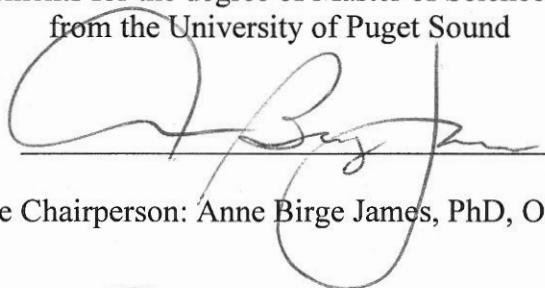



The Experience of Participating in a Mentor Training Course and its Effects on Mentoring
People with Traumatic Brain Injuries

May 2015

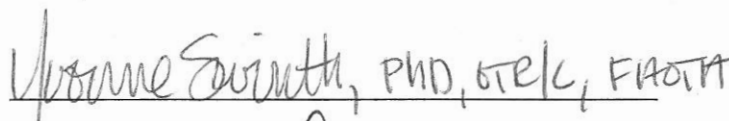
This research, submitted by Katherine Montgomery, has been approved and accepted in partial fulfillment of the requirements for the degree of Master of Science in Occupational Therapy from the University of Puget Sound



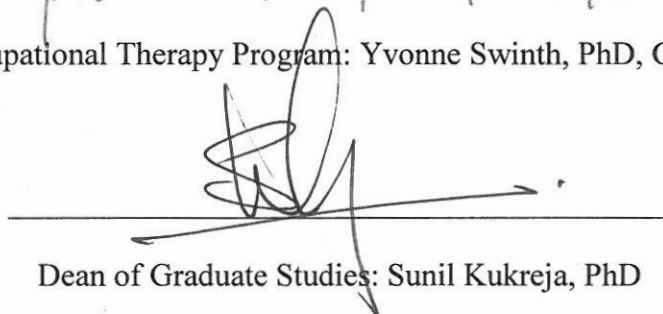
Committee Chairperson: Anne Birge James, PhD, OTR/L, FAOTA



Reader #1: Tatiana Kaminsky, PhD, OTR/L



Director, Occupational Therapy Program: Yvonne Swinth, PhD, OTR/L, FAOTA



Dean of Graduate Studies: Sunil Kukreja, PhD

Key Words: traumatic brain injury, mentoring, mentor training

Abstract

Community-based mentoring programs for people with traumatic brain injuries (TBIs) have been found to have several benefits, including decreasing social isolation, improving behavioral control, and increasing quality of life. There is limited literature, however, regarding the experiences of the mentors who participate in these programs. This qualitative study was completed to examine the lived experience of three mentors of people with TBIs following a training program to enhance mentoring skills. Four key themes emerged that included: Readiness to Learn, Density and Complexity of Content, You Got Something Out of It, and Time of Day. This information may help occupational therapists educate clients and caregivers more effectively, and also help them to evaluate community-based mentoring programs that may be beneficial for clients who no longer qualify for occupational therapy services.

The Experience of Participating in a Mentor Training Course and its Effects on Mentoring
People with Traumatic Brain Injuries

Traumatic brain injuries (TBIs) are a serious health concern in the United States. In 2010 alone, TBIs accounted for 2.5 million emergency department visits, hospitalizations, or deaths (Centers for Disease Control and Prevention [CDC], 2014d). Men were 29% more likely to experience a TBI than women that year (CDC, 2014b), while people over the age of 65 years had the highest incidence of TBI related hospitalizations and deaths CDC, 2014a; CDC, 2014c). The economic impact of TBIs that year was \$76.5 billion, including direct medical costs and indirect costs such as inability to return to work (CDC, 2014d). Military personnel are especially vulnerable to TBI; the incidence of U.S. Army service members with TBI has been between 19,000 and 20,000 each year from 2008 to 2011 (Armed Forces Health Surveillance Center, 2012).

People with TBIs and their families may experience lifelong difficulties. These challenges likely include issues with at least some of the following: behavioral control, memory, attention, executive functions, use of alcohol or other drugs as coping strategies, depression, financial and physical dependency on others, social isolation, and poor quality of life (Daggett, Bakas, Buelow, Habermann, & Murray, 2013; Guise, Feyz, LeBlance, Richard, & Lamoureux, 2005; Holm, Schönberger, Poulsen, & Caetano, 2009; Wolters, Stapert, Brands, & VanHeugten, 2009; Xue-Bin, Zhe, Yu-Cong, Zhi, & Qi-Wei, 2012; Zonfrillo, Durbin, Winston, Xuemei, & Stineman 2014). Caregivers and family members not only feel the effects of these challenges, but also feel unprepared to meet the personal challenges of strain, social isolation, and changes in family roles (Fay, 2012; Koskinen, 1998; Marsh, Kersel, Havill, & Sleigh, 1998; Murray, Maslany, & Jeffery, 2006; Nonterah et al., 2013).

Though the deficits that people with TBI experience may be lifelong, improvements have been found after participation in post-acute services such as inpatient rehabilitation, adult day services, vocational training and outpatient therapy (Gill, Wall, & Simpson, 2012; Malec & Basford, 1996). Unfortunately, these services tend to be high cost, causing many people with TBI or their families to carry large amounts of medical debt or declare medical bankruptcy (Chen et al., 2012; Relyea-Chew et al., 2009). Insurance companies may also consider post-acute rehabilitation investigational, and not cover the expenses of post-acute services (Insurers balk at TBI coverage, 2007)

Since the medical post-acute services are not affordable for many people with TBI, less expensive community-based services may be a valuable option to address some of their needs. Mentorship programs for people with TBI are one such service have been found to be effective at increasing mood, developing positive coping skills, improving quality of life, facilitating goal achievement, and promoting overall cognitive and social functioning (Fraas, & Bellerose, 2010; Hanks, Rapport, Wertheimer, & Koviak, 2012; Hibbard et al., 2002; Kolakowsky-Hayner, Wright, Shem, Medel, & Duong, 2012; Struchen et al., 2011). Mentorship programs also provide social interaction, which may reduce the isolation that people with TBI and their families typically experience.

Background

TBI. The effects of each TBI are unique depending on the mechanism of injury, pre-injury health, age, and additional injuries, but people with TBIs generally have similar psychosocial sequelae. TBI is associated with significant decreases in comprehension, problem solving, memory, attention, emotional regulation, and social skills, and these deficits have been found to negatively impact independence (Daggett et al., 2013; Guise et al., 2005; Holm et al.,

2009; VanHeugten et al., 2006; Zonfrillo et al., 2014). The effects of TBIs have been shown to significantly lower health-related quality of life two years post-injury when compared to an age-matched healthy group (Xue-Bin et al., 2012). People with TBIs are at a high risk for developing mood disorders such as depression; 42% of the sample of one meta-analysis met the criteria for clinical depression (Kruetzer, Seel, & Gourley, 2001). People with TBIs who also suffer from depression tend to have poorer social integration (Gomez-Hernandez, Max, Kosier, Paradiso, & Robinson, 1997) and have a greater risk of suicide than people with TBIs who are not depressed (León-Carrión et al., 2001). A retrospective study that examined data from Holland from 1973 to 1993, found that a person with a TBI was 2.7 to 4.1 times more likely to die of suicide than an age and gender matched peer (Teasdale & Engberg, 2001). Similarly, people with TBI living in Colorado were found to be 2.5 times more likely to die within a given year than the average population of that state (Ventura et al., 2010).

TBIs not only affect the individuals who experience them, but also family members. It is estimated that 75-80% of the caregivers for people with TBIs are family members (Hastings Center, 2014), and these caregivers experience strain. Caregiver strain related to TBIs may include emotional fatigue (Fay, 2012; Koskinen, 1998), financial burden, social isolation, changes in roles and self-identity (Fay, 2012, and frequent physical demands such as transferring the person with a TBI or helping them with self-care (Fay, 2012; Koskinen, 1998; Marsh et al., 1998; Murray et al., 2006; Nonterah et al., 2013). If the primary caregiver is the spouse, marital dissatisfaction and separation are common: 44% of participants in one study who were in long term relationships pre-injury separated by five years post-injury (Koskinen, 1998). Family members who are not caregivers also reported that relatives with TBIs strain family

relationships, upset family routines, and are difficult to live with (Koskinen, 1998; Lefebvre, Cloutier, & Levert, 2008).

