

TRAUMATIC BRAIN INJURY: RECLAIMING 'SELF' THROUGH VOLUNTARISM

A Thesis
by
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Abstract

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This research investigated how volunteering influenced identity construction in individuals with traumatic brain injury. Focus group data and quality of life/depression assessments of three participants with TBI, was examined before and after volunteering experiences. A phenomenological qualitative approach was utilized to identify themes that emerged in both focus groups relative to identify. Pre and post assessment scores of the Brain Injury Grief Inventory (BIGI), Hospital Anxiety and Depression Scale (HADS), and LaTrobe Communication Questionnaire were analyzed qualitatively. Results indicated volunteering did not profoundly alter the participant’s sense of self, but it appeared as a catalyst in process of reclaiming the self.

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Table of Contents

Abstract.....	iv
Acknowledgments.....	v
Tables	17
Introduction	2
Literature Review.....	2
Methods.....	13
Results.....	19
Discussion.....	38
Conclusion	48
References.....	50
Appendix A.....	56
Appendix B.....	57
Vita.....	58

Traumatic Brain Injury: Reclaiming 'Self' Through Voluntarism

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Introduction

Numerous researchers have explored identity development in the Traumatic Brain Injury (TBI) population (Carroll & Coetzer, 2011; Fraas & Calvert, 2009; Muenchberger, Kendall, & Neal, 2008; Ylvisaker, Mcpherson, Kayes, & Pellett, 2008). These studies indicated a significant correlation between constructing a positive sense of self and engaging in meaningful activity among individuals with TBI. This study utilized a qualitative approach to uncover how identity construction might develop through a specific type of meaningful activity: volunteering.

Literature Review

Many people have experienced the sense of frustration when attempting to get to a specific destination with a poor GPS signal. Brought on by mountains, rural areas, or a sudden storm, many can understand that insecure sense of uncertainty prompted by the monotone hum of, “lost satellite reception.” This sense of anxiety and confusion motivated by a fuzzy reception may give the reader an idea of what it is like to be an individual with Traumatic Brain Injury (TBI). Individuals with TBI begin their lives like everyone else, moving along a particular route with the goals, dreams, expectations that fundamentally define them as an individual. When a TBI occurs this self-journey becomes altered. Most individuals maintain memories and aspirations of the post injury self; but, with instantly acquired limitations, discovering a sense of direction becomes difficult to navigate. Many studies (Carroll & Coetzer, 2011; Fraas & Calvert, 2009; Muenchberger, Kendall, & Neal, 2008; Ylvisaker, Mcpherson, Kayes, & Pellett, 2008) focus on not only understanding that loss of identity, but also on uncovering methods to redirect and empower individuals with TBI to reclaim a satisfying sense of self.

TBI centrally disrupts one's sense of self because of the nature of the injury. TBI occurs when either a blunt or penetrating object hits the head and/or a rapid movement of the head causes the brain to move back and forth within the skull. A majority of injuries incite damage to the frontal and temporal lobes (Bhatnagar & Andy, 2012). Damage to the frontal lobe can be detrimental to one's identity as this lobe is responsible for high mental functions such as problem solving, planning, judgment, thought inhibition, awareness, and personality (Heilman & Valenstein, 2011). Temporal lobe damage can cause auditory comprehension challenges and short-term memory loss (Kolb & Whishaw, 2015). It is significant to note that no one injury is the same and, neuronal connections and pathways are often unique, therefore there is variation among individuals. Any individual may experience one or all of these side effects ranging in severity. Many studies have shown trends when it comes to the experience of TBI in relation to identity to include: remorse for the pre-injury self (Carroll & Coetzer, 2011, Cloute, Mitchell, & Yates, 2008; Kovarsky, Shaw, & Adingono-Smith 2007; Nochi, 1997), passivity (Cloute, Mitchell, & Yates, 2008; Nochi, 1997), the theory of learned helplessness (Lubusko, Moore, Stambrook, & Gill, 1994; Sweeny 1994) the struggle for positive identity construction (Fraas & Calvert, 2009; Muenchberger, Kendall & Neal 2008; Ylvisaker & Feeney, 2000; Ylvisaker et al., 2008), and the importance of social capital in conceptualizing identity (Douglas 2010; Fraas & Calvert, 2009; Kilov, Togher, & Grant, 2009; Struchen, Pappadis, Sander, Burrows, & Myszka, 2011; Ylvisaker & Feeney, 2000).

Identity and Communication

Positive identity construction relies heavily on social communication. Humans are social beings; as a result, positioning ourselves in this world depends on the quality and extent of our relationships with others. Harré and Van Langenhove (1999) define "position"

as a relationship between “I” and “another.” This relationship is a placement of self that is fluid, constantly adapting to the opinions and negotiations of others. That is to say, one’s perceived identity is constantly molded by one’s interactions with people. As Tirado and Gálvez (2007, p. 21) note, “conversations constitute the essential element of social reality. In them our daily reality is reproduced and transformed.”

This relationship between communication and identity even affects the way Speech Language Pathologists (SLPs) conduct their services. For instance, there is concern regarding clients in the school system participating in the pullout method (in which students are taken out of the classroom for speech-language services) because of the social stigma placed on the student (Dawson, 2014; Madge, Affleck, & Lawenbraun 1990; Theoharis & Causton-Theoharis, 2010). Students see their communication impairment as something that separates them from the group. In other words, communication restrictions become negative facets impressed upon one’s developing identity. Humans are social beings, uniquely defined from other species by the connections and relationships built with others (Herrmann, Call, Hernandez-Lloreda, Hare, & Tomasello, 2007). Therefore it can be argued that communication disorders, by impeding one’s outlet to others, directly disrupt a positive construction of identity. It is no coincidence that depression is measured by withdrawal and disconnect from others, while satisfaction is dependent on usefulness and personal connections (Du, Bernardo, & Yeung, 2015; Girard, Cohn, Mahoor, Mavadati, Hammal, & Rosenwald, 2014; Shanker, Rafnsson, & Steptoe, 1987). Positive identity construction is interwoven into our ability to connect with each other and our world. SLPs need to consider identity construction because meaningful communication depends on it.

