

Parenting After Traumatic Brain Injury:

A web-based support for caregivers

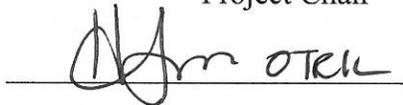
May 2015

This project, submitted by Arien N. McOmber, OTS and Kristin W. Moore, OTS, has been
approved and accepted

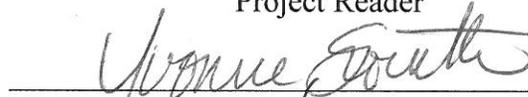
in partial fulfillment of the requirements for the degree of
Master of Occupational Therapy from the University of Puget Sound.

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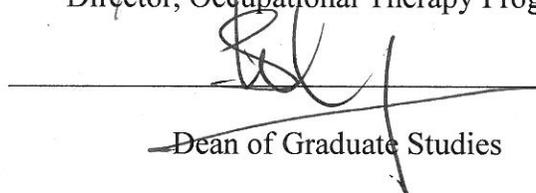
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Abstract

Aggression is common in traumatic brain injury (TBI) survivors (Rao et al., 2009) and can increase caregiver burden (Gan et al., 2006). For TBI survivors who are parents, aggression may also negatively impact parenting skills (Charles, et al., 2007). Resources that support survivors as parents are few (Kieffer-Kristensen, Teasdale, & Bilenberg, 2011), as are supports for their caregivers (Turner et al., 2010). We created a website to educate caregivers about TBI, stress-management techniques that help TBI survivors manage aggression, and family activities that facilitate positive interactions with children. When piloted to four people, feedback demonstrated that all goals were met and the website was reported to be helpful.

Keywords: TBI, parenting, aggression, brain injury, frustration tolerance, caregivers

Changes in emotional regulation, such as increased aggression, are common in survivors of traumatic brain injury (TBI) (Charles, Butera-Prinzi, & Perlesz, 2007; Rao et al., 2009). For TBI survivors who are parents, aggression may directly impact survivors' parenting skills, resulting in a changed relationship between survivors and their children (Charles, et al., 2007). At the same time, caregivers can feel overwhelmed by aggressive behavior in their loved ones and report increased feelings of anxiety and depression (Gan, Campbell, Gemeinhardt, & McFadden, 2006). While some resources address aggression post-TBI, few offer support specific to the effects of aggression on parenting (Kieffer-Kristensen, Teasdale, & Bilenberg, 2011). To serve this unmet need, a web-based support was created for caregivers of TBI survivors. This website is designed to empower caregivers with strategies to manage survivors' aggression and facilitate positive family interaction.

Literature Review/Background

Traumatic brain injury statistics

TBI is a type of acquired brain injury resulting from an extrinsic source, such as a fall or motor vehicle accident (Washington State Traumatic Brain Injury Council (WSTBIC), 2013). TBI can result in a variety of deficits, the most common of which are increased aggression (Charles et al., 2007; Rao et al., 2009), memory loss and difficulty sequencing (Charles et al., 2007), reduced cognition (Kieffer-Kristensen & Teasdale, 2011), motor and sensory deficits (Powell, 2014), and behavior issues (Powell, 2014). This project focused on the symptom of aggression due to the impact that it can have on survivors' relationships with their children.

In 2013, an estimated 5.3 million Americans were living with brain injury (WSTBIC, 2013). Men are 3.5 times more likely than women to sustain a TBI, with young men between the ages of 15 and 24 at greatest risk (WSTBIC, 2013). Close to 75% of people with TBI have a

mild brain injury (Centers for Disease Control and Prevention, 2003), which is determined through motor, cognitive, and visual assessments (Traumatic Brain Injury.com, 2004). Regardless of severity, TBI can have long-term consequences (Family Caregiver Alliance, 2003), including on the relationships TBI survivors have with family members (Kieffer-Kristensen et al., 2011). Self-reports from TBI support groups indicate that many adult TBI survivors are also parents of young children (personal communication with Velma [name assigned], June 15, 2014). Currently, no specific demographic information exists for TBI survivors who are parents; parenting after brain injury appears to be an often overlooked factor.