Social isolation is one of the most devastating and common sequela reported in the literature, for people with TBIs and their families. People with TBI are often excluded from social events because they may be impulsive, unable to read social cues, make socially inappropriate remarks, exhibit atypical movement or speech patterns, or are overwhelmed by the accompanying sensory input (Cannizzaro, Allen, & Prelock, 2011; Landon, Shepherd, Stuart, Theadom, & Freundlich, 2012; Spikman et al., 2013). Without specific intervention to improve the social support network, the social isolation experienced by people with TBIs has been associated with lower rates of employment and continual fear of job loss (Gomez-Hernandez et al., 1997), weakened family bonds, loneliness, sadness, limited social activity, and interactions with others that are characterized by pity (Bulinski, 2010).

The caregivers often lack the time or energy to meet with friends, participate in social leisure activities, or even work (Fay, 2012; Marsh et al., 1998; Murray et al., 2006; Nonterah et al., 2013). Parent caregivers may also find themselves with less time and energy to go out into the community if they must re-enter a caregiving role for their adult child after the child has experienced a TBI (Fay, 2012). Caregiving may also use up the caregivers energy by causing persistent feelings of stress and worry, even if the caregiver is able to compensate and maintain their network of social support (Inzaghi, DeTanti, & Sozzi, 2005).

Mentoring Programs. Mentoring programs are a possible solution that can help alleviate many of the difficulties that people with TBI experience. Five quantitative, peer-reviewed studies were identified that described mentoring programs designed to benefit people with TBI, or people with TBI and their families. While these studies varied significantly, they shared an

overall objective: to examine the efficacy of programs designed to improve the lives of people with TBI and their families in a community setting. Three of the five studies only examined the effects of mentoring on the group of mentees. One study included only youth with neurological disorders as mentees (Kolakowsky-Hayner et al., 2012), whereas the other two studies each had a mentee group of people with TBIs and a mentee group that consisted of relatives of people with TBIs (Hanks et al., 2012; Hibbard et al., 2002). Two studies explored the experiences of the mentors as well as the mentees (Fraas & Bellerose, 2010; Struchen et al., 2011).

Purpose and Design. The five studies included two randomized controlled trials (Hanks et al., 2012; Struchen et al., 2011), two single-group pretest posttest designs (Kolakowsky-Hayner et al., 2012; Hibbard et al., 2002), and one case study (Fraas & Bellerose, 2010).

The smallest study, Fraas and Bellerose (2010), used a case-study design to explore the effects of a once per week, 10-week long peer-mentoring program on the quality of life and level of functioning of both the mentee and mentor. They spent four hours each session participating in life-skills courses together, and one hour in conversation about topics of shared interest.

The research of Kolakowsky-Heyner et al. (2012) took place on a much larger scale. This single-group pretest posttest analyzed data from youth with neurological disorders, including TBI, spinal cord injury, and cerebral palsy, who participated in the Back on Track to Success program from 2005 to 2010 in California. Seventy-seven mentees were successfully matched to mentors, 72% of whom were peer mentors and 28% were caregivers or rehabilitation professionals. The mentees goals were to enroll in higher education, become employed, or both. Unlike Fraas and Bellerose (2010), mentors and mentees had conversations only, and did not participate in shared experiences.

The other single-group pretest posttest occurred with a smaller number of participants and included a new group of mentees; nine mentees were relatives of people with TBI, in addition to 11 mentees with TBI themselves (Hibbard et al., 2002). Both groups of mentees had peer mentors, that is, mentees with TBI were paired with mentors with TBI, and mentees who were relatives of people with TBI were mentored by relatives of people with TBI. Mentors and mentees engaged in conversations aimed at improving the overall quality of life and reducing social isolation felt by people with TBI and family members, but did not share experiences. The official intervention period lasted one year for each mentee-mentor pair, and data were collected then, but mentees and mentors were encouraged to continue the relationship outside of the one-year research period.

There were several differences in design between the two randomized controlled trials. Struchen et al. (2011) aimed to alleviate social isolation for the 12 mentees with TBIs through conversations and social outings with their peer-mentors. Eighteen people with TBI acted as the waitlisted control group, and data were collected from this group only when they were acting as the controls (Struchen et al., 2011). Hanks et al. (2012) was a larger study that included 47 mentees with TBIs and 31 mentees who were relatives of people with TBIs. Forty-nine people with TBI and 31 relatives of people with TBI were not mentored and acted as the control group. Each group of mentees was peer-mentored. Rather than focus exclusively on social isolation as Struchen et al. (2011) did, Hanks et al. (2012) considered the overall quality of life, emotional health, and social integration of each mentee group.

Outcomes for the mentors. Two studies of the five discussed the effects that the mentoring experience had on the mentors. The mentor satisfaction survey in Struchen et al. (2011) indicated that the majority of the peer mentors felt they were well trained, helped their

mentee, and would recommend this experience to others. The peer-mentor in the case study by Fraas and Bellerose (2010) experienced positive changes in feelings of self-esteem, self-actualization, adjustment, and participation. Levels of statistical significance were not reported. The mentor did experience a negative change in feelings of love and belonging. While Struchen et al. and Fraas and Bellerose found that mentors benefitted from their experiences, all mentors in these two studies were peer mentors. Mentors without TBIs, caregivers or family members, may have had different experiences.

Outcomes for mentees. Mentees with TBI experienced statistically significant objective improvements in multiple dimensions of well-being, regardless of whether the mentoring relationship included shared experiences or only conversations. These positive outcomes included increased social support (Struchen et al., 2011), increased cognitive independence, increased participation, decreased ratings of disability, and decreased amount of supervision needed (Kolakowky-Hayner, 2012). Other statistically significant improvements included using fewer avoidant coping strategies, less chaotic home environments, better health-related quality of life, and better behavioral control (Hanks et al., 2012). The mentee in the case study also experienced significant improvements in his level of overall functioning and adaptability (Fraas & Bellerose, 2010). Goal attainment was another positive effect attributed to participation in a mentoring program (Kolakowsky-Hayner et al., 2012). From 2005 to 2010, the majority (54.4%) of mentees who participated in the Back on Track to Success program achieved their goals related to enrollment in higher education, gaining employment, or both.

In addition to the objective effects, the mentees with TBIs also reported that their participation in the mentoring program had benefitted them in several ways. Perceived benefits occurred regardless of whether mentoring relationships consisted of conversation only or of

conversation and shared experiences, and included improved well-being and quality of life (Fraas & Bellerose, 2010; Hibbard et al., 2002), increased social support (Struchen et al., 2011; Hibbard et al., 2002), greater empowerment, and knowledge about TBIs (Hibbard et al., 2002).

One statistically significant negative effect of the mentoring programs on the mentees with TBI was found. While the mentoring relationship in Struchen et al. (2011) was designed to improve social integration, mentees in that study had an increase in depressive symptoms after the mentoring program. The authors hypothesized that this may have been due to increased awareness of their social isolation.

Mentees who were relatives of people with TBIs also benefitted from being mentored, experiencing statistically significant improvements in a subjective measure of community integration (Hanks et al., 2012). Though not statistically significant, the majority of mentees who were relatives of people with TBIs also reported that being mentored increased their feelings of empowerment, improved overall quality of life, improved ability to cope with sadness, anger, and anxiety, and knowledge about TBIs (Hibbard et al., 2002).

Training mentors. While community-based mentoring has been shown to be an effective way to support people with TBIs, there is little research on the best way to train mentors to provide that support. Only one article was found in the literature that explicitly described how a mentor was trained to support a person with TBI, but that research took place in an academic framework rather than the community (Glang, Todis, Sublette, Brown, & Vaccaro, 2010).

In the five studies that described the effects of community-based mentoring programs for people with TBIs, or people with TBIs and their relatives, the training that the mentors received varied, including eight day-long workshops over two years (Hibbard et al., 2002), 20 hours of interactive training supervised by a researcher, nurse, and psychologist (Hanks et al., 2012), and

four hours of training with a manual provided (Struchen et al., 2011). One study described training topics, but did not mention how much time or the number of sessions that the mentor spent training (Fraas & Bellerose, 2010), and another study did not describe the training the mentors received at all (Kolakowsky-Hayner et al., 2012). The two studies that explored the experiences of the mentors in the support programs found that they felt prepared and supported but did not offer enough detail to enable one to design similar training protocols for mentors (Fraas & Bellerose, 2010; Struchen et al., 2011). The topics included in the mentor training were briefly described in most of the studies, but in a generalized manner that would make it difficult to replicate. Examples of topics included knowledge about TBI, communication and empathizing, how to access resources, and how to encourage appropriate social skills (Hanks et al., 2012; Hibbard et al., 2002; Struchen et al., 2011).