Loss of Former Self

Individuals with TBI often struggle with identity while mourning their pre-injury self. A notable study defined the mourning of the former self in terms of a void (Nochi, 1997). This void is defined as, “the disturbing unknown that people with traumatic brain injury may find when they try to understand themselves”(Nochi, 1997, p.538). This study looked at narratives prompted with open-ended questions of four individuals with TBI. A common theme that arose early in the recovery process was a sense of incompleteness that appeared to threaten their sense of self. This incompleteness initially results in a passive view of self, which requires the assistance of others for their wants and needs. This theme of passivity arose in a later study that consisted of personal narratives from six individuals with TBI (Cloute, Mitchell, & Yates, 2008). One individual described a feeling of being present in body but not in mind. This client felt that he lacked ownership over his own body. Another individual described themselves as being at the mercy, of the symptoms and excessively reliant on the speech pathologist. Others felt “held back” and “let down” by their caregiver—often feeling pushed aside or in a “position of abandonment” (Cloute, Mitchell, & Yates, 2008, p.662-663). The study concluded that there was a, “common pattern of passive positioning” where individuals often characterized themselves in a state of disempowerment. Kovarsky, Shaw, and Adingono-Smith (2007) highlighted how SLPs might enable an individual with TBI to see himself or herself not only as passive, but also as less of a person. This study focused on how one particular therapist reinforced the patients’ sense of self-loss in therapy sessions. Here, the SLP neglected opportunities to foster identity when this concept came up naturally in conversation. In one such incidence, an individual conveyed remorse about no longer being able to explain concepts as she did when she was a

schoolteacher. The SLP failed to pursue this concern, but rather said ‘okay’ and proceeded on with the previous dialogue. Additionally, this research concluded that too much emphasis was placed on the patients’ losses and little weight on their strengths. This disproportionate focus perpetuates the idea that these individuals were ‘damaged goods.’ When interactions draw more attention to an individual’s deficits, it enhances the sense of inadequacy and loss. Feelings like this often lead the client to compare their present self to their old self, consequently viewing their current selves in a negative light. This negative perspective was highlighted in a quantitative study of 29 adults who completed six questionnaires that examined the emotional impact of TBI (Carroll & Coetzer, 2011).

Significant changes were displayed in a wide range of areas to include: decreased feelings of happiness, interest in life, levels of capability, independence, calmness, as well lower self esteem and increased feelings of hopelessness. As can be expected, “individuals with the greatest change of self concept were most likely to report poorer adjustment and feel negative about themselves”(Carroll & Coetzer, 2011, p.301). In addition, increased levels of awareness were linked to a greater level of depression and increased psychological stress. This research highlights how during that early phases of recovery after TBI, these individuals experience a sense of passivity and uncertainty in the personal conceptualization of identity.

Learned Helplessness

Often what may result from a feeling of lost identity and passivity is an excessive reliance on other individuals. The theory of “learned helplessness” was originally coined by American psychologist Martin Seligman and occurs when an organism encounters unpleasant stimuli and becomes unable to overcome that unpleasant experience because of a perceived

inability to control the situation (Seligman & Maier, 1976). Sweeny (1994) described this theory in relation to TBI.

“When the helping or caretaking behavior extends beyond the scope of those needs that the individual cannot meet independently, learned helplessness or learned dependency may result” (Sweeny, 1994, p. 213).

This process begins when the caregiver feels the significant loss of the individual with TBI and overcompensates with excessive assistance. The individual may initially need the extra support. However, if complete loss of independence continues, the individual learns to always rely on others even when possessing the ability to perform the activity. This occurs often when the individual has the perceived belief that what he or she does is unimportant. The individual has lost a sense of “personal self worth and control on the world” (Sweeny, 1994, p. 213).

As a result of the symptoms associated with TBI (irritability, forgetfulness, inability to assess appropriate social responses, etc.), many individuals find it difficult to maintain control of their day-to-day lives (Lubusko et. al., 1994). This loss of control can develop into feelings of depression, which then leads to decreased motivation, ultimately crippling one’s potential to actively engage in the world. Lubinski (1995), while assessing individuals with dementia, concluded that once one perceives their role in communication as insignificant, one ceases all efforts to communicate, falling into a state of “learned helplessness.” The same is true of TBI. “Learned helplessness” hinders identity development by encapsulating the individual with the belief that others know what is best for them. This attitude creates the perception that they are a stranger to their own wants and needs. These individuals essentially become a stranger to themselves.

Positive Identity Development

Later studies focused on methods to help these individuals reestablish a positive sense of self to counteract this self-deprecating attitude expressed by many individuals with TBI. Ylvisaker et al.(2008) proposed metaphorical identity mapping as a coping mechanism. In this study, five individuals were paired with trained facilitators to construct maps based on a hero or fictional character the patients admired and aspired to be. The client and facilitator collectively drew a circle map with the metaphoric character in the center and different attributes attached to include: facts, goals, feelings, affiliations/associations, and action strategies. In the following sessions, the pairs would work together to set up goals based on this metaphor and work to achieve them. Results indicated that patients often had difficulty remembering what was completed in the previous session and thus making appropriate connections. However, metaphorical identity mapping was successful in empowering individuals with TBI. Many individuals not only, “reported a feeling of improved mood resulting from being involved in a meaningful activity” but when asked about the activity, “participants often referred to the sense of achievement they felt when they achieved goals that they had set for themselves” (Ylvisaker et. al., 2008, p.731).

