI. Exercise has direct positive effects on brain function, including development of new cells and blood vessels, as well as increased production of molecules that promote synaptic plasticity (Dostes et al., 2016; Griesbach, 2011; Smallwood et al., 2015). Positive effects on learning and memory are associated, in particular, with changes in hippocampal function (Creer et al., 2010; Griesbach, Hovda, & Gomez-Pinilla, 2009). Studies in animal models of TBI have shown that exercise increases proteins that facilitate neuroplasticity and improve performance in a variety of cognitive tasks (Ding et al., 2006; Mustrup et al., 2012). Exercise induced increases in key proteins have also been observed in humans (Seifert et al., 2009). Likewise, clinical studies have shown improvements in memory and executive function after aerobic exercise in participants with TBI (Chin et al., 2015).

Physical activity after TBI is an important factor in maintaining good long-term health in a variety of domains (Kreber & Griesbach, 2016). A sedentary lifestyle increases the risk for developing secondary complications such as hypertension, osteoporosis, obesity and non-insulin dependent diabetes mellitus (Shavelle et al., 2001). Exercise has also been found to promote emotional health. Clinical studies have observed that aerobic exercise decreases symptoms of depression following TBI (Hoffman et al., 2010; Wise et al., 2012). Although physical limitations and logistical challenges can make it difficult for persons with TBI to stay active; promoting safe and appropriate physical activity after TBI can lead to multiple benefits for cognitive, physical, and emotional status, including protection against age-related cognitive decline (Bherer, Erickson, & Liu-Ambrose, 2013; Hyodo et al., 2016).

The role of community participation and social support

Social and community engagement also promotes better long-term functioning for those living with chronic brain injury. Community participation is associated with decreased depression (Erlor et al., 2018), more positive affect (Juengst et al., 2014), and improved life satisfaction following TBI (Juengst et al., 2015). Due to the cross-sectional nature of the current literature, it is unclear whether decreased depression and increased positive affect precedes higher levels of participation, or if it is participation that is responsible for the decreased rate of depression and higher levels of positive affect. Andelic and colleagues conducted longitudinal interviews of 44 individuals following TBI. Overall, community integration improved between the 10- and 20-year follow-up periods. Additionally, those with greater community integration at 10 years post-TBI had improved mental health at 20 years post-TBI (Andelic et al., 2018), suggesting that community integration is important for mental health among long-term survivors with TBI.

There is a decline in social support after TBI with decrease in size of social networks with loss of friends and increased reliance on family. Unfortunately, this loss of social support may lead to poorer psychosocial outcomes. Greater social support is associated with improved quality of life (Steadman-Pare et al., 2001) and decreased depression following TBI (Douglas & Spellacy, 2000). Living with others, compared with living alone, was also associated with greater community participation following TBI (Erlor et al., 2018). In a study of 245 individuals 6 months to 13 years following TBI, close to half of individuals experienced unhealthy family function, and family function was moderately correlated with depression and resilience (Wardlaw et al., 2018). For some, religious groups can be an important source of social support.

Prior studies have demonstrated that participation in religious services has been associated with improved life satisfaction, social participation, and decreased depression following TBI (Juengst et al., 2015; Philippus et al., 2016).

Putting it all together

For some individuals, the effects of TBI persist for many years or even a lifetime. Individuals living with chronic brain injury are at risk for increased rates of psychiatric diagnoses as well as decreased subjective well-being and quality of life. Activities and interventions that promote psychological resilience may provide protection against these issues, leading to improved psychosocial outcomes and life satisfaction. Resilience interventions should encourage adaptive coping strategies, positive sleep behaviors, regular exercise, social engagement and support, and active community participation. It is recommended that TBI rehabilitation and research efforts incorporate an emphasis on resilience building to improve the lives of those living with chronic brain injury.

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expert interview

The Trials and Triumphs of Traumatic Brain Injury with Mrs. Nicole Keller

Interviewed by **Monique R. Pappadis, MED, PhD**



Nicole Keller

Briefly share when and how you sustained a traumatic brain injury.

I sustained my TBI as a result of a car accident on July 28, 2009. After 'the jaws of life' got me out of my car, I was flown by Memorial Hermann Life Flight® to its Red Duke Trauma Institute in Houston, Texas. I spent some time in the surgical and intensive care units before being transferred to the nearby inpatient rehabilitative hospital, TIRR Memorial Hermann Hospital. Once I learned to talk and walk again, and daily activities of living, like using the toilet and eating, I was discharged to continue outpatient therapies at TIRR's Challenge program and on my own to continue off and on for the rest of my life.

Following a traumatic brain injury, individuals may notice cognitive (e.g., thinking and memory), emotional (e.g., anxiety and depression), and physical (e.g., muscle weakness and pain) changes. Describe some of the significant changes you have experienced.

My thinking and memory have changed significantly over time. After my injury, I have had a hard time with short term memory, making decisions, poor judgment, being very impulsive, and many more difficulties. Over time, I've seen periods of tremendous improvement. In fact, I didn't experience any improvement for a long time; then all of a sudden, I saw huge improvements. For instance, I couldn't understand directions, and I couldn't make out heads or tails on maps. I had no idea how to get from one place to another; then one day I was able to understand maps.

It's been nearly ten years since you had a traumatic brain injury. Are there symptoms or changes that you are still dealing with?

Yes, anxiety and depression. I was very, very depressed and angry early on in my injury.

This has been a slow and difficult process, but right now I feel pretty good. This is more of a process than anything. Also, I have muscle weakness and pain. I don't have as much trouble with balance and weakness as I originally had; however, I still have some loss of ability on my left side. As I have suffered significant physical injuries, it is hard to tell what is TBI-related and what is as a result of other injuries. I still have difficulty focusing and must take medication. I have mood swings and suffer from low self-esteem. I'm currently seeing a counselor who has dealt with patients with TBI, which is helping me deal with my self-esteem issues and learn to cope with my frequent and drastic emotional swings.

How has the traumatic brain injury affected your overall life (e.g., relationships, employment, interests/activities)?

I was not able to finish my degree. I do not have the reading comprehension I once had. I do not have the type of social life a person my age would have, which at times is a source of sadness. I have difficulty in social situations; I get overwhelmed in groups and when I'm in an environment with lots of stimuli.

Do you think the traumatic brain injury will always have an effect on your life? If so, how? If not, why not?

When I was in TIRR Memorial Hermann, the staff would tell my family and me that my life would be different, and it would likely never again be what we considered normal before my wreck. It would be a new "normal" that I quickly realized my loved ones, and I would have to learn eventually to accept and hopefully love. It was hard for me to imagine myself or anyone else ever loving the new me, but after several years of hard work and lots of ups and downs, I slowly began to accept and love the new me. I finally could see that others who loved me pre-TBI continued to love me after my TBI. I will never be the person I was before my TBI. I know my personality is somewhat different and now realize that I comprehend things wrongly a majority of the time. That has been a big factor in all these years of lost friendships and me having a lot of unnecessary hurt feelings. I will always have trouble with memory and focus, but maybe one day I will not need medication to help me focus and to help me sleep.

I cannot imagine I'll ever feel completely comfortable in social situations, but I have learned many coping strategies to make life a lot easier, which helps me not to get so overwhelmed or at least not as easily overwhelmed. I accept that I will always laugh and talk a little too loud, although I try very hard not to, and sometimes say inappropriate things. But that's ok. It's the person I am now; although, I continuously unintentionally embarrass myself and my loved ones (or whoever's with me). For a while, I was apathetic and seemed to be like a zombie, and I couldn't wait to not be annoyed by everyone around me. But with time, I've found that I have become much more empathetic to others than I ever was before my head injury. My views have slowly changed with time, and I now appreciate what I have and appreciate my life more than I ever did before my head injury.

Individuals may have long-term effects after their injury. Therefore, some professionals view traumatic brain injury as a chronic health condition, similar to a stroke, diabetes, and hypertension. What are your thoughts and opinions on this way to view traumatic brain injury?

I think that a TBI is a lifelong condition. For me, I have improved so, so much since my accident, but I will never be the person I was before. I was very fortunate because I had extremely good care after my wreck, and I don't think I would have improved as quickly or as well as I did without that excellent care and education given to me and my family. I do strongly believe a TBI should be considered similar to having a stroke based on the lifelong challenges it causes. I realize I will always suffer from the injury, even though I was lucky to sustain my head injury when young and had very good care.