Currently, there is a lack of research about how to design effective mentor training that prepares mentors to support people with TBIs. Effective and excellent mentor training is one component that can enhance the success of these programs. Another important point to consider is the perception of the training by the mentors themselves; without perceived value, the training will be less effective (Mirriam & Bierema, 2014). For that reason, it is important to gather the perspective of the mentors about the training they received; how they felt about it, whether they felt prepared to be mentors, and the effectiveness of the training based on later interactions with their mentees. Therefore, the purpose of this study was to explore the experience of mentors who participated in a mentor training program offered by a community-based program and how that training affected mentoring people with TBI.

Method

Research Design

This qualitative study used a phenomenological design. Phenomenology is a philosophical approach that has been used in research to examine the lived experiences of participants (Moran, 2002). The purpose is to emphasize the human experiences, to find the deeper meanings behind the perceptions, and beliefs of the participants (Moran, 2002).

A phenomenological design was the most appropriate way to address the purpose of this study, which was to explore the experience of participating in a mentor training course and mentoring a person with TBI afterward. This study was not concerned with the content of the training nor the details of the mentoring relationship, but rather the experience of the mentors as they interacted with content and engaged in mentoring after the training. The unique experiences of the mentors were created by the emotions, predispositions, and opinions that they brought with them, combined with the content of the workshop and the presence and contributions of the other attendees. A depth of detail concerning the lived experience is the hallmark of phenomenology (Moran, 2002), and that design served well to explore the nuances of the participants' experiences.

HeadStrong

This study explored the phenomena experienced by mentors who participated in training offered by HeadStrong, a community-based support program for youth with TBI and their families in the Seattle-Tacoma region of Washington (HeadStrong, 2014a). HeadStrong became a 501.c.3 nonprofit in 2007, and provides support to people with TBI and their families, through group outings, caregiver support groups, presenting at TBI conferences, distributing resources to families with relatives with TBIs, legislative advocacy, and the mentor training courses

(HeadStrong, 2014a). Anyone can attend the HeadStrong mentor training and be considered a mentor, including professionals, volunteers, family members, healthcare students, caregivers and people living with a brain injury (HeadStrong, 2014b). The training course is based on a five-module New York State TBI Apprenticeship Program designed by Mark Ylvisaker and Tim Feeney, PhD (Feeney, Ylvisaker, Rosen, & Greene, 2001; Ylvisaker, Hibbard, & Feeney, 2006).

Each four-hour long training course consists of three of the five training modules (Douglass & Parker, 2014). Every training session begins with the Neuroplasticity module, which introduces the concepts of neurological pruning, growth, and change as a result of repeated environmental and emotional patterns. The first course also includes modules that explore Identity and Meaningful Projects. Attendees work in small groups to develop and discuss the identity map of a volunteer participant. This is followed by the Meaningful Projects module, which begins by identifying a topic the person with TBI is passionate about and working through a step-by-step action plan in small groups.

The second training course follows the Neuroplasticity module with Positive Behavior Supports and Conflict Resolution (Douglass & Parker, 2014). The Positive Behavior Supports module provides attendees with strategies to create a positive environment and support effective interactions with the person with the TBI, preventing conflict before it begins. Conflict Resolution helps training attendees with several strategies to deescalate conflict, such as self-monitoring and self-calming, and attendees are shown how to create a safety plan collaboratively with the person with TBI that they mentor.

After taking the training, mentors for HeadStrong provide a supportive relationship with their mentee through shared activities and conversations. These activities may include learning skills for daily life, tutoring and connecting to vocational rehabilitation programs, organizing and

participating in health events (e.g., 5k runs and sports), attending events (e.g., concerts), and going places together (HeadStrong, n.d.). Many HeadStrong mentor-mentee relationships are developed through a project that the mentee chooses and the mentor assists with (HeadStrong, n.d.). An example of one such mentoring project was designing and building shelves to hold a mentee's extensive vinyl record collection (HeadStrong, n.d.).

Participants

The inclusion criteria for this study included participation in the HeadStrong Mentor Training course between September 2014 and February 2015, regular interaction between the mentor and mentee (minimum of once every two weeks), the ability to reflect, analyze, and communicate about his or her experiences as a mentor, the ability to recall details of the mentoring experience before and after the training course, being over 18 years of age, the ability to speak fluent English, and willingness to be audio-recorded.

As this study was concerned with depth of information and the uniqueness of each mentor's experience, it was anticipated that four to six participants would have been sufficient to reach data saturation. Due to logistical restrictions of time and funding, three mentors participated in this study.

Data Collection

The data for this study were collected using semi-structured interviews (See Appendix). The course evaluations, completed by each participant after participating in the HeadStrong Mentor Training courses, were collected from the Director of HeadStrong. Information from the evaluations was used to inform the development of the interview questions. The course evaluations were not used as an additional data source for analysis, because they were filled out

anonymously and it was not possible to identify which evaluation was attributed to the participants of this research study.

Procedures

This study was approved by the University of Puget Sound Institutional Review Board (IRB Protocol Number: 1415-045). Interview questions were developed by the primary researcher and then reviewed by the other researchers in order to determine if there were key aspects of the mentorship relationship or the training experience that may have been omitted. These revised questions were then pilot-tested with the Director of HeadStrong. The interview focus was then refined, and suggestions given to the primary researcher.

The Director of HeadStrong then invited mentor training participants who met the inclusion criteria to participate in the study. Interested mentors contacted the primary researcher and initial interviews of 30 to 60 minutes were completed. The interviews were audio-recorded and transcribed.

After the initial interview data were analyzed for all participants, an individual follow up interview with each participant occurred by telephone or email. The follow-up interviews lasted an average of 15 minutes, and included member checking regarding how well the themes resonated with the participant's experiences. Additional data were also gathered regarding any changes in the mentoring experience that occurred since the first interview. Data from the follow-up interviews were used as a source for analysis and further exploration of their experiences.

Data Analysis

Data were transcribed from the audio recordings, coded, and then thematically analyzed using a conventional content analysis approach (Hsieh & Shannon, 2005). This entails allowing

the fundamental phenomena to emerge from the interviews without imposing a preconceived structure upon them. It is necessary to immerse oneself in the interviews, to gain familiarity and understanding before one can extract meaning (Hsieh & Shannon, 2005). At the beginning of the analysis for this study, exact key phrases were noted, which became the preliminary codes, and the overall purpose of the codes in the beginning was descriptive rather than analytic. Another term used for this stage would have been coding in-vivo, by using the words within the interview as the codes (Saldaña, 2009). Commonalities across participants, intense emotional reactions, and concepts that were repeated within one interview were used as indicators of key concepts. As the coding process continued, the codes became more analytic, and began to refer to deeper commonalities within multiple phrases in multiple interviews. Eventually, the codes developed into categories, and further analysis revealed fundamental themes within those categories (Saldaña, 2009). Coding took place after data gathering, not concurrently, in order to provide an overall picture that highlighted the similarities of all participants' experiences.

Rigor

In an effort to increase the rigor of this qualitative study, several measures were put into place. Credibility, the ability to of the study's findings to appear accurate from the perspective of someone who has experienced the same or a similar phenomenon, was strengthened through member checking of the interview themes (Thomas & Magilvy, 2011). This ensured that the researcher had not misinterpreted what the participant said and that the participant agreed the themes resonated with their experiences. An audit trail, a detailed description of the step-by-step process, was also created in order to improve the dependability of the results so that future researchers may examine the process and participants and draw their own conclusions (Thomas & Magilvy, 2011). The primary researcher should be contacted for further information regarding

the audit trail. The process of bracketing was also used to help improve the rigor of the study, by helping the primary researcher to acknowledge and deliberately place aside opinions or bias that may have altered the process of coding and resultant themes (Wall, Glenn, Mitchinson, & Poole, 2004). The primary researcher used a written record for bracketing before and after each interview, and periodically throughout data analysis.