Muenchberger, Kendall, and Neal (2008) found that maintaining a positive sense of self was a tentative balance of grappling with past loss and acceptance of their present ability. Individuals described a circular nature of identity with no clear end. Each identified three fluctuating roles of identity which included: (a) contraction defined as an emphasis on their lack of ability and limited self confidence, (b) expansion identified as a belief in a personal journey with independent decisions and goal making, and (c) tentative balance which is a process described as vulnerable where the individual attempts to construct the self while in a

dynamic struggle between contraction and expansion. The study suggests that clinicians should allow for a flexible setting to enable clients to navigate the limbo between pre and post injury self. Therapy needs to focus on creating new possibilities while accepting that clients will always struggle with questioning their ability and sense of purpose.

Another narrative study considered how individuals with TBI developed productive lifestyles after brain injury by identifying factors that lead to a successful recovery (Fraas & Calvert, 2009). Similar to the concept of contraction, individuals described mourning for their old life and withdraw from social interaction. This feeling of loss took many challenging years to accept. Individuals identified flexibility, adaptability, and positivity as key attitudes that lead them to acceptance. This study delved into specific ways in which individuals were able to suppress a self-deprecating attitude. Acceptance of both who they had become and who they no longer were was a major factor in gaining a positive view on their identity. That acceptance liberated them to allow for new identity roles and goals. Ultimately individuals were empowered through engaging in activities within the community and assisting others who had experienced similar trauma. This study further solidified theories proposed in earlier studies, which demonstrated that reconstruction of a positive sense of self often results from meaningful life activities (Ylvisaker & Feeney, 2000).

Social Capital

The previously discussed research emphasizes the clear link between positive identity reconstruction and actively engaging in activities that are perceived as meaningful (Ylvisaker & Feeney, 2000). Additional research has examined how social capital assists these individuals with TBI in reclaiming their identity. One such study evaluated 184 individuals with TBI using a series of questionnaires that assessed individuals overall social

involvement, behavioral functions, and social communication (Struchen et al., 2011). Results indicated that there was a significant correlation between social communication abilities and social integration. Kilov, Togher, and Grant (2009) took the idea of social integration a step further and looked specifically at how involvement with friends impacted the individuals' ability to perform a task. The individual with TBI sat in a room paired with a friend and determined the name and function of an unfamiliar object. Different speech moves were calculated and compared. Results showed that there were relatively equal contributions between the individuals with TBI and their friend pair compared to the control individuals and their friend pair. Therefore, individuals with TBI did not differ in how they problem solved with friends. When individuals with TBI believe they have an equal knowledgebase to their counterpart they feel empowered to engage in meaningful interactions.

Both these studies support the idea that interaction with others while engaging in meaningful activities leads to a sense of self-fulfillment and agency, despite the limitations of brain injury. Douglas (2010) stressed the importance of the connection between meaningful activity and self-identity construction by highlighting the significant contributions of Mark Ylvisaker. Douglas stressed that most individuals with TBI complain of being stigmatized by their limitations. Their injury has made them “A client—a brain injury—rather than the person with a brain injury” (Douglas, 2010, p.198). The injury becomes the summation of their identity. However, many of these individuals, as highlighted by one patient, “would just like to do something useful”. Douglas underlined a central theme present in Ylvisaker's work: Meaningful activity is central to self-identity construction. Douglas related this idea to a study he completed in 2006 which further emphasizes the effectiveness of meaningful involvement. Of the 25 participants evaluated, those that regularly participated in community

activities showed improved mental health, reduced depression levels, and attributed the experience as having a positive influence on their sense of self. In looking back at these individuals' self-narratives, empowerment stems directly from gaining a sense of independence by reentering their communities and becoming involved (Fraas & Calvert, 2009).

Voluntarism Promoting Self –Purpose

From these studies one can gather that the primary struggle of individuals with TBI is a positive self-image. Numerous studies support the method of incorporating social interaction and meaningful activities to boost self-satisfaction (Li & Ferraro, 2005; Mellor, Hayashi, Firth, Stokes, Chambers, & Cummins, 2009; Thoits & Hewitt, 2001). The research for this study evaluated a specific form of social integration: volunteering. Research on volunteering has shown that volunteers of numerous backgrounds (to include age, gender, life style, etc.) report a more positive sense of self, fulfillment, and purpose than those who do not volunteer (Li & Ferraro, 2005; Mellor et. al., 2009; Thoits & Hewitt, 2001). Mellor et al. (2009) evaluated 1,175 individuals and found that volunteering was significantly related to well being. Results revealed that there is a direct relationship between voluntarism, and perceived control and optimism. Perceived control and optimism are two attributes individuals with TBI strive for, but struggle, to achieve. The research also shows how volunteering contributes to a positive sense of self. For instance, one study revealed beneficial effects of formal volunteering on depression (Li & Ferraro, 2005). Results of Thoits and Hewitt (2001) revealed that volunteer work enhances six aspects of well being to include: happiness, life satisfaction, self-esteem, physical health, depression, and sense of control over life. Ultimately it is this feeling of worth that is effective in facilitating an

improved mood resulting in positive formation of self. While this research indicates that volunteering may serve as a relevant rehabilitation technique, this is the first available research that evaluated how this activity would influence identity construction in individuals with TBI. This study sought to examine and describe the experiences of individuals with TBI as these individuals engaged in volunteer activities. This research undertook a descriptive focus: 1) to seek insight into personal perspectives of individuals with TBI based on their involvement in charitable service; and 2) to determine if there was a changed perspective, to what extent? And what impact, if any, did that perspective have on identity construction?

In a recent documentary, which follows a female aphasic client post stroke, there is a scene in which she is speaking to a group of clinicians (Lynch, Robinson & Sodderland, 2014). The client expresses empathy for clinicians whose biggest challenge is assisting patients who are, “continually being defined by what [they] can no longer do...” She recommends that clinicians focus on a patient’s undiscovered capabilities rather than all their inabilities. Near the conclusion of this film she states, “ I don’t need to return to my old life, this is a new existence, a new dynamic where I wasn’t defined by my limitations but rather about endless possibility.” By volunteering individuals with TBI may be able to reclaim a new existence that fosters feelings of control and optimism, as shown by Mellor and colleagues (2009). The focus is shifted from limitations to agency (i.e., “endless possibility”) and perhaps that shift facilitates the refinement of wellbeing that was identified by Thoits and Hewitt (2001).