Aggression

Aggressive behavior is common in TBI survivors (Rao et al., 2009). Roughly 25% of adults with brain injury will develop aggression (Baguley et al., as cited in Ylvisaker, 2005, p. 770), which typically presents in the form of anger and verbal outbursts. Deficits in emotional regulation are also frequently reported (Rao et al., 2009; Yang, Hua, Lin, Tsai, & Huang, 2012; Dyer, Bell, McCann, & Rauch, 2006). Challenges in emotional regulation and emotional expression (e.g., aggression) can inhibit survivors' abilities to participate in work, family, and leisure roles (Gan et al., 2006).

Aggressive behaviors may present an additional barrier for TBI survivors who are parents. Gan et al. (2006) assert that negative behavioral and affective traits, such as aggression, in a survivor are obstacles to family adjustment and functioning post-injury. Dealing with aggressive behaviors is more burdensome to caregivers than only assisting adults with personal self-care tasks of toileting, feeding, and bathing (Gan et al., 2006). Verbal aggression and mood swings greatly impact caregivers, children, and overall family functioning (Yang et al., 2012).

Insight

TBI survivors are often unaware of their outbursts, reporting fewer explosive episodes than their families, and may consequently not understand the impact of their behavior on others (Yang et al., 2012), including their children. Rehabilitation outcomes can be negatively influenced when an individual exhibits decreased self-awareness of deficits. Research has shown that self-awareness is directly correlated with participation in everyday tasks, such as parenting (Schmidt, Lannin, Fleming, & Ownsworth, 2011). Fleming and Strong (as cited in Gillen, p. 68, 2009) report that deficits in insight can be most impaired during socio-emotional tasks that also require a high level of cognition. In parenting, these tasks may include conflict resolution, disciplining children, setting appropriate boundaries, soothing upset children or teens, and managing negative behaviors in children or teens. Survivors of TBI are more likely to struggle with tolerating frustration in arguments, expressing emotions appropriately, and having the insight required to recognize how their words and actions affect the adults and children around them (Fleming and Strong, as cited in Gillen, p. 68, 2009). This is significant because it demonstrates that many individuals may not be able to identify when they are aggressive towards their partners or children. Memory deficits that inhibit survivors' capacities to accurately recall events or aggressive incidents can be confounding factors as well (Powell, 2014).

Effects on caregivers

The average length of acute care hospitalization for individuals with mild to moderate TBI is 2.8-3.0 days (Russo & Steiner, 2007). Nine out of ten patients with TBI are discharged directly home (Harrison-Felix, Newton, Hall, & Kreutzer, as cited in Kreutzer et al., 2009, p. 535), forcing rehabilitation specialists to prioritize treatment goals toward specific physical and safety concerns (Kreutzer et al., 2009). In the meantime, families are left reeling from the

traumatic event of their loved one. Spouses often do not have time to adjust to their new caregiving role before discharge (Gan, Campbell, Gemeinhardt, & McFadden, 2006; Turner et al., 2010) and may not be able to correctly identify their full range of rehabilitative needs to professionals before being sent home (Kreutzer et al., 2009; Turner et al., 2010). At discharge, caregivers have reported that they feel overwhelmed and ill equipped to deal with their new role (Kreutzer et al., 2009; Gan et al., 2006).

Once home, families typically become the primary health care providers of survivors of TBI (Gan et al., 2006), due to limited access to long-term professional help (Degeneffe, Chan, Dunlap, Man, & Sung, 2011). The role of caregiver for an adult with TBI entails substantial responsibilities that may include learning to provide affective and emotional care (Degeneffe et al., 2011), as well as behavior management (Ylvisaker, Turkstra, & Coelho, 2005). Furthermore, the severity of symptoms expressed by survivors directly correlates with the level of stress, anxiety and depression experienced by their families (Verhaeghe, Defloor, & Grypdonck, 2005).

The experience of providing daily care can be exhausting (Degeneffe et al., 2011). In Kreutzer, Gervasio and Camplair's (1994) study of families affected by TBI, 47% of caregivers developed emotional difficulties that affected their own levels of functioning to a significant degree. Care providers demonstrate significantly higher rates of depressive symptoms (Turner et al., 2010), and cite increased feelings of anxiety and mental exhaustion (Kreutzer et al., 1994). Caregivers have reported feeling the same level of distress experienced immediately after their loved one sustains a brain injury for up to 15 years (Kreutzer et al., 1994), and potentially longer.