Results

This phenomenological study explored the experiences of mentors who participated in a training course offered by HeadStrong and the effects that this training had on mentoring a person, or people, with TBI. Three mentors participated in this study who were given the pseudonyms Grace, Jane, and Alice.

Grace was a 56-year woman who had professional experience supporting people with TBIs. She was employed as an administrator and educator by a TBI, support organization (not HeadStrong). Her partner had a TBI, so Grace also had personal experience as a mentor and a caregiver. She attended two HeadStrong training sessions, one each in October and November of 2014. The topics of both training sessions were Neuroplasticity, Identity, and Meaningful Projects.

Jane was a 75-year old woman, employed as a rehabilitation counselor and case manager. She estimated that she professionally supported 12 people with TBIs who were on her active caseload. She also had personal experience caring for a person with a TBI. She attended the HeadStrong training on Neuroplasticity, Identity, and Meaningful Projects during November of 2014.

Alice was a 39-year old woman. She stated that she was unemployed and that she had acted as a caregiver for a friend since 2011. Alice attended the February 2015 HeadStrong training on Neuroplasticity, Positive Behavior Supports, and Conflict Resolution.

The term *mentors* will be used to refer to the three participants who were interviewed for this study. The term *mentees* will mean the people or clients with TBIs whom the participants help. The term *attendees* will mean people who attended the HeadStrong trainings who were not participants of this study.

Four themes emerged from the data, including Readiness to Learn, Density and Complexity of Content, You Got Something Out of It, and Logistics.

Readiness to Learn

Readiness can be defined as both willingness and a state of being prepared (Oxford Dictionary, n.d.). Mentors who participated in this study all approached the HeadStrong training with different levels of readiness to learn. Previous experience with the concept of mentoring, as defined by HeadStrong, and self-identification as a mentor appeared to be the primary factors that affected the readiness with which mentors approached the training. Their readiness to learn also affected how the mentors used or did not use the training concepts when mentoring afterwards. HeadStrong defines mentoring as a working partnership in which the mentor is an “empowering support person” (p. 2) who can be anyone, including family, friend, paid caregiver, or volunteer (Douglass & Parker, 2014). Mentors may or may not have a brain injury themselves.

Grace came to the HeadStrong training with a high level of readiness to learn, because she already shared HeadStrong’s vision of mentoring. She stated several times that “ideologically [HeadStrong and I] believe in the same things,” and that they both see the ideal mentoring relationship as “a partnership.” Grace viewed mentoring as a relationship in which the

mentor is “here to guide you, not tell you. It’s not me on high. It’s me respecting the fact that you are tripping over stuff so let’s reevaluate what’s not working.” Her experiences as a caregiver without a brain injury for her partner, who had a significant brain injury, also helped her to self-identify as a mentor. Since the training, Grace and her organization have used the Meaningful Projects exercises with “half a dozen people,” seeing it as “absolutely” beneficial. Grace’s self-identification as a mentor and ideological alignment with the philosophy of HeadStrong equipped her with a readiness to learn that has since helped her to apply the training exercises in her mentoring relationships.

Alice approached the HeadStrong training with high levels of readiness as well. Her mentee, who had participated in a previous HeadStrong training session, invited Alice to attend. The mentee introduced the HeadStrong mentoring as “pretty much what you’re already doing.” Alice recalled the training as having “a wow factor” and thinking, “that was neat,” which indicated that she was open to the concepts, and ready to learn and participate. Alice also was highly ready to experience a change in self-identity, and the HeadStrong training helped her to actualize the change from a friend to a mentor. Prior to the training, Alice considered herself “a friend helping a friend,” and felt uncomfortable in situations that identified her in a caregiver role, such as registering for TBI support conference. “When I checked the [box] at the TBI conference, [that asked] ‘are you a caregiver?’ I’m like ‘I guess I am.’” This attitude changed after the training, as Alice reflected “I feel like I have more of a responsibility now... I felt more sure about doing what I was doing, instead of ‘yeah I guess I can make an appointment’ I was like ‘yes, I’ll take care of it!’”

Jane, in contrast to both Alice and Grace, attended the HeadStrong training with less readiness to learn. Her prior concept of mentoring, established through her years of experience as

a case manager, differed from HeadStrong's. Jane perceived mentoring as a peer-to-peer relationship, in which a person with a brain injury mentors another person with a brain injury who has less experience in living with TBI. The model of mentoring that HeadStrong presented was new to her, so Jane was "trying to see how those fit together, where do we go from [non-peer] mentors to peer-to-peer... I need to know how they complement one another."

Jane's prior perception of mentoring only applying to peer-to-peer interactions seemed to prevent her perceiving herself as a mentor. Jane stated that she acts as a "sounding-board [but] I would not use the word mentoring 'cause I'm not comfortable with it yet." Her goals in attending the training were "simply to understand the concept [of mentoring] better, as applied to serving people with disability challenges, and trying to think about [mentoring] more at the level of who in my clientele had mentorship capacity."

Another factor that contributed to Jane's low readiness to learn was that she did not perceive the concepts that were presented in the training as relevant to her needs. She stated, "I would say 95% of my client contact is with people that are closer to crisis than talk. And mentorship [about identity and meaningful projects] doesn't always fit ... It doesn't always fit with crisis." Jane did not seem ready to learn about concepts she did not perceive as relevant to her situation. As a result, she did not utilize the Identity and Meaningful Projects modules' exercises in her interactions with her clients after the training.

Within the experiences of these three mentors, there were different levels of readiness to learn the concepts that HeadStrong presented. Readiness to learn appeared to be influenced by factors such as self-identification as a mentor, alignment between the concept of mentoring used by HeadStrong and the mentor's concept of mentoring, and fit between the topics presented and the current needs of the mentors.

Density and Complexity of Content

Each mentor responded differently to the amount of information in the HeadStrong training, but all agreed that a lot of information was presented in a short amount of time. Mentors may have processed the training differently because of different capacities to comprehend dense and technical information. This ability was influenced by previous educational experiences and knowledge regarding the topics, such as neuroplasticity.

The density of the material overwhelmed Alice, who qualified her answers to several questions by beginning with the statement, “It was a lot of information in a short amount of time...” The amount of information also made it difficult for her to recall details, for example when discussing self-calming strategies for conflict resolution, she said, “there was so much information that it’s just hard to remember back, but I think one of the big things ... [was] the time out.” The concept of a “time out,” that is, taking a break in a conflict to let everyone’s levels of adrenaline and norepinephrine to decrease so that the problem can be approached in a less emotional state, was just one of the strategies presented in the Conflict Resolution module. It proved to be a valuable tool for Alice, and she believed that the time out worked very well with her mentee. When discussion turned to the other strategies and plans that were discussed in that training, however, Alice was unable to recall them. Alice had no previous medical or caregiving experience, and stated that several parts of the training were “still above my head” and “it would be good to have refreshers.” Due to her lack of previous knowledge about the topics discussed and little previous experience participating in workshops of this type, Alice had a low ability to process the training’s dense and complex information.

Grace found the pace and complexity of material easy to handle. She said, “I thought it was great, but then, I am from New York.” She was used to dense information delivered at a

rapid pace, and had a high capacity for accepting information in that style. Grace was also able to judge the effect of the density and complexity of the training content on the other training attendees, due to her experiences leading classes at the TBI support organization for which she works. She believed the pace of the training, rather than the technical nature of the content, was more overwhelming to the other attendees and noted that any presenter could get excited about the material, go too fast, and lose the audience. As Grace said, “you have to know when to pull back.” Despite that observation, Grace believed the content of the training was necessary and useful, despite its complexity, “I am definitely not saying dumb it down, but to pull out what are the most salient points and just share those.”

Jane had a similar experience. The training pace and density were “fine for [her] because [she did] a lot of trainings” but she believed it was true that other attendees were overwhelmed by the density of the information. Jane was also already familiar with some of the more technical and biologically-complex topics, such as neuroplasticity. She explained “I know about neuroplasticity because I’m interested in it and took a webinar.” This prior knowledge about neuroplasticity along with Jane’s previous experiences taking workshops and continuing education courses prepared her to handle the density and complexity of HeadStrong’s material with ease.