Methods

Design

This study took a qualitative approach to analyzing the results. Qualitative analysis is advantageous when the researcher is taking on a learning role and seeking to understand social phenomena, particularly when the research question pursues “how” a particular phenomena occurs rather than “why” it occurs (Damico, Simmons-Mackie, Oelschlaegers, Elman, & Armstrong, 1999). Such an approach is ideal for this study as it considered questions of identity and how an individual constructed that identity based on new experiences—volunteering. A qualitative approach also allows for phenomena to be examined in a naturalistic setting, which is essential for understanding authentic feelings and beliefs of individuals with TBI in context. Additionally, this method enables an open and unstructured approach to research, which yields useful and developing descriptive data that may, otherwise, go unnoticed. Damico et al. (1999) further support qualitative analysis noting, “... actual descriptions of social action in terms of strategies, activities, devices, behaviors, and knowledge systems rather than using predetermined categories or numbers enables a better understanding of those behaviors and patterns of interaction” (p.655). Therefore, eliciting descriptive data from conversational focus groups of individuals with TBI before and after engaging in charitable service, generated a richer understanding of participants’ possible changes in identity construction through personal anecdotes regarding: emotional well-being, confidence, social relationships, and sense of purpose. Ultimately, a qualitative approach allowed the researcher to have a greater understanding of the subject’s personal perspective on the effect of volunteering and determine if, in fact, volunteering should be used as a therapy technique.

Focus Groups are the preferred method of study used by researchers who wish to enhance disclosure, gain additional detail on personal accounts, and desire “the opportunity observe co-construction of meaning” (Wilkinson, 1998 p.329; Leung & Savithitiri, 2009). One might be under the impression that group studies may intimidate the individual participant resulting in reduced disclosure, but more often it is the structured interview where this intimidation occurs. Group members who share the same experience have a greater rapport, which is more inviting than the removed interviewer (Wilkinson, 1998). Members often ask questions the researcher cannot, that both challenge and affirm each other’s responses. Therefore, focus groups have a greater likelihood than structured interviews of offering more detailed and authentic accounts. Eliciting a spontaneous interchange lead to profound insights for this research as identity appears to be not limited to the individual, but rather, an interplay of ideas that converge in a social context of shared experience. As is shown by Wilkinson’s (1998) study, construction of meaning is an integral part of everyday social contexts:

Such beliefs [patient’s ideas about what causes a disease or what cures an illness] are forged and shaped in everyday social contexts: in discussions between family members in the home, in conversations with others at school and at the work place, in exchanges with medical professionals or members of self-help groups. People build their ideas, beliefs, understandings and worldviews in interaction with others.

(p. 338)

A focus group approach was used to allow the researcher to analyze the co-formation of meaning as it was happening. In other words the researched had the opportunity to witness how each individual created meaning in relation to identity from the experience of

volunteering. This research also incorporated three surveys, the Brain Injury Grief Inventory (BIGI; Ruddle, Coetzer, & Vaughan, 2012), Hospital Anxiety and Depression Scale (HADS; Dahm, Wong, & Ponsford, 2013) and the La Trobe Communication Questionnaire to (LCQ; Douglas, Bracy, & Snow, 2007) which were analyzed qualitatively.

Surveys

The BIGI determines an individual's level of grief post TBI and measures quality of life through a 20-item survey in which individuals rank (never, sometimes, mostly) reactions in response to questions addressing: loss, depression, avoidance, social connections etc (Ruddle, Coetzer & Vaughan, 2012). The HADS, through initially designed for hospital patients, has been administered to individuals with TBI to determine anxiety and depression levels (Dahm, Wong, & Ponsford, 2013). This assessment is also a survey measuring quality of life in which individuals rank (often, sometimes, not often, and seldom) in response to questions regarding: enjoyment, humor, worry, interest, etc. (Snaith, 2003; Zigmond & Snaith, 1983). The LCQ was designed to measure perceive communication ability of individuals with a TBI. Like the previous two assessments the LCQ is also a survey in which participants rank (never, sometimes, often, usually) in response to questions addressing levels of engagement with a conversation partner (LCQ; Douglas, Bracy, & Snow, 2007). Each participant completed all surveys before and after the volunteer experience. Changes in pre and post survey results were described.

Recruitment

The researcher recruited participants from the local community through healthcare professionals, the office of disability services at a regional campus of a state university in the southern United States and local clinics in the same area. A flyer was distributed giving

a brief description of the study and the researcher's contact information. A brief meeting was held prior to the study to discuss risks and benefits and answer questions by prospective participants.

Participants

The study consisted of three self-consenting adults who suffered a traumatic brain injury but had no other known neurological problems. Individuals were not restricted by the severity of the injury, but were required to have a documented medical brain injury. Participants in this study were all English speakers, and at least one year post-injury to account for spontaneous recovery. Participants were between the ages of 18 and 65. Exclusion criteria included participants who had provided charitable services, free of charge, in the 3 months prior to joining the study. IRB approval was granted prior to recruiting participants. Participants were informed of the risks and benefits of partaking in this study. I reviewed the risks and benefits of involvement, listed on the consent form, at an informational meeting and answered any questions or concerns before a participant signed the form. As is typical of research relation to human subjects, there was a risk regarding breach of privacy, however every measure was taken to keep data private and maintain anonymity (e.g., pseudonyms were assigned and identifying data was made anonymous). Participants were informed he or she could leave the study at any given time if he or she felt the need to do discontinue for any reason. By participating in this study, individuals benefited from gaining satisfaction in the knowledge that he/she contributed to research that may result in positive outcomes for brain injury rehabilitation.