Effects on children

Caregivers are not the only family members affected by TBI. Children of survivors are more likely to experience elevated psychological and social challenges, such as anxiety,

difficulty maintaining friendships, and trouble handling arguments, than their peers (Janotha, 2011). Some children of survivors may even meet the diagnostic criteria for post-traumatic stress disorder (Uysal, Hibbard, Robillard, Pappadopulous, & Jaffe, 1998). Holmes, Rauch, and Cozza (2013) report that children often express feelings of aloneness and distress in response to the changes observed in their parents post-TBI. Unseen injuries can be difficult for children to understand (Kieffer-Kristensen, Siersma, & Teasdale, 2013) or explain to peers. Children of survivors further report experiencing a “parentification” or role-reversal in which they feel forced to parent their caregiver (Sherman & Barnett, 2012).

Children of TBI survivors may fear family disintegration and can react with defiance, opposition, withdrawal, and rejection of the injured parent (Charles et al., 2007). These behaviors can be a barrier to reestablishing a family relationship (Charles et al., 2007). Information regarding typical child responses to family crises may benefit families with TBI during the adjustment to new roles and family dynamics (Charles et al., 2007). Successful interventions include providing outlets for children to express feelings of fear and grief (Charles et al., 2007).

Effects on the family system

The challenges faced by these children can be an obstacle to reestablishing the family dynamic (Charles et al., 2007), especially when confounded with the sequelae of symptoms experienced by the parent following brain injury. Research shows that changes in emotional regulation can greatly impact parenting skills (Kieffer-Kristensen & Teasdale, 2011) and survivors’ relationship with their children (Charles et al., 2007; Kieffer-Kristensen & Teasdale, 2011). Cognitive deficits may further restrict survivors’ capacities to problem-solve, learn elaborate parenting strategies, or to independently implement challenging new parenting techniques (Ducharme, Davidson, & Rushford, 2002). Uysal et al. (1998) additionally found that

survivors are challenged with encouraging skill development, rule-following, work values, and goal setting in their children.

A primary consequence of these behaviors is a new family dynamic (Kieffer-Kristensen et al., 2011). Survivors report feeling a loss of their previously established relationship (Charles et al., 2007) as their families are confronted with the task of redefining each member's participation in roles (Gelech & Desjardins, 2011). Research has revealed that after a TBI, families may struggle to develop effective coping, problem-solving, and communication skills (Kreutzer et al., 2009). Chronic illness, including TBI, can be isolating (Ponsford, Oliver, Ponsford, & Nelms, 2003) due to specific symptoms that limit social participation, activity tolerance, and physical endurance (Charles et al., 2007). Families' opportunities to learn from other parents in the social environment may be limited (Janotha, 2011). Restricted access to supports thus inhibits families' growth and adaptation (Janotha, 2011).

Intervention

To increase family functioning, family-based interventions must directly address the unique challenges faced by individuals with TBI, while incorporating the needs of the family. Symptom severity, characteristics of the spouse and child, as well as access to resources, all impact treatment (Kreutzer et al., 2009). Foster et al. (2012) note that treatment interventions should be stratified to incorporate family preservation, cultural needs, education, community supports and skills training.

There is evidence that strategies for enhancing parent-child interactions increase the quality of life for all family members (Ducharme et al., 2002). Effective interventions have been shown to include caregiver empowerment (Degeneffe et al., 2011), accessibility in the home environment (Kendrick, Silverberg, Barlow, Miller, & Moffat, 2012), cognitive-behavioral

interventions (Ylvisaker et al., 2005), increasing regular play between parent and child (Ylvisaker et al., 2005), environmental restructuring (Ylvisaker et al., 2005), creating client-centered plans with the family (Janotha, 2011), and preserving family time and daily routines (Foster et al, 2012).

Professionals need to train the families of survivors in ways to become more effective care providers (Kreutzer, 1994). With few supports available (Kieffer-Kristensen, Teasdale, & Bildenberg, 2011), caregivers are in need of accurate, continuing education regarding the behavioral and emotional challenges demonstrated by brain injury survivors, the effect TBI may have on the family system, and strategies to best support family functioning (Kreutzer et al., 1994).

Techniques for emotional regulation

Specific family support strategies that benefit families affected by TBI include de-escalation of aggression techniques. People with effective de-escalation skills have been found to have affect control (e.g., appear calm and non-threatening), communication skills (e.g., using a soft voice and active listening skills), and nonverbal skills (e.g., appropriate use of eye contact, not invading personal space) (Price & Baker, 2012). These skills are essential for caregivers, as their behavior may set the tone for survivors' de-escalation, and in establishing rapport with survivors in order to assist with decreasing aggressive behaviors (Price & Baker, 2012). Because they have a history of a positive relationship, caregivers have the unique opportunity to reminisce about the past with survivors or to find common ground within conflicts.