You Got Something Out of It

The name of this theme was derived from a statement that Alice made during her follow-up interview, “no matter how heavy [the training] was, you got something out of it.” She identified several lasting and unexpected positive effects that the training had on her. Grace and Jane also identified positive and lasting outcomes.

Alice developed a stronger sense of self-identity as a mentor after the training. She reported feeling “a sense of more responsibility” and being more sure of herself. During the follow-up interview, she explained that feeling “more [like] a mentor” had helped her develop better boundaries with her mentee, and as a result, her self-care had improved:

Before ... [the mentoring] would ... drain my energy, and... now I know the boundaries, the steps I need to take to pull myself back ... So I don't get drained since that training, and hearing [the HeadStrong Director's] story... gave me tips on how to take better care of myself too. So yeah, self-care!

Alice also experienced a realization during the training that helped her approach her mentoring relationship differently. She said she learned “...how [the brain] changed. So you have less of a judgment when you're in a situation like I'm in with [my mentee], knowing that, that they really can't help it at times with some of the things. Because the brain has been changed.” Approaching her mentee with more understanding and less judgment was a lasting positive impact that the training has had on their relationship. Alice reported in the follow-up interview that the change in her mentoring style helped her mentee become “a little bit more proactive, like following up now with long-standing doctor's appointments. She wouldn't do that before, but I'm also working with her differently.”

Grace's most positive take-away from the training were the exercises about developing meaningful projects. She appreciated “[t]he value in being able to have a take away and an action plan for a project so an individual with a brain injury, who wants to accomplish something, can.” She viewed the tools as applicable and practical, and stated they have been used in the TBI support program for which she works with “half a dozen people” between November 2014 and February 2015, to “absolute” benefit. Grace also appreciated the quality of the training itself. She

stated, “this training that is given to individuals [with brain injuries] and caregivers through HeadStrong kind of kicks it up a notch.”

Jane experienced positive changes to her perception and awareness as a result of her participation in the HeadStrong training. She became “more mindful now of the concept of mentoring” and “saw [the exercises] as a way to help people stay focused, and [to help] people learn how to prioritize what the focuses should be.” Jane also agreed that it would be correct to say she valued the training.

Time of Day

All mentors felt that attending the HeadStrong training in the evening was not optimal. The time of day posed challenges for getting to and from the training as well as having the energy and attention to process the dense and complex information. For example, Grace stated, “I have challenges with vision and try not to drive at night, especially where I am not familiar with too much of the landscape.” Alice found that the time of day and the density of the content left her “brain tired” and less able to process and comprehend the dense and complex content in the training. Similarly, Jane stated, “I’ll be the first to say I’m not a night person and so I would have made the effort to come to a daytime training. And maybe got more [out of it].” Though previous educational experience and prior knowledge of neuroplasticity were the primary factors that affected the mentors’ abilities to process the dense and complex content of the training, Alice and Jane felt that the time of day also negatively impacted their ability to comprehend the training content.

Discussion

This study examined the experience of participating in the HeadStrong training course for mentors of people with TBIs and the effects that the training course experience had on the

mentoring relationship. Several themes emerged regarding the training experience itself, which included: Readiness to Learn, Density and Complexity of Content, You Got Something Out of It, and Time of Day.

Two studies in the reviewed literature briefly discussed the experiences and perceptions of mentors for people with TBI (Fraas & Bellerose, 2010; Struchen et al., 2011). There are similarities between the mentor experiences in those studies and the theme found in this study of You Got Something Out of It. Mentors in the Struchen et al. (2011) study indicated that they felt prepared by the training they received and they felt like they had the skills needed to help their mentees. They had a sense of increased self-efficacy as a mentor after the training they received. The mentor in the peer-to-peer case study (Fraas & Bellerose, 2010) indicated that he also experienced several positive changes in his self-perception as a result of his experience mentoring a young man with a brain injury. The mentor felt he was able to make a positive difference in the life of his mentee, he gained skills and knowledge about brain injuries, and he gained an increased sense of self-efficacy as a mentor. While the positive effects that the mentors in Fraas and Bellerose (2010) and Struchen et al. (2011) experienced were different than positive outcomes each that the mentors in this study experienced, there was still the similarity of getting something positive out of the experience.

Neither Fraas and Bellerose (2010) nor Struchen et al. (2011) described the experience of their mentors in enough detail to determine if the other three themes found in this study, Readiness to Learn, Density and Complexity of Content, and Time of Day, were also present in their research.

Implications

The results of this study imply that the experience of participating in the HeadStrong mentor training course and mentoring a person with TBI afterwards was impacted by the readiness of the mentor to be open to the concepts HeadStrong presented and the mentor's ability to process dense and technical information. The time of the day that the training was held, in the evening, was not the ideal time for any of this study's participants, but all participants still experienced positive changes.

The mentors appeared to come to the training with varied Readiness to Learn and differing capacity to process the Density and Complexity of Content. Vygotsky's zone of proximal development (Kozulin, 2003) is a concept that may help to understand participants' varied learning experiences and also inform continued refinement of the mentor training. For this concept, one can picture a venn-diagram of two overlapping circles, creating three zones (Figure 1). The zones depict the degree to which the learner can master the learning task. A learner who falls in the zone defined exclusively by the first circle is within their area of mastery; and is able to learn completely independently. The second zone, where the two circles overlap, is the zone of proximal development. This is where the learner is challenged and requires some guidance, or scaffolding, in order to master the learning (Kozulin, 2003). Learning is optimized in the second zone, as long as the learner receives effective support. The third zone, exclusively in the second circle, lies outside the learner's current abilities. The learner cannot learn effectively in the third zone, even with guidance (Kozulin, 2003). This structure can also inform teachers, who must attend to the amount and type of scaffolding needed by individual learners that is gradually lessened as the learner moves towards the area of mastery and gains more independent skills (Kozulin, 2003).

Grace began the HeadStrong training within the zone of proximal development, and during the training she benefitted from active engagement with the material. She was able to connect the content to her work with people with brain injury, which enabled her to shift in the direction of the area of mastery. Her high readiness to learn combined with her self-identification as a mentor, her previous educational experiences, and the belief that the concepts presented were relevant to her placed Grace within the zone of proximal development during the training. She was not yet in the area of mastery, as she found value in the training experience and would not have benefitted as much from studying the materials independently. She moved towards the area of mastery after the training because she frequently practiced using the HeadStrong exercises and concepts with her mentees. By the follow-up interview, Grace had begun to demonstrate a level of mastery of the content because of her frequent practice and application of HeadStrong's concepts.

Alice was in the zone of proximal development during the HeadStrong training, although at times she seemed to find the material difficult to access, suggesting that more scaffolding was needed. Small group work that allowed application of the concepts may have moved her more comfortably within the zone of proximal development. Though Alice had a high readiness to learn and found the concepts of the training relevant to her needs, she did not have previous experience processing dense and complex information in a short period of time. After the training, Alice was only able to explicitly recall one strategy, taking a time out in a conflict, and found much of the information "over [her] head." By the time of the follow-up interview, Alice had moved back to the area of inaccessibility, that is, without the direct guidance of the mentor training instructor, Alice was unable to recall or apply most of the concepts that were presented.

Jane began the training in the area of inaccessibility and remained there during the training. Interacting with her clients afterwards, Jane continued to perform in the area of inaccessibility in regards to the Headstrong training and concepts. In contrast to Alice, who was ready to learn but unable to process the information, Jane had the ability to process the dense and complex information but was not ready to learn. The concepts presented in the training she attended revolved around identity work and developing meaningful projects, whereas Jane wanted information about crisis management. Jane's experience had supported a perception of mentoring as a peer-to-peer experience, whereas HeadStrong presented a broader concept of mentoring. That disconnection between Jane's expectations and what was presented by HeadStrong further decreased her readiness to learn. Jane's ability to process dense and complex information was not enough to shift her into the zone of proximal development because she was not ready to learn about these concepts. As a result, Jane could not access the majority of the content presented in the HeadStrong training.

The variation in mentor placement in relation to the zone of proximal development indicates that some mentors who attend the training need differing types and amount of support in order to be able to maximize their learning. There are several strategies that may be useful for mentors to support them in the zone of proximal development as they learn the knowledge and skills necessary for effective mentoring of people with TBI.