JB was a 40-year-old male who fell 25 feet from scaffolding while working construction and landed headfirst resulting in a left frontal temporal intracranial hemorrhage

in March of 2012. He had surgery 2 years prior to the study that damaged his optic nerve and resulted in blindness. JB was no longer working at the time of the study, but identified productive activity such as gathering firewood, hiking, and riding his stationary bike. He also indicated prior and present involvement with two local support groups for individuals with TBI. JE was 54-year-old female who contracted encephalitis in 2013, followed by a more recent meningioma 4 months prior to the study. JE also did not work at the time of the study, due to reported struggles with continued exhaustion. SW was a 63-year-old male who fell down a flight of stairs in 2009, which resulted in a skull fracture and massive hemorrhage in both hemispheres along the frontal and temporal lobes. Prior to his injury he was a professor at philosophy professor at Appalachian State University. He attempted to continue work post injury, but was unable to due so due to side effects with his injury as well as sleep Apnea.

Table 1: Participant Characteristics

<i>Demographics</i>	JB	JE	SW
Age	40	54	63
Gender	M	F	M
Cause of Injury	Fall	Tumor	Fall
Type of Injury	Left frontal-temporal intracranial hemorrhage	Encephalitis	Bilateral temporal-frontal skull fracture
Years Post Injury	5	4	8

Procedures

At the beginning of the study, before the first focus group, all participants were administered the BIGI, HADS, and LCQ surveys and engaged in a 60 minute focus group. Focus groups were used to extract detailed personal anecdotes through an open-ended 60 min open discussion, guided by the researcher, which was filmed for later analysis. After the focus group, the researcher provided participants with a volunteer hours recording form

(Appendix A), and a condensed list of volunteer organizations in the local area (Appendix B) to assist with volunteer enlistment.

JB chose to complete all his hours through the humane society by making phone calls to obtain donations from local businesses throughout the community. JE initially had difficulty acquiring a volunteer experience through the pre-provided list. The researcher worked with her to find a volunteer experience that matched her needs. She completed all of her hours with the VocaliD, an online voice banking service that donates voices to individuals who cannot use their own voice. SW attempted to work with the Land Conservancy but was unable to find a volunteer opportunity through that organization that fit his needs. He decided to work on an interdisciplinary grant that involved a robot, MAX, that is utilized to assist individuals with TBI to communicate. SW had difficulty remembering to document his hours, but claims to have completed all 15 through researching and writing for this grant project.

Table 2: Volunteering Experiences

Participants	JB	JE	SW
Volunteer Organization	Humane Society	VocaliD	Interdisciplinary Research Grant
Volunteer Activity	Phone calls	Voice Banking	Research/Writing
Hours Completed	15	15	?

Participants completed 15 hours of volunteer service, over a three-month time frame. Thus, three months later, when all members had completed their volunteer hours, another meeting was scheduled and the BIGI, HADS and LCQ surveys were administered again to all participants. Participants engaged in another video & audio recorded 60-minute focus group in which the participants were encouraged to share insights on their experiences volunteering. This discussion was again guided, by open-ended questions.

Analyses

Both pre and post volunteering focus group discussions were recorded and such recordings were transcribed, with large margins on either side for analytic comments. This data was analyzed, using a phenomenological approach, for themes relative to their experiences of volunteering. As qualitative analysis is a personal process, the focus was on gaining insight in how the group constructed meaning in descriptive terms of identity, rather than measuring the frequency of a certain response (Smith & Osborne, 2008). The transcription was then separately read and reread by graduate student and doctoral professor whom separately noted interesting and significant statements. The two researchers then compared analyses in order to triangulate the data and integrated these insights into cohesive themes that emerged in the focus groups. Similarly, the survey questionnaire data was scored and descriptively analyzed to examine differences between the pre and post volunteering administration.

Results

The following table provides the pre and post volunteering results from the BIGI, HADS, and LCQ scores for all participants.

Surveys

Table 3: Pre and Post Focus Group Surveys

PARTICIPANT	JE		JB		SW	
Time	Pre	Post	Pre	Post	Pre	Post
BIGI	F1: 9	F1: 5	F1: 6	F1: 3	F1: 18	F1: 14
	F2: 15	F2: 15	F2: 14	F2: 17	F2: 12	F2: 11
HADS	D: 5	D: 2	D: 4	D: 2	D: 8	D: 4
	A: 6	A: 5	A: 5	A: 4	A: 14	A: 13
LCQ	54	64	46	50	74	83

BIGI: A high F1 score indicates a high level of grief and a high F2 indicates a low level of grief. F1 ranges (0-22) and F2 ranges (0-18)

HADS: Anxiety (A) and Depression (D) are rated 0-7 normal, 8-10 borderline, and 11-21 abnormal.

LCQ: Higher scores indicate increased perceived difficulty.

Baseline results from the BIGI suggest JE and JB did not have atypical levels of grief, where as scores for SW indicate a much higher level. Following the volunteer experience, scores for JB and JE also indicate typical scores for grief and show a slight improvement indicated by a drop in F1 scores. However, it should be noted that JB's F2 score did decrease by 3 points, which may contraindicate the drop in F1 scores; as a decrease in F1 reflects a increase in perceived grief. SW's F1 scores also decreased suggesting improved levels of grief. Baseline results of the HADS revealed JE and JB had normal levels of anxiety and depression. SW rated borderline for depression and abnormal for anxiety at baseline. Post volunteering scores indicate JE and JB remain within normal limits for anxiety and depression. SW's scores improved revealing normal scores for depression. Results from the LCQ suggest decreased perceived communication ability as indicated by an increase in scores by all participants.

Themes

Five major themes emerged from the focus group data in relation to identity:

1. Emotions

2. Fatigue
3. Challenges
4. Coping Strategies
5. Achievements

These themes are discussed in detail in the following sections.