There are some critics of this new way to view a traumatic injury. They believe that a TBI is an acute event (event that causes immediate changes). How would you respond to such critics?

I guess a TBI could be considered acute when it first happens, but the resulting effects are chronic and continuously impact the survivor's life greatly. A TBI is not like having the flu; it's not even like having diabetes, where medicine can be taken to improve or control the condition. It's a lifelong, very complicated condition, which includes continuous physical, emotional and psychological issues that are constantly getting better, then worse, and then better.

Others believe that by viewing TBI as a chronic condition will cause individuals to be stigmatized or negatively viewed. What are your thoughts?

People can be stigmatized for pretty much anything. If someone is upset because I have a TBI, it's better I'm not around them. I would much rather let someone know I have a TBI than not, it makes it easier for others to understand my challenges. Also, because my behavior is sometimes "different," I am not shy about telling people I have a TBI. If people start believing that a TBI is like a cold, something that can easily be cured, then those of us who haven't gotten over our TBIs will really be taunted. I feel life would be a lot easier if everyone really understood how much brain injuries affect our everyday living. And how every single thing in life is a lot harder for someone with a brain injury. Although a lot of us look 'normal,' we feel very far from 'normal.'

What advice would you give someone who has recently had a TBI? And what should they expect in the months to years following their injury?

Having a TBI is hard, the anger, sadness, frustration is sometimes impossible to deal with. The feeling of being a burden can be overwhelming. It may seem like it won't get better, can't get better, but it will. The trick is understanding that what you are feeling is normal. You will laugh again, I did, it took a while, but it happened.

What suggestions would you give to the healthcare professionals and researchers aiming to improve the lives of persons with TBI?

TBIs are not the same for everyone, and you must understand that it takes a really long time to heal, if ever. Those of us who suffer from them and get great care for one year, maybe two years, continue to need care. There needs to be more psychologists or counselors that care for TBI patients and understand our challenges. We need to be able to speak to people after five years and ten years and after.

Any last words you would like to share as a female living with traumatic brain injury.

I was 21 when I had the accident that caused my TBI. It's been hard because I've never been able to really experience being a 20-something woman. After my accident, I became a little girl again and was treated like a little girl. I've had to grow up in the last ten years, and I've had to convince my loved ones that I am not a little girl anymore. After my accident, I married my long-time boyfriend, who stood by me through tough times. He didn't realize there were going to be more tough times, because being married to a person with a TBI is not easy. Our marriage has withstood the mood swings and anger issues, it is still a work in process but getting better all the time. If you are or love someone with a TBI, please try and be patient and understanding, we are and will always be a little slower and more sensitive than others.

When I was able to be home for the first time in a long time, I was hit with the harsh reality of my new challenging life. People don't realize, and neither did I that living with a brain injury is extremely hard and every task is challenging and will continue to be for a long time. It's a very long road, but with hard work, perseverance, and determination the road does get easier to travel. Never before had I truly known the meaning of suffering and never before had I really noticed how fortunate I was. I didn't ever think to appreciate every second I was living without being in debilitating pain. I couldn't even imagine the thought of dying, let alone imagine staring it in the eyes. After many years of constant embarrassment of being myself, and years of thinking about how much easier death would be than life, I eventually began to find and love the new me. Life still has many challenges, but I am fortunate to now see clearly for what really matters in life.

After years of doctors telling me I could never be pregnant and if I miraculously ever got pregnant, then I would not survive a child growing inside me. I wanted more than anything my whole life to have children. After many years of sadness and then several miraculous pregnancies ending with miscarriages, I just about lost hope. Then, God finally blessed me with the final pregnancy, which I never thought would be successful but prayed and prayed. Well, on Feb 3, 2017, my prayers were answered when the world was given one of God's most precious angels, and my Grace Marie was born healthy and happy, and I lived to talk about it. Life is hard and painful and will continue to be until the end, but perseverance and strong will is key to happiness. Although my new life is harder than I ever imagined, I believe I am now happier than I ever would have been had I never sustained a severe traumatic brain injury as well as the many orthopedic traumas. I can proudly say... I am a survivor, and although I struggle daily, I love the life I am blessed to live.



About the Interviewer

Monique Pappadis, MEd, PhD, is an Assistant Professor of the Division of Rehabilitation Sciences, School of Health Professions at the University of Texas Medical Branch at Galveston (UTMB) and a Co-Investigator on the Texas TBI Model Systems at the Brain Injury Research Center of TIRR Memorial Hermann.

Self-Management Training: A Tool for the Long-Term Management of TBI?

Tessa Hart, PhD, FACRM

As highlighted in this issue, moderate-to-severe traumatic brain injury (TBI) is increasingly seen as a chronic condition, with symptoms and comorbidities that may evolve over time (Corrigan and Hammond, 2013). Unfortunately, at least in the US, services for TBI remain front-loaded, with the bulk of healthcare resources devoted to emergency and acute medical treatment. Even those receiving specialized inpatient care may “fall through the cracks” as they try to navigate a fragmented outpatient system. The result is often a high rate of unmet needs for the affected person and family (Corrigan, Whiteneck, and Mellick, 2004), and a host of social and medical problems that might be prevented with a different approach to care. This article addresses whether a type of long-term care model designed for other chronic health conditions, known as **self-management** or **self-management training (SMT)**, might be adapted to help meet the long-term needs of people affected by TBI.

What is self-management?

Self-management models were developed as greater longevity led to higher incidence of chronic age- and lifestyle-related conditions such as arthritis and heart disease, even as changes in healthcare reimbursement meant less time available for professionals to educate patients about how to manage these conditions. In contrast to traditional patient education, SMT places the patient in a more active role, as shown in [TABLE 1](#).

It follows that there is also greater responsibility placed on the patient—or, the patient and family—for the management of care.

The most comprehensive and thoroughly tested self-management model is the Chronic Disease Self-Management Program (CDSMP) developed by Kate Lorig and colleagues at Stanford University (Lorig and Holman, 2003). Numerous trials have shown that CDSMP leads to reduced symptom burden, improved emotional coping, and fewer Emergency Room visits for people with arthritis, diabetes, and other conditions (Marks, Allegrante, and Lorig, 2005). This is not to say that the CDSMP is a miracle cure— it may not work equally well for all chronic conditions (Warsi et al., 2004), and it remains to be determined how best to tailor the components to individual patients (Trappenburg et al., 2013). But the model is well-defined enough to serve as a starting point for examining its utility for TBI.

The main components of the CDSMP, as described in articles by Lorig and colleagues, are listed in [TABLE 2](#). This group program consists of 6 weekly sessions of several hours each, led by trained volunteers (who may have the condition addressed in the group). Inspection of [TABLE 2](#) shows that while the program emphasizes skill development, education is still a critical component. SMT is not intended to replace traditional healthcare, but to act as a supplement. One important objective of SMT is to help patients learn to communicate and form more effective partnerships with providers.

TABLE 1. Traditional patient education compared to self-management training

Patient Education	Self-Management Training
Patient is in a passive role, receiving information from an expert	Patient is actively engaged in acquiring <i>skills</i> as well as information needed to manage the condition
Expert tells patient what to do to manage the condition	Patient creates <i>action plans</i> that will help manage condition
Information is received in brief contacts such as doctor’s appointments	Intensive education and training are received separately from healthcare contacts
Information is generic, intended for many patients with same condition	Highly individualized, focused on specific problems and goals of each patient

What accounts for the positive effects of self-management programs?

Self-efficacy, which roughly translates to confidence in your ability to manage and improve your condition, is thought to mediate many of the improvements in symptoms and quality of life (Lorig and Holman, 2003). You can gain self-confidence by learning new strategies, by seeing your own success or the success of others with similar problems, or by being persuaded by someone you trust that “you can do it.” This confidence can lead to more persistent efforts toward symptom management, as well as an open-minded approach to new activities.

Could self-management work for TBI?

There are several appealing features of SMT. First, it is a positive approach that assumes every person with a chronic condition can gain some control over his or her symptoms. A person who has suffered many losses and setbacks due to disability could find encouragement in this central principle. Second, as noted in TABLE 2, SMT focuses on building skills and competencies. Instead of struggling to remember the information given by a doctor or therapist, let alone figuring out how to put it into practice, the person involved in SMT is supported in creating and implementing plans and decisions. In addition, a group format reinforces the idea that “you are not alone” and allows each participant to learn from the successes and challenges of others.