The first strategy would be to decrease the pace and complexity of the information. This was the primary barrier for Alice. While she was able to process the content within the training because she had the support of those around her, she was unable to use more than one concept afterwards, when that support was gone and she was interacting with her mentee. It is known that learners who are new to a particular learning task, such as Alice, require scaffolding in order to

maximize their learning, and that one way of scaffolding the information is distilling it to the simplest and most important factors (Safeer & Keenan, 2005). If the information is delivered in a way that is too complex and overwhelming, the mentor cannot learn (Plass, Moreno, & Brücken, 2010; Safeer & Keenan, 2005). If the information was delivered in a less complex and dense manner, Alice may have been able to understand and recall more of the learning.

Another way of scaffolding that may have helped Alice retain more of the training would be offering more support after the training. This support could be in the form of small refresher courses, an online supplemental training resource, or follow-up conversations with a HeadStrong representative. By providing the mentors with additional supports after the training, the mentors can reinforce their learning while experiencing a lower cognitive load (Plass, Moreno, & Brücken, 2010). Cognitive load refers to the amount of mental effort that a learner must put forth while trying to process and learn. High cognitive load is associated with inefficient and poor learning, while lower cognitive load is associated with more effective learning and better outcomes (Plass, Moreno, & Brücken, 2010). As a result, providing supports after the HeadStrong training would reinforce the training concepts while the mentors are experiencing a lower cognitive load, and may reduce forgetfulness, reinforce the concepts that the mentors already learned, and help them to learn concepts that they were too overwhelmed to process during the original training.

A strategy that may have helped increase Jane's readiness to learn would be to advertise and prepare the mentors for the training experience more explicitly. Jane expected the training to be about peer-to-peer mentoring, and was surprised when it was not. If the advertising materials contained a brief description of HeadStrong's concept of mentoring, it is possible Jane would have been prepared. Spending some time at the beginning of the training to clarify who mentors

are, and how those roles can be filled by a variety of supportive people, may have helped make the concept clear to Jane and increased her readiness to learn.

The last strategy is to promote readiness to learn is to continue to provide training attendees with the opportunity to practice and apply content in a way very clearly relevant to their needs, as currently occurs in the small group work. Mentors learn best when the material is presented in a way that they find relevant to their own needs, and then they are more likely to use the concepts presented in their interactions with their mentees after the training. Grace was able to engage in the small group work in a way that directly linked to her work with people with TBI and Alice collaborated directly with her friend/mentee who had brought her to the training. Adult learners are motivated to learn about and explore solutions to problems they are currently experiencing (Mirriam & Bierema, 2014). This follows the concepts of problem-centered learning by engaging learners in problems that are personally relevant in order to maximize their ability to learn (Mirriam & Bierema, 2014).

All three participants identified the time of day that the training was held as problematic. HeadStrong may wish to consider scheduling the training during daytime hours to meet the needs of those attending the training.

Implications for Occupational Therapy

HeadStrong shares ideological values with the field of occupational therapy (OT). The American Occupational Therapy Association (AOTA) supports the idea of community integration for people with disabilities and values the benefits of engaging in meaningful occupations and projects (AOTA, 2015a; AOTA, 2015b). To be consistent with this idea, occupational therapists may find it beneficial to be aware of community-based resources that help to further the increased occupational engagement of clients after they no longer qualify for

OT services. HeadStrong is one such community-resource for clients with TBI or other brain injuries.

Occupational therapists may also find the themes in this study helpful when educating caregivers and clients. Research has shown that education by occupational therapists does not always meet the needs of clients or caregivers; health literacy among some client groups is lower than the educational materials provided by occupational therapists (Griffin, McKenna, & Tooth, 2006), and clients and caregivers who are not ready for the education given to them will not benefit from it (Hammond, 2004; Kendell et al., 2007). This study contained themes of Readiness to Learn and Density and Complexity of Content that reflect these difficulties identified in educational literature, which indicates that occupational therapists should account for client or caregiver readiness and health-literacy level when providing client or caregiver education.

Limitations

There are several factors that limit the conclusions drawn by this study. Data saturation was not achieved through the interviews with three participants. The three participants all had very different experiences and perceptions, so new codes and themes continued to emerge from each participant. Though data saturation was not reached, limitations of time and funding precluded the inclusion of additional participants. As such, there may be themes that are related to the HeadStrong training that did not emerge from this study. Additionally, this was the primary researcher's first experience performing qualitative research, which may have impacted the depth of information gathered in the interviews as well as the themes that emerged.

Conclusion

This study explored the experience of participating in the HeadStrong mentor training and the resultant effects on mentoring a person, or people, with TBI. Mentors had different levels of readiness to learn the concepts presented by HeadStrong, and also had different capacities of understanding dense and complex information. All three mentors experienced positive changes to some degree after participating in the training. Several implications of the themes were discussed that may be useful for HeadStrong and other mentor training programs for those working with people with TBI. It may also be helpful for occupational therapists who are educating clients or who exploring community-based programs that can enhance occupational engagement for people with TBIs. Due to the uniqueness of HeadStrong and the participants' experiences, more research should be conducted in this area.

References

- American Occupational Therapy Association (2015a). *Supporting community integration and participation for individuals with intellectual disabilities*. Retrieved from <http://www.aota.org/about-occupational-therapy/professionals/wi/intellectual-disabilities.aspx>
- American Occupational Therapy Association (2015b). *About occupational therapy*. Retrieved from <http://www.aota.org/about-occupational-therapy.aspx>
- Armed Forces Health Surveillance Center. (2012). *Incidence by armed forces branch*. Retrieved from http://www.defense.gov/home/features/2012/0312_tbi/chartaf_hires.jpg
- Bulinski, L. (2010). Social reintegration of TBI patients: a solution to provide long-term support. *Medical Science Monitor: International Medical Journal of Experimental and Clinical Research*, 16(1), PH14-PH23.
- Cannizzaro, M., Allen, E. M., & Prelock, P. (2011). Perceptions of communicative competence after traumatic brain injury: Implications for ecologically-driven intervention targets. *International Journal of Speech-Language Pathology*, 13(6), 549-559.
doi:10.3109/17549507.2011.596571
- Centers for Disease Control and Prevention. (2014a). *Rates of TBI-related deaths by age group – United States 2001-2010*. Retrieved from http://www.cdc.gov/traumaticbraininjury/data/rates_deaths_byage.html
- Centers for Disease Control and Prevention. (2014b). *Rates of TBI-related emergency department visits, hospitalizations, and deaths by sex – United States, 2001-2010*. Retrieved from http://www.cdc.gov/traumaticbraininjury/data/rates_bysex.html

- Centers for Disease Control and Prevention. (2014c). *Rates of TBI-related hospitalizations by age group – United States 2001-2010*. Retrieved from http://www.cdc.gov/traumaticbraininjury/data/rates_hosp_byage.html
- Centers for Disease Control and Prevention. (2014d). *Severe traumatic brain injury*. Retrieved from <http://www.cdc.gov/TraumaticBrainInjury/severe.html>
- Chen, A., Bushmeneva, K., Zagorski, B., Colantonio, A., Parsons, D., & Wodchis, W. (2012). Direct cost associated with acquired brain injury in Ontario. *BMC Neurology*, *76*, 0-12. doi:10.1186/1471-2377-12-76
- Daggett, V., Bakas, T., Buelow, J., Habermann, B. & Murray, L. (2013). Needs and concerns of male combat veterans with mild traumatic brain injury. *Journal of Rehabilitation Research and Development*, *50*, 327-340. doi:<http://dx.doi.org/10.1682/JRRD.2011.09.0168>
- Douglass, D., & Parker, A. (2014). *Headstrong mentor training manual*. Unpublished Manuscript.
- Fay, A. (2012). *Family perspectives on traumatic brain injury: Caregiver training*. Master's thesis, University of Puget Sound, Tacoma, WA. Retrieved from http://soundideas.pugetsound.edu/cgi/viewcontent.cgi?article=1032&context=ms_occ_therapy
- Feeney, T., Ylvisaker, M., Rosen, B., & Greene, P. (2001). Community supports for individuals with challenging behavior after brain injury: An analysis of the New York state behavioral resource project. *Journal of Head Trauma Rehabilitation*, *16*(1), 61-75.
- Fraas, M., & Bellerose, A. (2010). Mentoring programme for adolescent survivors of acquired brain injury. *Brain Injury*, *24*, 50-61. doi:10.3109/02699050903446781