Emotion.

In the pre-volunteering focus group JB and SW both reported that impulsive anger was a significant problem that accompanied their injury. Both participants were aware of impulsiveness associated with this emotion and independently introduced this topic, describing it as a re-occurring challenge. This is clear from the excerpt below.

Excerpt 1: Impulsive Anger

<p>JB: I still deal with that. The emotional part of it at night. SW: Oh, big time! JB: You know with my sweetie and she could say something. I would just turn into the “Incredible Hulk”. JE: Uh, oh. JB: Yeah! SW: Oh, yeah. My a... JB: Which my awareness of it has definitely increased. JE: Well that’s a blessing. SW: I’m on that same path. Particularly, let’s say twenty ten, twenty eleven, twenty thirteen, that (<i>unintelligible word; gestures with hands an inch a part</i>). Oh I’d get pissed off in a heartbeat. I mean I would just go off on you and not even realize it.</p>

Both JB and SW describe “anger” as this instantaneous reaction that takes hold of the moment without much anticipation by them or the conversation partner. JB uses the metaphor of the incredible Hulk, suggesting his response to this emotion is amplified beyond a reasonable reaction to the situation; he continues a few lines following the excerpt above, “it’s something that just takes over you.” JB acknowledges he is improving in recognizing these instances, whereas SW appears to still struggle with identifying an angered reaction in

the moment. Both agree this response is one that is unreasonable, for instance SW describes his thoughts following the instance as, “that was not cool at all;” However, both participants are challenged by identifying that angered state, and considering the most appropriate response before reacting.

In the post-volunteering group impulsive “anger” was not mentioned as prevalently. SW makes one comment describing anger in this manner, “You know [individuals with] TBI have a hard time in the beginning communicating. I did. (JE and SR nod) People would think I was angry, you know.” However, frustration appeared as a more frequent theme. JB demonstrates this emotion when discussing possible ramifications were worker’s compensation to find out about his abilities to volunteer or work.

Excerpt 2: Worker's Compensation

<p>JB: That’s if Worker’s Comp doesn’t take two thirds of my weeks check away. JE: Yeah, yeah thank you very much! JB: If I do get a job. Or volunteering, don’t tell them I did any volunteering or they’ll loose my check, which is crazy.</p>

JB alludes to a frustration with the system as well as distrust associated with fear. He expresses a sense of being stuck in a state of dependence feeling that if he did have some type of productivity, “a job” or “volunteering,” worker’s comp would restrict his pay. SW and JB, though joking, also note a sense of frustration when dealing with limitations of having short-term memory deficits.

Excerpt 3: Frustration

<p>JB: You can sit there, and think about it, and think about it, and get mad about it. (<i>All laugh</i>) SW: I know man, you just, it’s frustrating, you know.</p>

Fear, associated with anticipation of what might happen, was also indicated by comments JE made when mentioning selection of an at home volunteer experience. She notes, “I’m

relieved it worked out the way it did. That I did not have to go out because you know, I do that enough.” This quote suggests JE had a sense of anxiety associated with the anticipation of a volunteer experience that would take her outside of the home. In this way fear becomes a genuine emotion expressed by both JE and JB that discourages independence. For JB fear of workers compensation creates a sense of hesitation, and, a similar sense of hesitation is noted here, by JE. This emotion then encourages both individuals to remain disengaged.

JB and SW also discuss a fear that lingers with them as a direct result of their injury.

Excerpt 4: Fearing the Unknown

JB: Does it scare you sometime when you really get into the, what caused it? (*Referring to the onset of injury*)

SW: Yeah.

JB: I do too, I get spooked a little bit.

SW: I get, I get, well, was it this or was it this? I start trying to (*gesturing*) just wrestle with it.

Following this quote both SW and JB perseverate on the specific details of the injury contained in their medical reports. For both these participants the initial event and the immediate hours following are unknown to their memory. This sense of fear may stem from a lost sense of control. Both identify feelings of shock when reviewing their medical reports. JB explains that a majority of the contents was, “stuff I didn’t even know they did to me.” This fear appears to be not just from the injury itself, but the knowledge that there was a significant period of time in which JB and SW cannot personally account which is an uncanny sensation that remains present.

Fatigue.

Two participants expressed fatigue as a recurrent symptom of brain injury prior to the volunteer experience. SW describes his difficulties with sleep Apnea.

Excerpt 5: Sleep Apnea

SW: I'm supposed to but I have Apnea so I'm taking... this is my excuse for being late. (*points to SR*)
 SR: Oh, okay.
 SW: I'm taking Ambien
 JE: Oh.
 SW: Because I'll stare at the ceiling all night long.
 SR: Oh, that's the worst.
 SW: So I'm on Ambien and it works great, it puts me out. It puts my mind at rest because I'm fatigued a lot.

SW highlights how exhaustion directly impacts his ability to keep commitments and appointments because it affects his punctuality. JE also describes the limitations fatigue places on her social activities and daily routine.

Excerpt 6: Exhaustion Dominates

JE: Mmm hmmm. Yep. I was too tired to do much so, you know, I, you know, just it's kinda like I've sacrificed some getting out cause I can't drive and so I'm really just dependent on certain people and that's hard.
 SW: See I'm blessed that I can do things, that I can drive. But I am, I just feel exhausted.
 JE: Yeah, do ya?
 SW: All the time.
 JE: Yeah, it's pretty frustrating. It's like my life revolves around my naps (*laughs*)
 SW: Yep, yep.
 JE: Try to stay up after 8, last night I was going to bed at 8 o'clock, you know. (*laughs*)

This fatigue not only disrupts her social-activities but also limits her independence. She comments, "it's like my life revolves around my naps." She alludes to a loss of control in which this consequence of the injury, fatigue, dictates how she interacts with the world.

JE expressed feelings of being constantly overwhelmed after struggling with the physical challenge of continuous fatigue in the day-to-day. After discussing being extremely tired she notes.