Early intervention can also be a successful method of preventing further escalation (Price & Baker, 2012). Recognizing survivors' triggers to escalation and stepping in early may allow caregivers to prevent aggression altogether. Removing possible weapons, establishing the safety

of children, or separating survivors from challenging situations are other ways caregivers can prevent or deflate aggressive behaviors (Price & Baker, 2012). Specific de-escalation strategies include allowing survivors to express their feelings, shared problem-solving, and offering alternatives to aggression (e.g. taking a timeout to cool off, taking deep breaths) (Price & Baker, 2012). All of these strategies aim to give survivors ownership in self-regulation, with the added intent of reducing caregiver burden (Price & Baker, 2012).

Purpose

The purpose of this project was to create a web-based support to educate caregivers about strategies that can be used to prevent and manage emotional dysregulation in their partner with TBI, activities that can increase positive interactions between children of all ages and TBI survivors, and other web-based resources for the family.

Procedure

Upon the decision to create a website, we contacted graphic designer Maria Radloff of Via Maria, who now provides hosting for the site. We researched available domain names and settled on Parenting After TBI (PAT) due to the title's expected ease of access. The established URL is www.parentingaftertbi.com.

The next step of website creation was to organize the website to best suit the needs of caregivers and individuals with TBI. Discerning the number of pages to ensure ease of website navigation guided our determination of the final amount of content to be presented. An appropriate Wordpress theme further influenced the accessibility of the website for both caregivers and survivors of brain injury. Conferences with Lauren Nicandri of University of Puget Sound's Information Technology Services informed decisions regarding website sustainability, the appropriate amount of text per web page, and formatting printable templates.

Library liaison Eli Gandour-Rood provided guidance regarding the obtainment of legal images for website use, as well as copyright concerns.

Developing a clear plan for the content, headings, and images to be included on each page increased visual coherence and ease of use. Writing tasks were delegated between team members, and edits to all written content were made collaboratively.

Content was then transposed onto the website. This step involved developing fluency in Wordpress widgets and programming in order to add and format pages. Formatting changes was an ongoing process until the website achieved visual coherence for optimal ease of use.

The following list details the skills and knowledge needed in order to complete this project: information from TBI survivors regarding what online supports have and have not been helpful; knowledge of the children of TBI survivors and their needs; knowledge of the skills needed by parents of children across all ages of development; activity analysis in order to understand the impact of aggression on parenting skills; how to use Wordpress, including the use of widgets and plug-ins, the ability to add and change pages, the ability to change page layout, the ability to add and remove content, and the development of a plan to address potential technical difficulties; how to increase website hits on search engines; how to market our website to organizations so it can be linked as a resource; further knowledge about TBI, strategies to increase emotional regulation and decrease aggression; and a deeper understanding of person-environment-occupation theory, as well as how this theory guides treatment.

To assess the quality, accessibility, and usefulness of our website, we conducted pre-test and post-test surveys with four participants, including a graphic designer, caregiver of adult parent with TBI, and co-parents of healthy adult parents in the community. Most participants in the pilot did not have professional clinical knowledge. The piloting phase of our project was

conducted over a two-week period. During this time period, participants were surveyed regarding their initial understanding of TBI, parenting after brain injury, and caregiving needs. They then explored the website and took a brief online survey (see Appendix A) to determine their understanding of the presented content. Participants were asked to identify common triggers for aggressive behaviors or a de-escalation task with their TBI survivor. Feedback was received via an online survey (created through SurveyMonkey) to assess the readability, usability, and effectiveness of the website. Survey questions related directly to goals and objectives.

Feedback informed changes to the website, including clarifying content and adding pictures.

Description of Project

PAT supports caregivers in learning strategies to help prevent and manage emotional dysregulation in their partners, and suggests activities that promote positive family interaction. The focus of the website is on strategies for increasing participation in family activities for parents of children of all ages. The virtual environment reaches a broader audience at home, as well as provides an ongoing support for caregivers and survivors as they parent post-injury. Educational websites have proven effective for teaching strategies to people struggling with self-regulation (Wade et al., 2011) and providing a support for caregivers. To be effective for both caregivers and brain injury survivors, PAT incorporates elements of universal design and was written at an 8th grade reading level in large, easy-to-read font, and moderate-contrast text on a plain background.