- Gill, I., Wall, G., & Simpson, J. (2012). Clients' perspectives of rehabilitation in one acquired brain injury residential rehabilitation unit: A thematic analysis. *Brain Injury, 26*(7-8), 909-920. doi:10.3109/02699052.2012.661118
- Glang, A., Todis, B., Sublette, P., Brown, B., & Vaccaro, M. (2010). Professional development in TBI for educators: The importance of context. *Journal of Head Trauma Rehabilitation, 25*, 426-432. doi:10.1097/HTR.0b013e3181fb8f45
- Gomez-Hernandez, R., Max, J., Kosier, T., Paradiso, S., & Robinson, R. (1997). Social impairment and depression after traumatic brain injury. *Archives of Physical Medicine and Rehabilitation, 78*(12), 1321-1326. doi:10.1016/S0003-9993(97)90304-X
- Griffin, J., McKenna, K., & Tooth, L. (2006). Discrepancy between clients' ability to read and comprehend and the reading level of written educational materials used by occupational therapists. *American Journal of Occupational Therapy, 60*, 70-80. doi:10.5014/ajot.60.1.70
- Guise, E., Feyz, M., LeBlance, J., Richard, S-L., & Lamoureux, J. (2005). Overview of traumatic brain injury patients at a tertiary trauma centre. *Canadian Journal of Neuroscience, 32*, 186-193.
- Hammond, A. (2004). Rehabilitation in rheumatoid arthritis: A critical review. *Musculoskeletal Care, 2*, 135-151. doi:10.1002/msc.66
- Hanks, R., Rapport, L., Wertheimer, J., & Koviak, C. (2012). Randomized controlled trial of peer mentoring for individuals with traumatic brain injury and their significant others. *Archives of Physical Medicine and Rehabilitation, 93*, 1297-1304. doi:10.1016/j.apmr.2012.04.027

Hastings Center. (2014). *Family caregiving*. Retrieved from

<http://www.thehastingscenter.org/Publications/BriefingBook/Detail.aspx?id=2172>

HeadStrong. (2014a). *Mission*. Retrieved from <http://headstrongforlife.org/mission/>

HeadStrong. (2014b). *Mentor training program*. Retrieved from

<http://www.headstrongforlife.org/mentor-training/>

HeadStrong. (n.d.). *Mentor program for youth with brain injury, youth and mentor stories* [PDF

document]. Retrieved from [http://www.headstrongforlife.org/wp-](http://www.headstrongforlife.org/wp-content/uploads/2014/03/13-05-22-HS-Mentor-Stories.pdf)

[content/uploads/2014/03/13-05-22-HS-Mentor-Stories.pdf](http://www.headstrongforlife.org/wp-content/uploads/2014/03/13-05-22-HS-Mentor-Stories.pdf)

Hsieh, H. & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative*

Health Research, 15, 1277-1288. doi:10.1177/1049732305276687

Hibbard, M. R., Cantor, J., Charatz, H., Rosenthal, R., Ashman, T., Gunderson, N... & Gartner,

A. (2002). Peer support in the community: Initial findings of a mentoring program for

individuals with traumatic brain injury and their families. *Journal of Head Trauma*

Rehabilitation, 17, 112-131.

Holm, S., Schönberger, M., Poulsen, I., & Caetano, C. (2009). Development and predictors of

psychological adjustment during the course of community-based rehabilitation of

traumatic brain injury: A preliminary study. *Neuropsychological Rehabilitation*, 24, 202-

219. doi:10.1080/09602011.2013.878252

Insurers balk at TBI coverage: Clinical experts challenge “investigational” designation. (2007,

August). *ASHA Leader*. Retrieved from [http://business.highbeam.com/3/article-1G1-](http://business.highbeam.com/3/article-1G1-168049813/insurers-balk-tbi-coverage-clinical-experts-challenge)

[168049813/insurers-balk-tbi-coverage-clinical-experts-challenge](http://business.highbeam.com/3/article-1G1-168049813/insurers-balk-tbi-coverage-clinical-experts-challenge)

Inzaghi, M. G., De Tanti, A., & Sozzi, M. (2005). The effects of traumatic brain injury on

patients and their families. A follow-up study. *Europa Medicophysica*, 41(4), 265-273.

- Kendall, E., Catalano, T., Kuipers, P., Posner, N., Buys, N., & Charker, J. (2007). Recovery following stroke: The role of self-management education. *Social Science and Medicine*, *64*, 753-746. doi:10.1016/j.socscimed.2006.09.012
- Kolakowsky-Hayner, S., Wright, J., Shem, K., Medel, R., & Duong, T. (2012). An effective community-based mentoring program for return to work and school after brain and spinal cord injury. *Neurorehabilitation*, *31*, 63-73. doi:10.3233/NRE-2012-0775
- Koskinen, S. (1998). Quality of life 10 years after a very severe traumatic brain injury (TBI): The perspective of the injured and the closest relative. *Brain Injury*, *12*, 631-648.
- Kozulin, A. (2003). *Vygotsky's educational theory in cultural context*. Cambridge, United Kingdom: Cambridge University Press.
- Kruetzer, J., Seel, R., & Gourley, E. (2001). The prevalence and symptom rates of depression after traumatic brain injury: A comprehensive examination. *Brain Injury*, *15*(7), 563-576. doi:10.1080/02699050116884
- Landon, J., Shepherd, D., Stuart, S., Theadom, A., & Freundlich, S. (2012). Hearing every footstep: Noise sensitivity in individuals following traumatic brain injury. *Neuropsychological Rehabilitation: An International Journal*, *22*(3), 391-407. doi:10.1080/09602011.2011.652496
- Lefebvre, H., Cloutier, G., & Levert, M. J. (2008). Perspectives of survivors of traumatic brain injury and their caregivers on long-term social integration. *Brain Injury*, *22*(7-8), 535-543. doi:10.1080/02699050802158243
- León-Carrión, J., Serdio-Arias, L., Cabezas, F., Roldán, J., Domínguez-Morales, R., Martín, J., & Sanchez, A. (2001). Neurobehavioral and cognitive profile of traumatic brain injury

- patients at risk for depression and suicide. *Brain Injury*, 15(2), 175-181.
doi:10.1080/02699050117879
- Malec, J., & Basford, J. (1996). Postacute brain injury rehabilitation. *Archives of Physical Medicine and Rehabilitation*, 77, 198-207. doi:10.1016/S0003-9993(96)90168-9
- Marsh, N., Kersel, D., Havill, J., & Sleigh, J. (1998). Caregiver burden at 6 months following severe traumatic brain injury. *Brain Injury*, 12, 225-238.
- Merriam, S., & Bierema, L. (2014). *Adult learning: Linking theory and practice*. San Francisco, CA: Jossey-Bass.
- Moran, D. (2002). *Introduction to phenomenology*. London, United Kingdom: Routledge.
- Murray, H., Maslany, G., & Jeffery, B. (2006). Assessment of family needs following acquired brain injury in Saskatchewan. *Brain Injury*, 20, 575-585.
doi:10/1080/02699050600664590
- Nonterah, C., Jensen, B., Stevens, L., Cabrera, T., Jimenez-Maldonado, M., & Arango-Lasprilla, J. (2013). The influence of TBI impairments on family caregiver mental health in Mexico. *Brain Injury*, 27, 1287-1293. doi:10.3109/02699052.2013.812243.
- Oxford Dictionaries. (n.d.) *Readiness* [online]. Retrieved from
http://www.oxforddictionaries.com/us/definition/american_english/readiness
- Plass, J., Moreno, R., & Brünken, R. (2010). *Cognitive load theory*. New York, NY: Cambridge University Press.
- Relyea-Chew, A., Hollingworth, W., Chan, L., Comstock, B., Overstreet, K., & Jarvik, J. (2009). Personal bankruptcy after traumatic brain or spinal cord injury: The role of medical debt. *Archives of Physical Medicine and Rehabilitation*, 90, 413-419.
doi:10.1016/j.apmr.2008.07.031