Excerpt 7: Treading Water

JE: Yeah, so I just feel like I'm treading water a lot of the times. You know, I'm not gonna try to go back to work any time soon (JE nods with a smile). So, it's just a completely different animal than once upon a time.

In this remark, JE suggests work is not even an option due to the “different animal,” continuous fatigue, she experiences on a daily basis. Fatigue has become a physical aspect of life that limits her desire to be away from home. She alludes to this a few lines later, “But it’s just. You know, I don’t have to be somewhere most of the time. So it’s a blessing in many ways.” In this way her struggle with fatigue limits her opportunities to be active outside of the home and may limit her social network.

Fatigue from socialization was much more overtly discussed in the second focus group among all participants. Consider this instance in which the participants reflect on the socialization aspect of volunteering.

Excerpt 8: Fatigue and Socialization

JE: Yeah, yeah that’s one of the things we talked about, like for this volunteer project, I was doing everything from home.

SR: mmmhmm

JE: And then we were wondering well is it volunteerism, like as having a factor of socialization.

SR: Yeah, Mmmhmm so can you

JE: Mine didn’t really have that on this one. (*interrupting*)

SR: Yeah, definitely so talk more about that. Do think because, well was that good for you that it wasn’t as social or did you think you were lacking... like it was a less fulfilling volunteering experience because you had to do it from home?

JE: I thought it was really good though. I mean, since I’m just worn out a lot of the time (laughs)

SR: mmhmm

JB: Yeah we get in the situation where there is a lot of noise, a lot of people talking. It wears, it wears you down and it’s not we’re trying, or intentionally doing it, it’s just, it just happens.

SR: Yeah

SW: I am so glad you broke that up.

JB: Yeah

SW: Seriously, because I have been thinking it’s me because any more I lay around the house reading, always playing music.

JE: Yeah

JB: Especially if you’re tired

SW: Yeah

JB: That really has to,

SW: Yeah

JB: effects you worse.

SW: You know I've only been out of bed, I have apnea so I take Ambien, so I wake up at ten and then I'm thinking and it's one thirty and I'm exhausted. (JE laughs)
 SW: And I can't, can't nail it...

JE identifies feeling “worn out” in reference to socialization. JB describes a similar sensation of it “wearing you down” and SW notes “I’m exhausted” by early afternoon. While the anticipation of social fatigue limited the modality of the volunteer experience, participants did not allow this challenge to detour them from volunteering. Instead, avoidance of social fatigue became a strategy that participants used to succeed at volunteering.

Challenges.

All participants identified cognitive and physical challenges that occur on a daily basis in the first focus group. Often these struggles interfere with social aspects of their lives. JB and SW allude to cognitive loss, describing frequent instance of lacking a “filter” coinciding with an inability to remember. Both feel a need to interject a thought the instant it surfaces, while acknowledging its social inappropriateness. JB explains, “my sweetie she can get mad...like I’m rude or inconsiderate...which I understand because I’m not listening to what they are saying. I’m thinking about what I want to say.” SW explains that these interjections are necessary because of his short-term memory deficits. He notes, “ In fact, I’ll tell people that, “I’m sorry I got to interrupt you but if I don’t tell you it’s gone (motioning “apart” with hands).” For both these participants, cognitive deficits, in memory and filtering, interfere with the quality of their social interactions.

In the post volunteering group JE and SW continue to identify short-term memory as a recurrent struggle that impedes upon their social interactions.

Excerpt 9: Short Term Memory impacting Social Interactions

SW: That’s one thing I do.
 SR: Yeah
 SW: And I know I, I know I’m being rude and interrupt people.

JB: We all do that.
 JE: Yeah
 JB: Was the thought if you don't get it out now, you might not?
 SW: I got to get it. I got to say it right now.
 JB: Yeah I do the same thing, I do the same thing and if I don't it's gone
 SW: It's gone.
 JB: Jessica will be like, "What was that you were saying" and I'll be like "I forgot" (*All laugh*)
 SW: The other night, the other night when we were visiting (*unintelligible word*)
 JB: I totally understand you there.
 SW: My buddies were sitting there and I mean I've known this people for 45 years you know
 SR: mmhmm
 SW: We'd be talking and whatever I thought of
 JE: yeah
 SW: I had to say it right then! Right now! (JB laughs) The whole thing and then after I'm through, "okay now, what were you saying" (all laugh) because (gesturing) "I don't know you just took over"
 JB: That's so interesting
 SW: and you know, I know it's rude I know it's inappropriate
 JB: But your brains like, "we got to get it out!"
 SW: I got to get it out (JE laughs)
 SW: because if I don't get it out
 JB: It's lost
 SW: Gone

SW and JB's conversation above is almost identical to one in the post volunteering focus group in which both express frustration with the need to interrupt a conversation partner. The impulsive need to immediately vocalize a thought conflicts with an awareness of the rudeness and social inappropriateness of the interjection. Neither participant indicated if these cognitive limitations had a direct impact on their volunteer experience or volunteer selection.

In both focus groups the "inability to drive" is discussed by the participants as a significant consequence of their physical limitations. JB in particular was concerned about his ability to initially participate in this study because of this limitation. In the post volunteering discussion, both JE and JB note that driving factored into their decision to

volunteer from home. JE notes matter-of-factly, “I did my volunteer work at home as well, because I can’t drive.” JB acknowledges, “Now I’m wondering, what if I would have done something different if I could see and drive?” Later in the discussion JB delves into this limitation; he further highlights the dependency “not being able to drive” places on an individual.

Excerpt 10: JB's Independence

SR: And then, going back, were there any limitations that this experience highlighted? ...Like your abilities that you didn’t have that were highlighted by the volunteer experience kind of the backhand of

JB: Being blind.

SR: It highlighted your blindness?

JB: Yeah, because I’m dependent on volunteering. Either someone has to come take me or someone has to come pick me up.