The home page states the project's purpose statement and provides clear instruction regarding how to navigate the website. A second page describes traumatic brain injury, the incidence of emotional regulation difficulties, and typical presentation of aggression in many

survivors of TBI (see Appendix B). Some of the effects of TBI on caregiver and child are also delineated, with an additional resource page for caregivers to access expanded information.

A “Managing Stress” page provides de-escalation strategies that families can use both in and outside of the home environment (see Appendix C). These strategies for managing stress during family activities are broken down into three categories: before, during, and after. In the “before” category, mindfulness techniques are presented to be practiced on a daily basis or before a particular family interaction. Strategies within the “during” category are graded to help increase activity success. Caregivers and survivors are presented with different ways for managing difficult situations or tolerating frustrations (e.g., take a break or walk away). Talking about what went well and developing a plan for future activities are components of the final group “after”.

The family activities page, with specific outlines for how to predict triggers of aggression and how to use de-escalation strategies to help ensure success, is central to PAT. Activities are divided into overarching categories of celebrations, sports and games (see Appendix D), outside activities, recitals, and homework help. A separate General Principles page lists strategies that can be used across family activities, and caregivers will be able to combine strategies from across the site in order to best meet the needs of their loved ones (see Appendix E).

Additional pages include administrator contact information as well as links to brain injury resources, parenting blogs, and brain injury support groups in Tacoma, Washington.

The PAT website was created with the needs and interests of caregivers and survivors of TBI. Minimizing the number of pages, clarity of menus and icons, and increasing contrast and font size increased ease of use. Text was written at an 8th grade reading level to be inclusive of TBI survivors, caregivers, and adult children of survivors. Links to other web-based resources

also considered the needs of caregivers. PAT provides links to current and evidence-based resources, as well as on-going and local support groups in the Tacoma, Washington area. A contact page provides users with the ability to access both administrators for further information, as needed.

To increase accessibility, key terms were used throughout the site to increase search engine optimization (SEO). Through the use of often searched terms, we have improved the visibility of our website, thus increasing our reach to a broader audience.

Outcome of Project

Goal 1: After visiting the PAT website, caregivers will become educated in effective de-escalation techniques survivors can use to manage aggression when parenting. Goal met.

Objective 1: After visiting the PAT website, caregivers will be able to independently identify at least three de-escalation strategies that they could use with the survivor with TBI. Objective met.

Objective 2: After visiting the PAT website, caregivers will be able to implement at least one de-escalation strategy with the TBI survivor during a parenting task, as measured by self-report in the pilot survey. Objective met.

Goal 2: After visiting the PAT website, caregivers will be educated in activities that facilitate positive interaction between the survivor and child. Goal met.

Objective 1: After visiting the PAT website, caregivers will be able to independently identify at least one provided family activity that they could imagine using with their family. Objective met.

Objective 2: After visiting the PAT website, caregivers will be able to independently identify at least one way to modify activity parameters to best support successful outcomes. Objective met.

Goal 3: After visiting the PAT website, caregivers will be educated in methods to prevent escalation of aggression during family activities. Goal met.

Objective 1: After visiting the PAT website, caregivers will be able to identify at least three common triggers of aggression. Objective met.

Objective 2: After visiting the PAT website, caregivers will be able to identify at least three common ways to prevent aggression (as listed on the PAT website). Objective met.

PAT was piloted to a graphic designer and three co-parents of healthy adult parents in the community. Most participants in the pilot did not have clinical knowledge, and were solicited via friend, family, and faculty connections, as well as through brain injury support groups. Piloters were given a two-week period of time to explore the website. After they read and participated in the website activities, participants took a brief online exam to determine their understanding of presented concepts and content. Feedback was received through an online survey (created via SurveyMonkey) to assess the readability, usability, and effectiveness of the website.

Survey questions related directly to goals and objectives. These goals and objectives were to assess the caregivers' knowledge and understanding of common causes of aggression, prevention of aggression, de-escalation techniques, family activities, and how to modify activity parameters to ensure success. All goals and objectives were met.

Based on feedback, team members made the following changes to the website: adding more images for aesthetic appeal, correcting typos, condensing introduction text to each activity,

and moving the “General Principles” page from the “Activities” section to the “About TBI” section. Positive feedback included clarity of writing, activity ideas, and de-escalation strategies (e.g. humming instead of yelling).