- Safeer, R., & Keenan, J. (2005). Health literacy: The gap between physicians and patients. *American Family Physicians, 72*(3), 463-468.
- Saldaña, J. (2009). *The coding manual for qualitative researchers*. London, England: Sage Publications.
- Spikman, J. M., Milders, M. V., Visser-Keizer, A. C., Westerhof-Evers, H. J., Herben-Dekker, M., & van der Naalt, J. (2013). Deficits in facial emotion recognition indicate behavioral changes and impaired self-awareness after moderate to severe traumatic brain injury. *Plos One, 8*(6), e65581. doi:10.1371/journal.pone.0065581
- Struchen, M. A., Davis, L. C., Bogaards, J. A., Hudler-Hull, T., Clark, A. N., Mazzei, D. M... & Caroselli, J. S. (2011). Making connections after brain injury: Development and evaluation of a social peer-mentoring program for persons with traumatic brain injury. *Journal of Head Trauma Rehabilitation, 26*, 4-19. doi:10.1097/HTR.0b013e3182048e98.
- Teasdale, T., & Engberg, A. (2001). Suicide after traumatic brain injury: A population study. *Journal of Neurology, Neurosurgery, and Psychiatry, 71*, 436-440. doi:10.1136/jnnp.71.4.436
- Thomas, E., & Magilvy, J.K. (2011) Qualitative rigor or research validity in qualitative research. *Journal for Specialists in Pediatric Nursing, 16*, 151-5. doi:10.1111/j.1744-6155.2011.00283.x
- VanHeugten, C., Hendriksen, J., Rasquin, S., Dijcks, B., Jaeken, D., & Vles, J. (2006). Long-term neuropsychological performance in a cohort of children and adolescents after severe paediatric traumatic brain injury. *Brain Injury, 20*(9), 895-903. doi:10.1080/02699050600832015

Ventura, T., Harrison-Felix, C., Carlson, N., Diguisseppi, C., Gabella, B., Brown, A., ...

Whiteneck, G. (2010). Mortality after discharge from acute care hospitalization with traumatic brain injury: A population based study. *Archives of Physical Medicine and Rehabilitation, 91*, 20-29. doi:10.1016/j.apmr.2009.08.151

Wall, C., Glenn, S., Mitchinson, S., & Poole, H. (2004). Using a reflective diary to develop bracketing skills during phenomenological investigations. *Nurse Researcher, 11*(4), 20-29.

Wolters, G., Stapert, S., Brands, I., & VanHeugten, C. (2009). Coping styles in relation to cognitive rehabilitation and quality of life after brain injury. *Neuropsychological Rehabilitation, 20*, 587-600. doi:10.1080/09602011003683836

Xue-Bin, H., Zhe, F., Yu-Cong, F., Zhi Yong, X., & Qi-Wei, H. (2012). Health-related quality-of-life after traumatic brain injury: A 2-year follow-up study in Wuhan, China. *Brain Injury, 26*, 183-187. doi:10.3109/02699052.2011.648707

Ylvisaker, M., Hibbard, M., & Feeney, T. (2006). *Tutorial: Approaches to teaching: Traditional training versus apprenticeship*. Retrieved from http://www.projectlearn.net/tutorials/training_vs_apprenticeship.html

Zonfrillo, M., Durbin, D., Winston, F., Xuemei, Z., & Stineman, M. (2014) Residual cognitive disability after completion of inpatient rehabilitation among injured children. *Journal of Pediatrics, 164*, 130-135. doi:10.1016/j.jpeds.2013.09.022

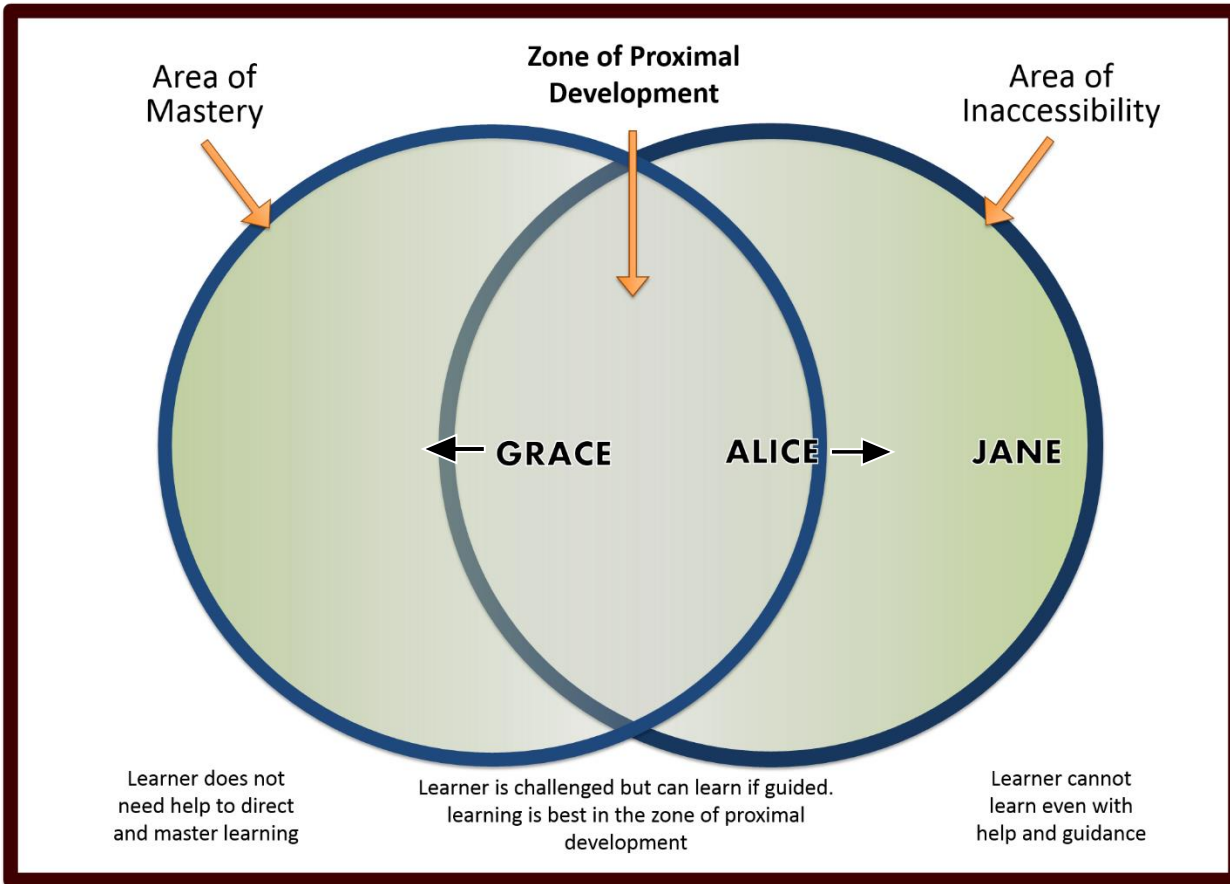
Appendix

Grand Tour Questions: Tell me about what taking the HeadStrong mentor training course was like? Tell me about how your experience as a mentor to [person with TBI] has been before and after completing the HeadStrong mentor training?

More Specific Guiding Questions (as needed):

- Experience of the training course
 - Tell me about why you signed up for the HeadStrong training.
 - How long ago did you take the training?
 - What stood out to you about the training?
 - What do you remember feeling like during and after the training?
 - Examples if needed: Interested, overwhelmed, sad, excited, etc.....
Why did you feel that way?
 - What topics were of interest to you? Were those topics covered?
 - What topics did the training cover that you did not need or find useful?
 - Did the training reflect your needs?
 - Logistics of training
 - How was the experience of registering for and getting to the training course?
- Experience mentoring before the training, if recalled
 - What were areas you needed more help/information about?
 - What were areas you felt you did well in?
- Experience mentoring after the training
 - Did you try to use any information from the training?

- What worked well?
 - What worked a bit?
 - What did not work at all?
 - What created problems?
- What were barriers in applying the training?
 - What helped you in applying the training?
 - What did you find out you wanted more training in while you were trying to use it?
 - Are there things that training cannot prepare you for?



➡ : indicates projected direction that the mentors were moving in regards to the HeadStrong training concepts, at the time of follow up interviews, approximately four months after participating in the training. Jane has no direction indicator because she remained in the area of inaccessibility

Figure 1: Mentors in relation to the zone of proximal development while participating in the HeadStrong mentor training

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