SMT principles have been applied successfully to other rehabilitation populations. For patients with limb loss, a group self-management treatment resulted in better pain management and higher self-confidence compared to a support group (Wegener et al., 2009). Heterogeneous treatments with SMT components have also been administered to patients with cognitive impairment, including those with stroke (Jones and Riazi, 2011) and multiple sclerosis (Rae-Grant et al., 2011). One uncontrolled trial tested a group program incorporating some features of CDSMP for persons with stroke and TBI; the severity of injury was not specified, and results were equivocal (Muenchberger et al., 2011). To date, there has not been a systematic effort to adapt SMT to TBI.

What are the challenges?

Several potential obstacles might limit the effectiveness of SMT for TBI. The most obvious one is that some of the very skills that are critical to self-management might be affected by the cognitive impairments so frequently caused by moderate to severe injury. TBI may cause limitations in self-awareness, affecting the ability to set

realistic goals and self-monitor progress. Difficulty with reasoning and problem-solving could undermine the ability to decide on appropriate actions, and deficits in memory and initiation could impede follow-through.

Another potential barrier is the well-known heterogeneity of TBI sequelae. Two people with superficially similar injuries may experience very different constellations of physical, cognitive, and behavioral effects. And considering the dynamic nature of the condition, these manifestations may also change in different ways for different people.

Both of these obstacles could diminish the effectiveness of a treatment delivered in a group format: It could be difficult to formulate a group of people with TBI whose concerns are similar enough for them to learn from one another, and those with more severe cognitive limitations might not receive needed attention or guidance.

Recommendations for next steps

What needs to happen for SMT to be adapted to the needs of people with chronic, moderate to severe TBI? Here are a few suggestions based on the literature to date as well as clinical research experience.

1. **Obtain input from the people who may benefit from the treatment.** Surveys or focus groups with people in the target population, as well as caregivers and family members, would help determine what features of SMT are both attractive and realistic, and what the barriers might be. Such input would also help to determine the appropriate content for an SMT program. For example, focus groups with people with spinal cord injury revealed a critical need for learning how to “manage” others, i.e. paid caregivers (Munce et al., 2014).
2. **Consider a 1:1 format and/ or a model that includes family members.** While it is potentially more costly, a 1:1 treatment format could be considered for people whose needs might not be met effectively in a group. Although the prospect of learning from other participants is appealing, some research on SMT has suggested that peer interaction may actually be detrimental (Jonkman et al., 2016). Conversely, designing a program that explicitly includes family members (or other caregivers) might offset some of the barriers related to cognitive dysfunction. There is a growing literature on family-centered approaches to chronic disease management (Deek et al., 2016), which could be tapped for ideas. Regardless of the format chosen, materials should be adapted for TBI and subjected to cognitive testing before use.

TABLE 2. Core components of the CDSMP

Component	Description
Education about the condition	Didactic information about symptoms, their causes, and what happens during the course of the condition
Setting realistic goals	How to set short-term (1-2 week) goals for managing or improving the condition that can be accomplished within one's resources
Taking action	How to plan and implement actions that will enable one to meet goals
Decision-making	How to decide whether self-management action plans are working; how to determine if symptoms are serious enough to require professional help
Problem-solving	How to identify and resolve obstacles to taking action and meeting goals
Resource utilization	How to find information relevant to the condition; how to be proactive in seeking help and services
Effective communication with healthcare professionals	How to communicate needs; how to interpret and understand recommendations from healthcare providers; how to form partnerships with providers

- 3. Capitalize on advances in measure development to examine both the predictors of success in SMT, and the effectiveness of programs.** The Patient Activation Measure (PAM) is a recently developed scale that might help determine the individual's pre- and post-treatment knowledge, skill, and confidence in self-management (Hibbard et al., 2004). There is also a scale for measuring readiness to engage in self-management following traumatic injury (Wegener et al., 2014), and a TBI-specific measure of self-efficacy (Cicerone and Azulay, 2007), which has been shown to improve following intensive holistic rehabilitation (Cicerone et al., 2008).
- 4. Include theoretically validated treatment components to promote long-term behavior change (i.e., habits).** This recommendation applies to SMT for any population, but may be especially important for those with neurologically based limitations in memory, drive, and initiation. Even when accomplishment of short-term goals leads to success, positive behaviors may dissipate unless there are components built in to help make them "stick." It is beyond the scope of this article to discuss such components in detail, but fruitful concepts and techniques may be borrowed from the field of Health Psychology, which is primarily concerned with helping people to develop and maintain new habits in the service of improved health and quality of life (Michie, van Stralen, and West, 2011). In addition, widely used and inexpensive technology, such as text messaging, is proving to be a feasible way of supporting behavior change in people with moderate to severe TBI (Hart et al., 2019).

Conclusions

Self-management models are effective for improving health and quality of life for many people with chronic medical conditions. In light of what we are discovering about the dynamic nature of chronic TBI, it seems worthwhile to try to adapt SMT principles and treatment components to the needs of this population. Doing so will require collaboration with the people most affected by TBI, careful consideration of the most effective treatment components, and inclusion of treatment ingredients to foster long-term change.

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What's working? Maintaining Employment After Brain Injury

Devan Parrott, PhD • Summer Ibarra, PhD • Terri K. Pogoda, PhD • Wendy Waldman, BS

Research has consistently demonstrated that employment rates following a moderate to severe brain injury are less than favorable with published rates ranging anywhere from 10-70% depending on the study (Yasuda, Wehman, Cifu, & West, 2001). In a recent large-scale study utilizing data obtained through the TBI Model Systems National Database, investigators found that 39.6% of individuals with TBI return to any work, with only 65% of those returning to full-time employment (Cuthbert et al., 2015). There is also evidence to suggest maintenance of stable employment is an issue for some persons with TBI. In fact, Cuthbert and colleagues observed that while some individuals may be successful in initially returning to employment post-injury, there appears to be a significant decline in rates five years post-injury (Cuthbert et al., 2015). Though specific reasons for this decline were not able to be identified in this particular study, it was postulated that the chronic effects of TBI, combined with aging, may have led to a decline.

Unfortunately, there are no identified standards or universal recommendations for ensuring individuals with TBI are able to return to work and maintain employment long-term. However, with the increased attention nationally of TBI in both the civilian and veteran populations, several programs have been established that are geared toward assisting individuals in the acute and chronic phases post-TBI in obtaining and maintaining competitive employment. On the civilian side, the Resource Facilitation program at Rehabilitation Hospital of Indiana (RHI) has demonstrated success in this area, while the Department of Veterans Affairs (VA) Polytrauma System of Care (PSC) addresses these needs in the veteran population.

Resource Facilitation (RF) is an evidence-based individualized intervention targeted at improving employment rates post-brain injury by connecting patients and care partners with community-based resources and services. This is met by approaching each patient at an individualized patient-centered level as well as a community level. The RF program begins with a comprehensive neuro-vocational assessment which includes an intake with the resource facilitator, consultation with a neuropsychologist, neuropsychological and vocational testing, and team conference. This culminates in a brain injury specialized team reviewing and producing goals, unmet needs, barriers, and a comprehensive treatment plan. The resource facilitator continues to work with the individual with brain injury by advocating for the individual within the community and navigating available resources.

This holistic approach for managing chronic brain injury has shown to be successful in two clinical trials as well as one effectiveness trial with all samples demonstrating higher than average employment rates for RF participants. In fact, in 2010, RHI published the first randomized controlled trial testing RF in 2010 with results demonstrating a successful return to work rate of 64% compared to 36% in the control group (Trexler, Trexler, Malec, Klyce, & Parrott, 2010). Similarly, a larger replication study found 69% of the treatment group returned to previous employment compared to 50% in the control group (Trexler, Parrott, & Malec, 2015). Published program evaluation outcome data show similar results demonstrating the effectiveness and generalizability of the RF intervention in the civilian population (Trexler & Parrott, 2018).

In the veteran population, the Department of Veterans Affairs (VA) Polytrauma System of Care (PSC) addresses the various needs of Post-9/11 Veterans with TBI history.