Implications for Occupational Therapy

The specific approach used to guide this project was the Person-Environment-Occupation (PEO) model (Bruce & Borg, 2002). PEO operates under the assumption that impaired occupational performance is a mismatch between person, environment, and task. This is an ideal frame of reference for the TBI population, whose cognitive ability often impacts their abilities to operate within the contexts of specific tasks and environments. Our website provides instruction to caregivers in de-escalation techniques that will assist TBI survivors to learn new ways to manage emotions and activities to encourage positive interaction with their children. We will also provide preventative strategies per the PEO model regarding ways to modify the activity or environment in order to maximize a goodness of fit. Ideally, modifying the task and environment will increase survivors’ social participation both in the community and within their own homes.

TBI survivors benefit from occupational therapy, a profession within the field of rehabilitative medicine that supports performance and participation in functional activities. Occupational therapists consider brain injury impairments, such as emotional regulation deficits, and the impact they have on client factors, occupation, and performance patterns, in addition to the ways that the person interacts with context and environment to affect occupational performance (American Occupational Therapy Association [AOTA], 2014).

Individuals with TBI who are also parents express that they value fulfilling their parental role (personal communication with Fred [name assigned], February 21, 2014), and maintaining a positive relationship with their child (Charles et al., 2007). Parenting practices, as well as the

deemed qualities of “good” parenting, are influenced by the cultural and personal beliefs of individuals with TBI. Changes in a range of mental, attention, process skills and social interaction skills further impact survivors’ abilities to effectively parent and participate in family activities (AOTA, 2014). Specific sensory functions that may be impaired in the TBI survivor include new sensitivities to lighting, sound, and temperature (AOTA, 2014), which may present obstacles when interacting with children or going outside the home. Occupational therapists address this gap by providing strategies to meet the demands of new contexts, parenting activities, and environments. Therapists may teach de-escalation techniques and control the amount of information processing required by survivors to address difficulties in emotional regulation, sensory sensitivity, and aggressive behaviors. PAT offers caregivers these same strategies that are used by occupational therapists. The website presents caregivers with ideas to prevent aggression and manage emotional dysregulation in the TBI survivor, as well as adapt family activities so that survivors can be more effective parents.

Furthermore, occupational therapists address difficulties with performance patterns (AOTA, 2014). These include the roles, habits, and routines necessary for parenting. Our website supports participants’ roles as parents and spouses, as well as their ability to meet expectations within the culture of the family and the broader community. The website further provides virtual instruction to increase adaptive behaviors that support emotional regulation in survivors, and activities that promote positive and predictable interactions between parents and children. In turn, this helps to promote healthy daily routines for the family.

Occupational therapists provide a unique contribution to this population due to their ability to analyze the environmental demands on the person with TBI. Occupational therapists identify the physical and social characteristics of the environment that may impede participation,

or that may elicit an aggressive response. Post-injury, survivors may experience a change in sensory functioning. Senses may be heightened or diminished, which in turn influences how survivors interact with the space, objects and people surrounding them. In addition to the environment, occupational therapists consider the contexts that may influence performance. These contexts include personal (e.g., demographic features of individual, socioeconomic status), cultural (e.g., traditions, norms), temporal (e.g., stage of life, time of day, duration of activity, history), and virtual (e.g., real-time, near-time) (AOTA, 2014).

Additionally, occupational therapists' analysis of the activity itself highlights task demands that may provide barriers to successful participation. These task demands may be physical (e.g., length of the activity, endurance needed to complete the activity, the physical space required), social (e.g., amount of people present, familiar vs. unfamiliar people, verbal and nonverbal communication), emotional (e.g., emotional regulation), or temporal (e.g., time of day that the activity takes place) in nature (AOTA, 2014). Occupational therapists may grade these demands in order to prevent aggression.

Limitations of the Project

A primary obstacle in the creation of this website was the dearth of research evidence regarding the challenges faced by parent survivors of TBI. Further research is necessary to fully understand the complexity and range of issues affecting survivors' abilities to participate in and maintain their roles as parents, as well as how occupational therapists and other healthcare professionals can best support families as they re-establish family roles, habits, and routines post-injury. The limited amount of evidence-based research forced team members to make links and assumptions from related literature in order to apply the principles of de-escalation to parenting after TBI.

Secondly, limited computer skills of team members inhibited the progress, impact, and content of the website. Due to a lack of funding, we were able to obtain a graphic designer only to host and set up the website. Team members were responsible for all other aspects of website creation. An initial lack of understanding of programming and widgets led to a great deal of time spent learning about website design. The eventual website design was influenced by the special considerations of the TBI population and caregivers, as well as content, and visual coherence. The Wordpress platform presented numerous constraints in web layout, font type and size, colors, or picture inclusion as page templates did not allow free creative design. Content ultimately was thus influenced by website and website designer capabilities.

Lastly, the web-based format may potentially limit this project's ability to meet the specific needs of families affected by TBI. Though many people are able to access this resource at one time and from any location, they are an unseen audience to the creators of the project. Audience members could potentially view parenting, age-appropriate activities, and positive family interactions differently based on cultural beliefs, environmental factors (e.g., access to safe outdoor excursions), or even the time elapsed since injury. PAT could potentially be a better support for this population if it was directly associated with an existing agency, which could provide specific feedback regarding outcomes and strategy effectiveness.

Future steps/Sustainability

Ongoing website hosting is necessary to maintain PAT, as well as payment of fees for hosting and domain name ownership. Domain name is purchased through fall 2017.

Administrators have agreed to add at least one new activity to the website every six months and maintain verification of resources. Administrator involvement is required to answer posted

questions or requests for information. Links to web-based and real-world resources for caregivers should also be assessed on a regular basis to ensure viability and applicability.

Potential next steps include the expansion of the website and possible in-service trainings at local agencies. Administrators have the opportunity to continue to add family activities to the website, as well as new or different general principles or de-escalation techniques. In-service trainings would enable the creators of this project to reach families affected by TBI face-to-face, role-play scenarios, answer questions unique to individuals, and identify unseen challenges or issues that should be incorporated into the website. Caregivers could also be trained as mentors to support and educate other families affected by TBI and aggression.

Future plans include linking this website to larger organizations that support people with TBI and caregivers, such as TACID, Brain Energy Support Team, or TBIWA.

Conclusion

Families are complex systems, and may be disrupted when a beloved parent has a TBI (Charles et al., 2007). Limited research exists regarding parenting after TBI. However, there is ample evidence demonstrating the effects that TBI can have on caregivers, children, and families (Gan et al., 2006) All members of the family are at risk for symptoms of caregiver burden, depression, and anxiety, and this becomes heightened when survivors exhibit aggressive behaviors (Gan et al., 2006). Moreover, survivors deeply value maintaining relationships with their children. Parenting is not simply a meaningful occupation, but an identified, essential role for many survivors of brain injury.

Caregivers and TBI survivors may benefit from a website that addresses aggression and parenting, thereby easing caregiver burden, supporting parent survivors' relationships with their

children, and meeting their goals of being effective parents (Charles et al. 2007; Kieffer-Kristensen & Teasdale, 2011).

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Appendix A

Pilot Survey

1. How would you rate the Mindfulness strategies?

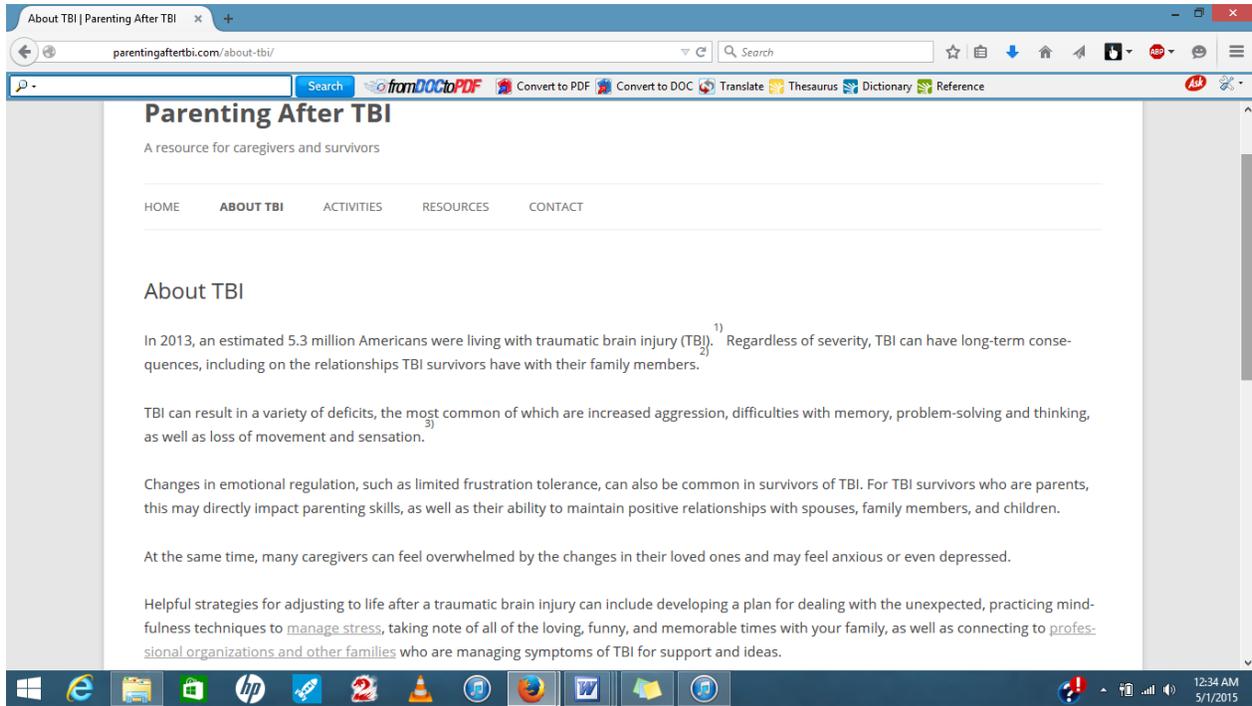
Unhelpful	A little helpful	So-so	A little helpful	Helpful
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2. How would you rate the Activities?