Polytrauma refers to multiple injuries to the body that result in physical, cognitive, emotional, or psychosocial impairment (Department of Veterans Affairs VHA Handbook, 2013). This often includes TBI, which typically co-occurs with posttraumatic stress disorder (PTSD), pain (Cifu et al., 2013), and other health conditions (Department of Veterans Affairs VHA Handbook, 2013).

Some VA polytrauma/TBI teams include a supported employment (SE) specialist (Pogoda, Levy, Helmick, & Pugh, 2017). SE is an effective vocational rehabilitation program that helps those in need find and maintain competitive employment in the community, rather than placing them in assignments that are set aside for individuals with disabilities (Bond & Drake, 2014). SE specialists work with individuals with disabilities to understand their job interests and skills, and also visit employers in the community to understand their business needs. Equipped with this knowledge, SE specialists match these consumers with employers. Jobs are not necessarily performed during a standard 8-hour workday. For example, if an individual has difficulty waking up early in the morning, the SE specialist may advocate for their work hours to be shifted to a later time or reduced to part-time. If an individual has particular skills that will meet at least some of the employer's needs, the SE specialist may negotiate with the employer for a modified role. The SE specialist provides as much support as needed with no time limit. This may include going on-site to ensure that that individual understands how to do the job, providing suggestions on improving performance (e.g., create a checklist or electronic reminders), and making other modifications such as having them face the door if s/he startles easily, adjusting the lighting if there are vision difficulties, and working in a quiet area to reduce distraction.

Similar to RF, SE specialists attend polytrauma/TBI team meetings weekly, and communicate with individual clinicians as needed, to discuss those for whom they are providing treatment. Polytrauma/TBI teams can include, but are not limited to, rehabilitation doctors, social workers, neuropsychologists, counseling psychologists, physical therapists, occupational therapists, and speech-language pathologists. Individuals with brain injury may have problems in the workplace that SE specialists cannot adequately address. The polytrauma/TBI team works with that person on an individual basis to treat these problems, and strategize with the SE specialists on what changes can be implemented in the workplace to increase success.

Regardless of population, those who experience TBI have a unique constellation of symptoms and co-occurring health conditions that require an individualized patient-centered approach to care. As a result, it's difficult to impose a standard one-size-fits-all treatment, as demonstrated by both programs described in this article developing individualized treatments to improve employment outcomes after brain injury.

Obtaining and maintaining employment after brain injury is one of the many obstacles patients face as they return to the community. Programs such as Resource Facilitation at the Rehabilitation Hospital of Indiana and the Supported Employment program at the Department of Veterans Affairs provide a foundation of assistance to support and boost competitive employment in the community while maintaining a patient-centered, individualized approach. Success of these programs supports the value of patient-centered care in management of TBI as well as the impact of multidisciplinary approaches.

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Is moderate drinking safe after traumatic brain injury?

Rachel Sayko Adams, PhD, MPH
John D. Corrigan, PhD

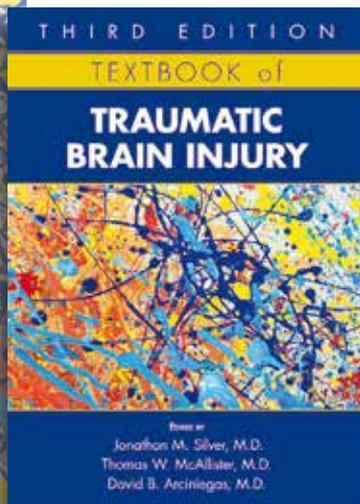
Most individuals who experience a traumatic brain injury (TBI) reduce their drinking in the immediate weeks or months after injury, yet many resume drinking over time, eventually returning to pre-TBI levels or greater. While excessive alcohol use; such as binge drinking, is clearly not recommended regardless of one's history of brain injury, little is known about the safety or risks of drinking at moderate levels after TBI. The National Institute on Alcohol Abuse and Alcoholism (NIAAA) defines "low-risk" drinking as no more than 4 drinks on any given day for men, 3 drinks per day for women, and no more than 14 drinks per week for men and no more than 7 drinks per week for women. Studies have found that individuals with a history of TBI who misuse alcohol following injury suffer from more negative consequences, such as lower subjective well-being, unemployment, seizures, suicide risk, and premature mortality. Yet, again, scientific studies have not examined if these risks remain for individuals with a history of TBI who drink at levels generally considered "low-risk" for healthy individuals according to NIAAA. We also do not know how alcohol use of any amount interacts with other aspects of chronic brain injury. Until longitudinal studies are done to systematically address this critical research gap, rehabilitation clinicians faced with questions about the safety or harms of moderate drinking after TBI will be limited to the following response - "We don't know, though we are sure that not drinking will not harm you."

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*Edited by Jonathan M. Silver, M.D.,
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Sexuality: A Neglected Discussion in Chronic Traumatic Brain Injury

Kathryn Farris, OTR/L • Marisa King, PT, DPT • Monique R. Pappadis, MEd, PhD • Angelle M. Sander, PhD

Sexual dysfunction is a problem for 25% to 50% of persons with traumatic brain injury (TBI) at one or more years post-injury (Downing, Stolwyk, and Ponsford, 2013; Sander et al., 2012). Dysfunction can occur at the stages of desire (Downing et al., 2013; Sander et al., 2012; Strizzi et al., 2015), arousal (Sander et al., 2012; Strizzi et al., 2015), and orgasm (Downing et al., 2013; Sander et al., 2012; Strizzi et al., 2015). Sexual dysfunction after TBI can result from damage to parts of the brain involved in regulating sexual function, including the frontal lobe, temporal lobe, and subcortical structures (Sandel, Delmonico, and Kotch, 2007). TBI-related disruption of neurotransmitters and the neuroendocrine system also impact sexual function (Behan et al., 2008).

TBI-related changes in physical, cognitive, emotional, behavioral, and social functioning can impact sexuality. Physical changes include spasticity, hemiparesis, balance/vestibular dysfunction, and impaired sensation (Gervasio and Griffith, 1999). Cognitive deficits can also negatively impact sexual function (Aloni and Katz, 2003). For example, impaired attention and concentration can affect a person's ability to stay focused during a sexual encounter or become aroused. Impaired initiation and planning can affect relationship building and frequency of sexual activity. Reduced abstract thinking and cognitive flexibility can limit ability to fantasize, impacting sexual arousal. Memory impairments can result in an excessive demand for sexual activity that can be distressing to partners. Impaired social communication can result in decreased empathy, reduced ability to read and respond to non-verbal behavior in others, and problems perceiving emotions (Zupan et al., 2014).

Depression and anxiety, which occur frequently post-TBI (Osborn, Mathias, and Fairweather-Schmidt, 2014, 2016), can inhibit sexual desire and arousal. While hypersexuality is not as common as hyposexuality after TBI (Simpson, Sabaz, and Daher, 2013), disinhibition and impulsivity contribute to decreased self-monitoring of sexual behavior in some people (Bezeau, Bogod, and Mateer, 2004). TBI can negatively impact social relationships, leading to marital dissatisfaction and/or reduced relationship quality (Hammond et al., Davis et al., 2011; Kreutzer et al., 2007). Reduced social participation or social isolation is common following TBI and contributes to sexual dysfunction (Sander et al., 2013).

Medication side effects also contribute to sexual problems. Many drugs used to facilitate sleep and reduce cognitive and emotional changes after TBI can have negative side effects on sexual function (Aloni and Katz, 2003; Moreno et al., 2015). Examples include anticonvulsants, selective serotonin reuptake inhibitors, serotonin antagonist and reuptake inhibitors, dopamine agonists, acetylcholinesterase inhibitors, stimulants, and baclofen.

Barriers to Integrating Sexuality into Rehabilitation

Sexual health is a topic that should be addressed in holistic rehabilitation, but is often overlooked (Arango-Lasprilla et al., 2017; Moreno et al., 2015).