Unhelpful	A little helpful	So-so	A little helpful	Helpful
------------------	-------------------------	--------------	-------------------------	----------------
3. Please rate the usefulness of web-based resources in supporting positive parenting.

Unhelpful	A little helpful	So-so	A little helpful	Helpful
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4. Please name one activity listed on the website that you would do with your children.
5. Please list one mindfulness strategy that you could use during an activity with your children.
6. Please list three challenges faced by parents with TBI.
7. Please list three strategies for staying calm in stressful situations.
8. Please list three ways to modify activities to support parents with TBI. These can be either general principles or "things to try".
9. Please list one way to modify a specific activity or its environment to best support positive family interaction.
10. Please take a moment to provide feedback to the overall ease of use and helpfulness of the website. Is this something you would recommend to caregivers of parents with TBI? Thank you!

Appendix B

Sample Webpage: About TBI



Appendix C

Sample Webpage: Managing Stress

The screenshot shows a web browser window with the address bar at `parentingaftertbi.com/about-tbi/mindfulness/`. The page content is as follows:

Parenting After TBI

A resource for caregivers and survivors

HOME **ABOUT TBI** ACTIVITIES RESOURCES CONTACT

Managing Stress

Being aware of how children can push our buttons is important to strengthening relationships with children and stress-free parenting .

All parents feel stressed or even angry sometimes. Some parents who have survived a brain injury may find that they feel stressed more often and can become angry more easily.

After a brain injury, it becomes important to develop strategies for managing stress before, during, and after it occurs.

Before

Think about what triggers your loved one with a brain injury. Does he have difficulty with bright

ALSO CONSIDER:

*Before each activity, sit with your child and take three breaths together. This is a calming activity and helps to teach children good stress management skills.



Appendix D

Sample Webpage: Sports and Games

The screenshot shows a web browser window displaying the website 'parentingaftertbi.com/activities-2/sports-and-games/'. The page title is 'Parenting After TBI' with the subtitle 'A resource for caregivers and survivors'. A navigation menu includes 'HOME', 'ABOUT TBI', 'ACTIVITIES', 'RESOURCES', and 'CONTACT'. The main content area is titled 'Sports and Games' and contains the following text: 'Participation in sports and cooperative games helps to develop parent-child bonding, family togetherness, teamwork, and promote a healthy lifestyle. Sports and games also teach children age-appropriate skills and good sportsmanship.' Below this, it says 'Review the [General Principles](#) and [Managing Stress](#) pages to help create a plan.' A section titled 'Challenge' states 'Brain injury can sometimes lead to difficulty learning new games.¹⁾' Under 'You can try', there is a bullet point: '• Read the directions out loud to the whole group.' To the right, an 'ALSO CONSIDER:' section notes '*Visual timers can be helpful when playing long games. Say, "We will play Monopoly for one hour." This way, play is not halted or limited based on anyone's endurance.' An image of children playing soccer is shown in the bottom right of the content area. The browser's taskbar at the bottom shows various application icons and the system clock indicating 12:56 AM on 5/1/2015.

Appendix E

Sample Webpage: General Principles