Many healthcare professionals believe that sexuality is not relevant during rehabilitation and that persons with TBI are not interested in sex (Dyer and das Nair, 2014). In reality, most survivors feel their sexuality is just as important after injury (Arango-Lasprilla et al., 2017; Kreuter et al., 1998), and are comfortable discussing their sexual/reproductive health and changes in sexual function (Moreno et al., 2015; Sander et al., 2012). However, only 6% to 36% of providers report discussing sexuality with their patients (Arango-Lasprilla et al., 2017; Ducharme & Gill, 1990). The most commonly reported barriers to rehabilitation professionals addressing sexuality include discomfort and lack of knowledge, resources, and personal support (Arango-Lasprilla et al., 2017). Diffusion of responsibility occurs when team members perceive discussing sexuality as the domain of a specialist (Dyer and das Nair, 2014) and professionals frequently take a reactive approach (Ducharme and Gill, 1990). An inability to recognize and put aside personal biases or beliefs can lead to moralizing, lack of objectivity, reduced empathy, and anger or denial (Ducharme and Gill, 1990). Providers have expressed fear that the patient might misperceive discussion of sexuality as a sexual advance (Ducharme and Gill, 1990). In reality, hypersexuality is rare after TBI, and can be reduced if the person is assisted in finding socially acceptable outlets.

Organizational or environmental structures are another barrier to addressing sexuality in rehabilitation. The organizational culture often lacks policies or procedures that support sexual rehabilitation after TBI (Dyer and das Nair, 2014), leading to stigmatizing or delegitimization of discussing sexuality (Richards et al., 2016). The resulting lack of dedicated time and resources can limit the providers' ability to address sexuality (Dyer and das Nair, 2014).

Lack of cultural competence can be a further barrier to addressing sexuality. Cultural factors, such as gender, religion, and race/ethnicity, can impact sexuality, ranging from the meaning of sex to variations in the presentation of sexual dysfunction (Heinemann, Atallah, and Rosenbaum, 2016). For example, vaginal dryness is often perceived as sexual dysfunction; however, in some cultures products are used to facilitate dryness to increase the partners' pleasure (Hilber et al., 2010; Levin, 2005). In other cultures, the amount of seminal fluid represents vitality (Sabhesan and Natarajan, 1989). Restrictive religious beliefs about sexual behaviors may cause negative emotional responses, like guilt or anxiety (Spadt et al., 2014). A lack of cross-cultural consideration (Moreno et al., 2013) and clinician awareness impacts the effectiveness of addressing sexuality in rehabilitation.

Need for Education

Most professionals do not receive clinical training in addressing sexuality issues. Sexuality training programs emphasize building staff knowledge and skills to improve comfort and staff engagement in sexual wellness activities (Gill and Hough, 2007; Simpson et al., 2006). They can include education in: terminology; sexual rights and responsibilities; sexual preferences, values, beliefs and culture; the impact of brain injury on sexual function; positioning, devices and medications to aide in sexual function; safe sex practices; and relationships and communication with partners. In addition, professionals should generally understand how to navigate challenges with cognitive capacity and decision making for sexual activity and issues regarding minors.

The PLISSIT model (Permission, Limited Information, Specific Suggestions, and Intensive Therapy) helps healthcare professionals better identify their role and gain comfort by incorporating sexuality into routine assessments and treatments.

Sexuality: A Neglected Discussion in Chronic Traumatic Brain Injury

Kathryn Farris, OTR/L • Marisa King, PT, DPT
Monique Pappadis, MEd, PhD • Angelle Sander, PhD

Create an underlying philosophy

Define what sexual concerns mean in your own organization. The philosophy should address the needs of all groups (race, ethnicity, gender, sexual orientation, socioeconomic status, age, physical ability, religious beliefs, political beliefs, or other ideologies), and include themes of choices, values, sexual rights, decision making and responsibility.

Build knowledge, skills and comfort among providers

Provide sexuality education in interdisciplinary group settings and include consumer input, didactic input, role play, group brain storming, and discussion regarding concerns and clinical applications. Shift your culture through ongoing opportunities to reflect on practices and allow for ongoing opportunities for education.

Support organizational structures

Develop sexuality guidelines that provide for basic sexual rights while reducing the danger of abuse and exploitation. Gain an understanding of sexuality-related legislation (e.g., human rights laws, public health legislation, disability services). Provide staff training to increase level of comfort and confidence in responding to sexual health concerns and create a network of providers to support referrals between rehabilitation and sexual health specialists.

Develop service provision guidelines

This entails the provision of informational resources and education that highlights the topic of sexuality for people with TBI, including the use of assessment measures to identify concerns and feelings, the impact of brain injury on sexuality and intimacy, and interventions addressing concerns and challenges among others.

Implement the framework

Identify champions to lead your sexuality initiative. Determine how to evaluate the introduction or enhancement of your program while keeping to a core set of objectives, performance indicators, timelines, and a review process for quality improvement and long-term monitoring of the services.

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The model allows individuals Permission to be sexual, to desire sexual activity and to discuss sexuality. They receive Limited Information about sexual matters and are given Specific Suggestions about ways to address sexual problems. Incorporating the PLISSIT model into professional training, supports self-reflection, challenging assumptions to develop knowledge and self-awareness (Taylor and Davis, 2007). By providing an avenue to routinely discuss these considerations, professionals become better equipped to meet most needs without specialized treatment or experience.

Using a multi-modal approach in interdisciplinary group settings is most successful when working with a range of disability and health areas (Arango-Lasprilla et al., 2017; Simpson et al., 2006). Interdisciplinary group settings normalize sexuality, allowing for sharing of experiences and problem solving outside of individual disciplines, creating an environment that fosters respect. Education should include consumer input, didactic information, observation and role play opportunities, brainstorming, and discussion regarding concerns and clinical application. Ongoing reflection regarding personal values and their influence on clinical practice, as well as the organizational culture, philosophy of care, programming, policies, attitudes and needs, should be incorporated into the training (Simpson et al., 2006). Self-directed learning platforms can be used to maintain the culture through regular conversations, classes and organizational updates.

Each survivor and partner will have different readiness for sexuality education at different points in the recovery process. Furthermore, sexual functioning is dynamic and can change over time, with decline following periods of healthy function. Providing education in the rehabilitation setting may result in increased readiness to seek help should problems arise later. Promoting an environment of openness is the responsibility of all disciplines, empowering persons with TBI to discuss their concern(s) when they choose. By improving the knowledge and comfort of rehabilitation professionals, we can close the gap and align ourselves as a community to address sexuality needs for people with brain injuries.

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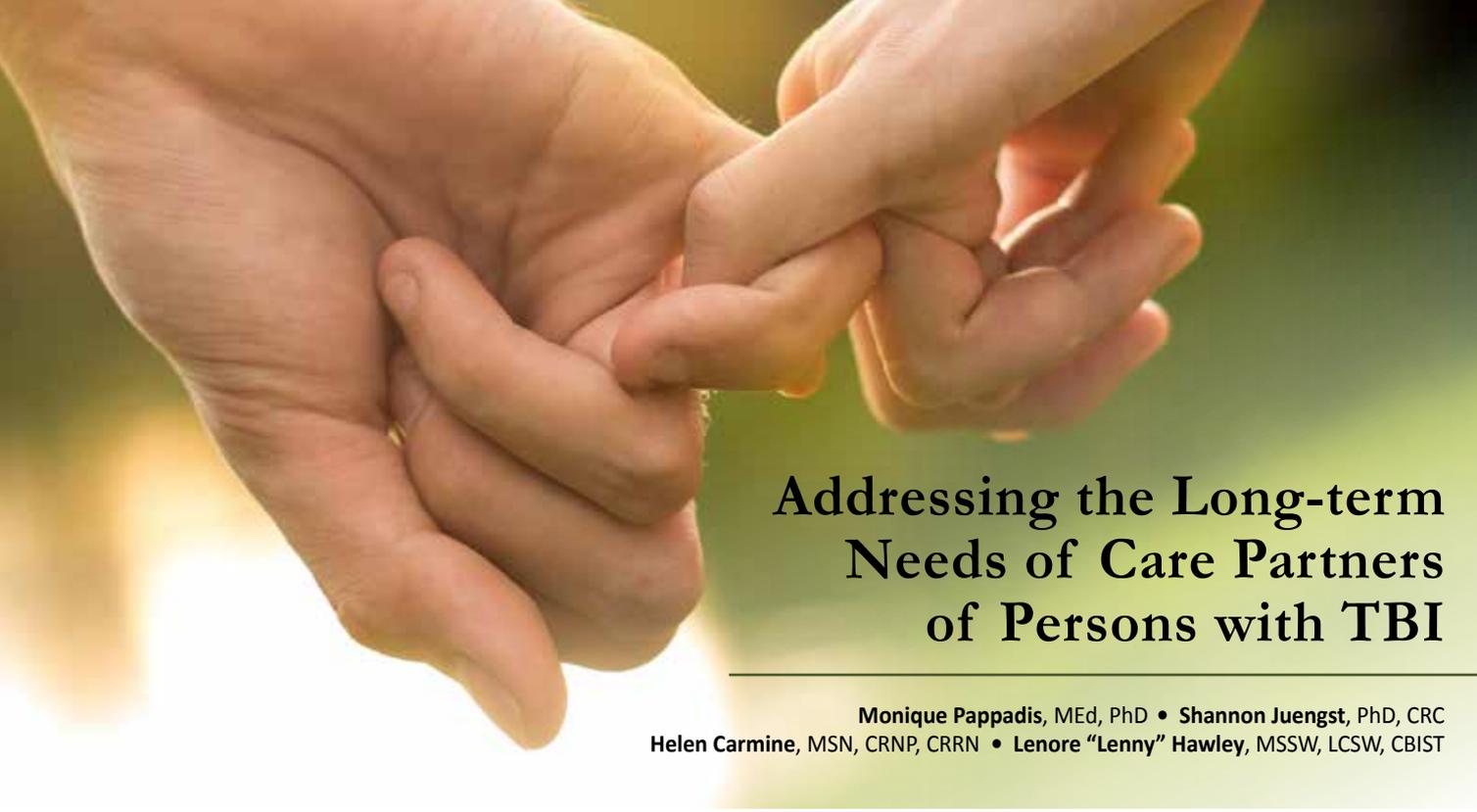
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Addressing the Long-term Needs of Care Partners of Persons with TBI

Monique Pappadis, MEd, PhD • Shannon Juengst, PhD, CRC
Helen Carmine, MSN, CRNP, CRRN • Lenore “Lenny” Hawley, MSSW, LCSW, CBIST

Individuals who sustain moderate-to-severe traumatic brain injury (TBI) may experience changes in their thinking, behavior, and emotions (Bhalerao et al., 2013). These changes can be lifelong and often require support from family members or friends – care partners – of the individuals with TBI. Most care partners who support individuals with TBI have no formal training or background in providing care or support (Powell, Wise, et al., 2016). Without training and faced with having to manage challenging behaviors, mental health issues, and other issues their loved one is experiencing, care partners often experience their own emotional distress and feel burdened by being a care partner (Carlozzi et al., 2019; Jeffrey S. Kreutzer et al., 2009; Powell, Wise, et al., 2016; Rotondi, Sinkule, Balzer, Harris, & Moldovan, 2007; Tam, McKay, Sloan, & Ponsford, 2015). About 40% of care partners reported moderate to high burden 1 year post-injury (Manskow et al., 2015), and 44% of care partners reported high burden at 4 years post-severe TBI (Bayen et al., 2016). One in five care partners of adults with TBI report depression, anxiety, and physical symptoms (Jeffrey S. Kreutzer et al., 2009), and 60-80% report some degree of emotional distress (Carlozzi et al., 2019; J S Kreutzer, Gervasio, & Camplair, 1994; Ponsford, Olver, Ponsford, & Nelms, 2003).

Care partners also report more medication use and substance use, suggesting they are using maladaptive coping skills to cope with burden (Hall et al., 1994). However, not all care partners feel burdened or distressed or turn to maladaptive coping strategies. These negative feelings and poor coping mechanisms happen most often when care partners’ needs are not being met (Gan, Gargaro, Brandys, Gerber, & Boschen, 2010; Manskow et al., 2015). Unfortunately, more than half of care partners surveyed felt that even though they received sufficient medical information, their educational and emotional needs were not being met, especially across transitions of care and over time, as their needs changed (Jeffrey S. Kreutzer et al., 2009; Powell, Wise, et al., 2016; Tam et al., 2015). Care partner needs early after TBI differ from their needs after discharge. During the inpatient hospital stay, care partners want clear information about the condition itself, realistic expectations and prognosis over time, resources (e.g. services, financial planning, etc.), and emotional support (Jeffrey S. Kreutzer

et al., 2009; Manskow et al., 2015; Powell, Wise, et al., 2016). After discharge, care partners want information on planning for lifetime management of changes, community integration and social belonging, and availability of resources (Carlozzi et al., 2019; Jeffrey S. Kreutzer et al., 2009; Tam et al., 2015). Over time, care partners report increasing difficulty meeting their ongoing needs, particularly as problems occur in the absence of any professional support (Bayen et al., 2016; Gan et al., 2010).

Interventions designed to meet the needs of care partners of individuals with TBI need to be sensitive to changes in needs over time, particularly as individuals transition out of formal care settings to community living, and should continue to be available over time to minimize feelings of burden and distress (Holland & Shigaki, 1998). Furthermore, as individuals with TBI age, they may experience mounting comorbid conditions and cognitive and functional decline that can increase the level of support they need, which can increase care partner burden. Care partners themselves experience functional and health-related changes as they age, affecting their ability to provide support to their loved one with TBI. Sometimes this requires shifting care roles to other relatives who may have only been distantly involved in the individual with TBI’s life and care.

Education is at the center of the most effective interventions for care partners (Gan et al., 2010; Grant et al., 2006; Rotondi et al., 2007). Education should include information on the effects of TBI, community resources, financial assistance, and realistic expectations for the future (Holland & Shigaki, 1998). Efforts to address the educational needs of persons with TBI and their care partners have varied based on the initial injury severity (Hart et al., 2018). Provision of education in the outpatient and community settings occur following an acquired TBI. The majority of studies focus on the educational needs in the acute phase of recovery with less attention given to evaluating the long-term effects of education for persons with TBI and families living in the community (Hart et al., 2018).

Of the few studies addressing the educational needs at least three years following an injury, educating family members increased

functional independence for the care recipient, effectiveness in managing behavioral challenges, and effectiveness in their caregiving role (Marshall et al., 2019). The content of the education should be current, evidence-based, relevant to familial needs, culturally-appropriate, and provided at the sixth- to eighth-grade reading level to ensure families can use and understand the TBI-related information.

Most programs include education as part of a larger component of an intervention aimed to effectively manage stress, enhance problem-solving and skills training, and improve family coping skills (Jeffrey S. Kreutzer, Stejskal, Godwin, Powell, & Arango-Lasprilla, 2010; Straits-Troster et al., 2013). When studied as a primary intervention, education or TBI-related information has been helpful in enhancing care partners' understanding of TBI and related symptoms, how to cope or adjust to the effects of injury, reducing burden and depression, and improving care partner self-esteem. Several modes of education delivery are helpful for training or providing information on how to effectively manage cognitive, behavioral and emotional problems following TBI. For example, web-based videoconferencing is a feasible option for the delivery of information and support to manage long-term emotional and behavioral problems for families in home or rural settings (Hernandez, Scholten, & Moore, 2015; Sander, Clark, Atchison, & Rueda, 2009). When addressing the long-term needs of care partners in the community setting, education is more effective when coupled with training families on how to manage the neurobehavioral consequences of injury (Fisher, Lennon, Bellon, & Lawn, 2015). Training care partners in adaptive coping skills may also improve their lives and well-being. Adaptive coping skills are necessary to work through the adjustment that comes after TBI. Therefore, teaching adaptive coping skills – such as effective problem-solving – to care partners could reduce their burden, depression, anxiety, and substance use (Elliott, Shewchuk, & Scott, 2001; Powell, Fraser, Brockway, Temkin, & Bell, 2016; Rivera, Elliott, Berry, & Grant, 2008). Self-management interventions may be especially effective for teaching adaptive coping skills to care partners of individuals with chronic conditions, including TBI (Baker, Barker, Sampson, & Martin, 2016; Powell, Fraser, et al., 2016; Rivera, Elliott, Berry, & Grant, 2008). Successful living after TBI may be a product of early and lifetime education for individuals with TBI, their care partners, and both healthcare and community support systems.

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Lenore “Lenny” Hawley, MSSW, LCSW, CBIST is the Brain Injury Education & Resource Counselor at Craig Hospital, where she also serves as a Research Clinician.

expert interview

Sustaining Love and Purpose after Brain Injury: an Interview with Rich and Cheryl Owens

Interviewed by **Lenore A. Hawley**, MSSW, LCSW, CBIST



In 2001, Rich Owens was living a full life as a businessman, husband and father. As he climbed into his car one evening after work, he was attacked by a carjacker and thrown from his car, sustaining a severe TBI. He slowly began to relearn to walk, communicate and complete daily tasks. The past 18 years have taken Rich and his family on a different path than originally planned. Unable to return to work, he became a stay-at-home dad, volunteered at school and neighborhood activities, and has maintained a happy marriage and social support system. He serves as a Consumer Advisor for the TBI Model System grant at Craig Hospital.

How has the injury impacted your life?

Rich - "Initially I had problems processing information, making decisions and getting overwhelmed. I also had a short fuse. I still have problems with multi-tasking and memory. I keep lots of lists! But overall things have gotten better. Sometimes I still have "bad brain days". But I realize everyone has bad days, and it might not always be because of the injury. I also find I have to be "in the moment" all of the time. I have to be focused and thinking about what I'm doing. Sometimes that takes away from my ability to focus on others.

One of the biggest changes is not being the family breadwinner. I tried to go back to work but multi-tasking was too hard. Cheryl became the breadwinner and my role became taking care of our boys. I've had the opportunity to have a great influence on my boys' lives; that's been a blessing."

Cheryl - "Rich has done an amazing job of being involved with our boys and supporting me in my work. I'm careful to never minimize his role. He does things around the house like fix the dryer, which I could never do. Our life turned out differently than we envisioned back when we got married.

I thought I would be the one more involved with raising the kids. I have some sadness and guilt about missing things with my kids. It still hurts. I remember both boys saying at different times that they knew our family was a little backwards from that of their friends. Their mom went to work and their dad was the one that went on field trips, baked cookies and worked the concessions stand. I don't think they saw it as a bad thing, just different. Sometimes people don't understand that Rich is still living with an injury - that can be frustrating. People think he looks fine and he should be able to do everything just fine."

Rich - "People need to find meaning in their lives, keep friendships and social connections, and find ways to contribute - to give back and help others."

What part of rehabilitation has had the greatest positive impact over the years since the injury?

Rich - "Of course, learning how to walk and talk again started my recovery journey. But helping me identify my limitations so I could focus on my strengths - that was big! I also think occupational therapy helped me in every way. They helped me with things that really made a difference, functionally, in my life. They helped me put the pieces together."

What is the "secret ingredient" for success in sustaining your marriage and raising two children after your injury?

Rich - "We had to make a decision to change our roles, and then to embrace those new roles. I take care of the house and the kids and I make her life easier. And she lets me know that she values that. We appreciate each other."



About the Interviewer

Lenore "Lenny" Hawley, MSSW, LCSW, CBIST is the Brain Injury Education & Resource Counselor at Craig Hospital, where she also serves as a Research Clinician.

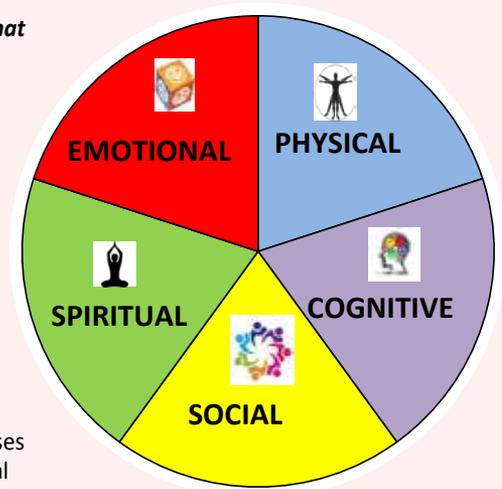
Living Well After Traumatic Brain Injury

Lenore Hawley, MSSW, LCSW, CBIST

Adhering to a healthy lifestyle can be challenging for all of us. However, individuals living with chronic brain injury face unique challenges to living well. Initiating healthy lifestyle changes requires self-awareness, initiation, goal-setting, planning, problem-solving, energy, and effort. In addition, reliable transportation and social support are invaluable resources in attaining healthy living goals. The sequelae of chronic brain injury therefore present significant obstacles to living well. Although recommendations for living a healthy lifestyle are readily available online through organizations such as the CDC and the American Heart Association, they do not address the unique challenges of those living with chronic BI. ACRM's Chronic Brain Injury Task Force developed an Information and Education Page (IEP) addressing recommendations especially designed for this population.

This IEP focuses on:

1. **Goal setting and self-awareness:** Getting started on wellness goals can be difficult for anyone, but can be an even bigger obstacle after BI. Setting short term goals can raise self-awareness and initiation.
2. **A concrete holistic view of wellness:** Using the concrete framework of The Wellness Wheel emphasizes a holistic view of wellness, including social, emotional, intellectual and spiritual wellness, as well as the physical aspects of living well. This framework aims to help individuals with TBI realize that living well is more than diet and exercise, and asks them to address some of the areas of wellness that may be especially difficult after TBI, such as social and spiritual aspects of life.
3. **Specific concrete activities that emphasize the 5 areas of wellness:** Providing concrete examples of activities that can be added to keep one's wellness wheel in balance, provides a visual map to help ensure that one area of the wheel is not neglected. In particular, there is an emphasis on activities that address more than one area at a time. For example, walking with a friend addresses physical, emotional and social wellness; doing volunteer work can address all 5 areas of the wellness wheel.



(based on the Wellness Wheel, originally developed by Dr. Bill Hettler)

The Living Well IEP can be copied to share with individuals with TBI and families (Archives of Physical Medicine and Rehabilitation, 2018;99:1441-2 Lenore Hawley, MSSW, LCSW, CBIST; Tessa Hart, PhD; Wendy Waldman, BSW,CBIST; Mel Glenn, MD; Flora Hammond, MD; and Kristen Dams-O'Connor, PhD)

Cheryl – “I’ve never had the attitude that he’s “broken.” I don’t think the word victim should be used in conjunction with an injury like this. He was the victim of a carjacking, but not a “brain injury victim”. We live from a place of gratitude. We’re thankful each day that our family is whole, our children are healthy, and that we have wonderful family, friends and neighbors. We tell each other “I love you” every day; we know how quickly life can take a turn. The “secret sauce” is probably that we take turns being each other’s rock, supporting each other. I’m not taking care of him - we take care of each other. We laugh a lot and tease each other. Our marriage is far from perfect, but we make a great team.”

What are the one or two important things that keep you going each day?

Rich – “Number one is attitude, the determination to do my part, to be productive. Second, is being involved, having a purpose and helping others. I was the Team Dad and the Scout Cubmaster; I helped with school plays and concerts. When they needed a parent to go to Boy Scout camp for a week, I was the one who could say yes! I help my neighbors shovel snow or fix a broken garage door.

And I help with the research studies at Craig. I also have interests like racquetball and cycling. I have friends I do those things with and my friends have stuck with me. And I’m active. When I exercise I get an endorphin rush that helps me be positive and avoid getting depressed.”

Cheryl - "We tell each other 'I love you' every day."

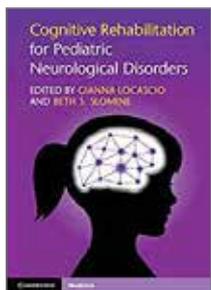
What message would you like to share with brain injury professionals about living life with a brain injury over the long-term?

Rich – “Life keeps going after the injury, long after rehabilitation is over. Here I am 18 years later, living my life with a brain injury. People need to find meaning in their lives, keep friendships and social connections, and find ways to contribute – to give back and help others.”

Author Bio

Lenore “Lenny” Hawley, MSSW, LCSW, CBIST, is the Brain Injury Education & Resource Counselor at Craig Hospital, where she also serves as a Research Clinician.

literature review



Cognitive Rehabilitation for Pediatric Neurological Disorders

By **Gianna Loscascio and Beth S. Slomine, PhD**
Cambridge University Press

This book provides a comprehensive resource for the topic of cognitive rehabilitation for children with neurological disorders. The authors define the term cognitive rehabilitation broadly, describing it as "an intervention designed to compensate or ameliorate the impact of cognitive and behavioral effects following neurologic injury or illness". Disciplines who traditionally deliver cognitive rehabilitation interventions include speech-language pathologists, occupational therapists, psychologists and neuropsychologists. Since children spend the majority of their time in school, teachers and therapists can also apply cognitive interventions to help children learn and thrive in an academic setting.

One strength of the book is the first section that provides evidence-based interventions written by specialists covering several core domains of cognition: Attention, memory, sensory perception, hemispatial neglect language/communication and executive functioning. Chapters 1-4 and Chapter 6 offer a specific focus on a cognitive domain that includes a definition of the intervention, available evidence and formation of practice recommendations for clinicians. The chapters also provide a description of developmental considerations, strategy training, and interventions utilizing technology. Each chapter also offers at least one case study of a child who participated in the domain intervention and describes outcomes. The chapters all end with a conclusion and recommendations for future directions for each domain discussed.

Children live in the context of a family environment and this aspect is recognized in Chapter 5 that focuses on family-based interventions. This chapter details the relationship between family functioning and children's cognitive/behavioral outcomes and provides implications for family interventions. Evidence-based interventions described in this chapter include family problem solving therapy and parent skills training. The chapter also provides insights into technology interventions by describing telehealth intervention approaches that can serve families who live a distance from rehabilitation settings. A strong section of this chapter provides guidance on developmental considerations and the timing of the intervention. Case studies are included at the end for both family problem solving and parent skills training that provide information about changes as a result of the training.

Pharmacologic intervention is an area that is not typically covered in cognitive rehabilitation books and articles, especially for children. The authors describe a paucity of literature for prescribing medication for children as an intervention for cognition and behavior but do reference the evidence on how this type of intervention can impact outcomes in these domains.

What is particularly helpful is the table the authors provide (Table 7.1) that illustrates key areas- medication names, mechanism of action, therapeutic targets and common adverse effects. A case study is presented but the authors make a point in their conclusion that because of the range of effects of acquired brain injuries and the age of the child, much more research is needed to provide evidence of the safety and efficacy of this type of intervention for children.

School is where children return to after an acquired brain injury but this location of service focuses on learning and the effects of health on learning rather than medical diagnosis and symptoms. Therefore, cognitive rehabilitation as a medical service area is most likely not to happen in schools; however, focusing on areas of cognition and instructional strategies in classrooms are areas that offer cognitive interventions that can be addressed at school. The authors are experts in education and offer valuable tables of learning characteristics and instructional strategies than can be included in a child's educational program (Table 8.1). They provide information on educational laws that can ensure students receive these services (Table 8.2). Case studies illustrate the ideas presented in the chapter. The conclusion section offers insights on how educational interventions targeting strategies and creating an environment to enhance learning is good methodology for serving the needs of children with acquired neurologic disorders to help them learn and progress at school.

Transition to adulthood is an a critical time for children with acquired brain injury and one that is not typically covered in a cognitive rehabilitation text book. The authors identify areas important to adulthood to address for children that include self-management and health management. Because cognition is a critical area related to acquired brain injury, Table 9.2 in the chapter covers the skills needed for independence in adulthood, necessary cognitive and behavior skills and questions designed to estimate if an adolescent meets those areas. The chapter offers a section on decision-making capacity and also includes techniques for skill training in executive functions, behavioral regulation and social competence to support decision making for adolescents in transition.

The last two chapters provide insight into how to support cognitive services in both healthcare and school settings. Chapter 10 discusses billing practices in the healthcare system and describes strategies for how to cover service reimbursement. Billing codes for psychotherapy, cognitive rehabilitation and behavior are discussed along with a comprehensive table (TABLE 10.1) that offers the codes, definition of services and the amount of time per session covered. Guidance for understanding both internal and external billing systems, authorization for services, documentation and peer review if described. What is particularly helpful are letter samples for justification of medical necessity and progress notes for documentation. Chapter 11 offers insights on how to ensure children receive needed cognitive services in both models of care -Healthcare and school settings. A significant gap for serving children that has been mentioned in previous reports and research is the connection between healthcare and school services and coordination of cognitive rehabilitation services after an acquired brain injury. The author proposes several recommendations to improve service access that includes education of professionals, building collaborations between agencies and case management of children.

In this comprehensive pediatric cognitive rehabilitation textbook for neurological disorders, Drs. Locascio and Slomine provide not only evidence supporting the importance of providing cognitive intervention to improve children's outcomes, but also offer suggestions for this intervention in models of service delivery that children and their families experience (healthcare and school settings) and the family environment. They engaged specialists from diverse disciplines to write about the topics presented. Every chapter offers evidence, intervention ideas, a case study in implementation and conclusions.

Each area of cognition and behavior impacted by acquired neurological disorders in children is addressed and further insights are offered on how to fund and advocate for services in healthcare settings as well as implement these ideas in school-based settings. The editors include chapters on important topics for children- family interventions and transition to adulthood that provide all inclusive information for across the childhood lifespan.

The book makes a unique and substantial contribution to the field by providing evidence and examples of interventions as well as health and school policies, laws, and reimbursement practices to support treatment of cognitive and behavioral effects of acquired neurological conditions. Further the authors writing about executive function intervention reference the work of Mark Ylvisaker, a pioneer in the field of cognitive rehabilitation.

Mark advanced the field by describing a culture of rehabilitation for children what encompassed context sensitivity, direct and intensive instruction, making intervention personally meaningful, emphasizing strategic thinking and including intervention over the long term to shape academic habits for children through out their school career. These principals of intervention encompass all aspects of cognitive rehabilitation for children living with acquired neurological disorders in both healthcare and school settings. All disciplines that provide interventions for children can benefit from this all-inclusive resource.



About the Reviewer

Juliet Haarbauer-Krupa, PhD is Adjunct Faculty in the Department of Pediatrics, Emory University School of Medicine. She is a co-author with Mark Ylvisaker on the first book about cognitive rehabilitation in children, titled, *Brain Injury Rehabilitation: Children and Adolescents* (1985). She has been in the field for 30 years both as a clinician and a researcher and has over 100

publications and presentations on traumatic brain injury in children and adults.

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2019

November

13 - 16: *39th Annual Conference of National Academy of Neuropsychology*, November 13 - 16, San Diego, California. For more information, please visit www.nanonline.org.

2020

February

26- 29: *ABI 2020: Best Practices in Brain Injury Medicine and Neurorehabilitation: Improving Outcomes Through Interdisciplinary Collaboration*, February 26 - 29, 2020, New Orleans, Louisiana. For more information on the official NABIS Conference, visit abi2020.org.

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PHOTO BY HERMAN PRIVETTE

SCARLETT LAW GROUP

Scarlett Law Group is a premier California personal injury law firm that in two decades has become one of the state's go-to practices for large-scale personal injury and wrongful death cases, particularly those involving traumatic brain injuries.

With his experienced team of attorneys and support staff, founder Randall Scarlett has built a highly selective plaintiffs' firm that is dedicated to improving the quality of life of its injured clients. "I live to assist people who have sustained traumatic brain injury or other catastrophic harms," Scarlett says. "There is simply no greater calling than being able to work in a field where you can help people obtain the treatment they so desperately need."

To that end, Scarlett and his firm strive to achieve maximum recovery for their clients, while also providing them with the best medical experts available. "As a firm, we ensure that our clients receive both

the litigation support they need and the cutting-edge medical treatments that can help them regain independence," Scarlett notes.

Scarlett's record-setting verdicts for clients with traumatic brain injuries include \$10.6 million for a 31-year-old man, \$49 million for a 23-year-old man, \$26 million for a 7-year-old, and \$22.8 million for a 52-year-old woman. In addition, his firm regularly obtains eight-figure verdicts for clients who have endured spinal cord injuries, automobile accidents, big rig trucking accidents, birth injuries, and wrongful death.

Most recently, Scarlett secured an \$18.6 million consolidated case jury verdict in February 2014 on behalf of the family of a woman who died as a result of the negligence of a trucking company and the dangerous condition of a roadway in Monterey, Calif. The jury awarded \$9.4 million to Scarlett's clients, which ranks as

one of the highest wrongful death verdicts rendered in recent years in the Monterey County Superior Court.

"Having successfully tried and resolved cases for decades, we're prepared and willing to take cases to trial when offers of settlement are inadequate, and I think that's ultimately what sets us apart from many other personal injury law firms," observes Scarlett, who is a Diplomat of the American Board of Professional Liability Attorneys.

In 2015, Mr. Scarlett obtained a \$13 million jury verdict for the family of a one year old baby who suffered permanent injuries when a North Carolina Hospital failed to diagnose and properly treat bacterial meningitis that left the child with severe neurological damage. Then, just a month later, Scarlett secured an \$11 million settlement for a 28-year-old Iraq War veteran who was struck by a vehicle in a crosswalk, rendering her brain damaged.

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