SR: So it still didn’t help, help with that need.

JB: Yeah

SR: You are still helping people, but you are still in a way dependent.

JB: Yeah, because your always dependent on that.

SR: Yeah

JB: Unless you have like Apple Cart but I live outside of the city limits so I have limited transit. AppleCart won’t even come to the house.

SR and JE: Right

JB: So yeah, it’s always depending yeah. I think as I blind person because you are striving to be independent.

JB emphasizes that “not being able to drive” places limitations on the quality of the volunteer experience. It places the individual with TBI in a position to still require assistance from others and in that way limits their agency. Indirectly this limitation encouraged both JB and JE to seek out a more isolated approach to volunteering. However, neither JB nor JE allowed this limitation to interfere with the ability to complete their volunteer hours. The participants did not let this limitation put them in a place of learned helplessness.

In addition to cognitive and physical challenges, participants also address specific challenges that came about as a result of the volunteering experience its self. Both JE and SW describe a similar struggle with attempting to initially find a place to volunteer. Both

mention reaching out to places by the phone and getting the impression that he/she was not an appropriate fit. SW alludes to a communication breakdown that occurred with someone at the Land Conservancy.

Excerpt 11: Communication Breakdowns

SR: That's awesome. So y'all have done them all (*referring to completion of hours*) from the same activity. And then, SW, tell us about your experience. (*laughs*)

SW: Well (*laughs and scratches head*)

JE: NO! (*joking...laughs*)

SW: The environmental, you know to go hike, looked into that, and I just blew the poor girl's mind. I came up with all these exotic ideas (*JE laughs and SW shakes head*).

JE: No, way

SW: Guess what? I never heard back from her.

JE: What was it that you were trying to figure out something with?

SW: Conserve

JE: Land Conservancy

Later in the conversation JE explains she called the same person with no success at lining up a volunteer opportunity. These participants' difficulty with the initial set up from a pre-provided list, may suggest difficulties with planning and organization.

Participants also discuss challenges that arose once engaged in the volunteer activity. JB completed all of his hours by recruiting businesses to donate to the humane society and communication over the phone could, at times, be unpleasant.

Excerpt 12: Cold Calls

JB: I can't believe some of the places I eat the most at. Like, Thai City, like when I could see I eat there like, shoot, three days a week for lunch.

JE: Nice!

JB: And when I was calling for the restaurant, seeing if they were interested in a charity give back, they hung the phone up on me.

JE: Awe

JB: And I don't think they knew, you know, that it was me talking. I called back and a different person, plus I think that language barrier, this was another thing with the phone you know, not that he didn't know any English but just to get him to understand that what I was saying was a hard thing and so that probably was part of why they hung the phone up on me.

JB explains that overcoming people's rudeness as well as occasionally language barriers was challenging. JE also alludes to challenges volunteering, although not overtly. When she was asked directly whether there were challenges specific to her volunteer experience she responded, "Not really, No I, it took me a little while to figure it out." During JE's experience she sought out both researchers to assist her with initially using the VocaliD, a voice-banking program. She expressed frustration over the phone with one researcher who worked with her for an hour, and then required additional in-person assistance to login in to the program. Yet, she minimizes these frustrations in the focus group. This may suggest that JE has a reduced awareness of her limitations. She does hint at few challenges, which occurred in the act of voice banking itself. She comments on difficulties: having to repeatedly recite the same sentence, collaborating her voice with the sound requirements, and dealing with interruptions in her environment. While she suggests difficulties indirectly, when asked directly about the experience she explains simply, "...it was easy."

One challenge that was specific only to the first focus group was reflections on grappling with identity following symptoms of their injury. SW and JB pinpoint a time of existential crisis shortly after their injury. JB explains, "I didn't know who I was. I would look out the window and I would just cry and cry cause I had no clue who I was or what I was doing. I felt so uncomfortable in my own skin." SW reports a similar instance in which he "wrestled" with the sense of "not knowing." Consider the exchange between JB and SW below; both describe their life now as "different," as a result of learning to navigate an alternative reality.

Excerpt 13: Navigating an Alternative Reality

<p>SW: Could think...something you said just nailed me, about you were trying to figure out who you were (<i>to JE</i>). I went through a big time of who am I? What am I doing? Where is everybody?</p>

JE: Wow
 SW: Why am I here?
 JB: Everything is completely different than it was.
 SW: Yep
 JB: It feels different.
 SW: And I tried to link it to...ah, we're being filmed aren't we... being a sixties child
 JB: Haha!(*all laugh*)
 SR: Right
 JB: I think it's your TBI. You're learning to accept your new self. Who am I? My emotions, my cognition, my physicalness is different.

Both acknowledge dealing with new emotions and cognitive deficits that are reshaping their new self. While navigating this new reality, JB and SW are learning to “accept” who this self is now that emotions, cognitions, and their physicality have all been altered.

SW also appears to grapple with his identity as an intellectual; exclaiming, “Why me...of all people?” He reminisces on instances of flattery unique to an academic, “Students would stroke your ego to get a write off on their thesis.” These references to previous interactions with students, though marginal, highlight that academic status is central to his identity. He felt he was at the prime of his career, due lecture at Oxford, and then this injury occurred. The academic achievements that defined him were suddenly disrupted.

Each participant described their identity as caught between feelings of loss and acceptance. This can be seen in SW's comments about interacting with his students before his injury. The researcher inquired if the participants typically engaged in their hobbies solitarily or with others. SW was quiet for a few minutes while the other participants answered and then interjected with this:

Excerpt 14: A Normal Life

SW: You see what froze me up when you asked that. I go back to my life as a professor and I was teaching three classes, I was advising students like you (*to SR*), so I was always interacting...
 SR: Right.
 SW: deeply engaged with students.
 SR: Students, mmm hmm.

SW: So, for a long time I just felt like, well it's true. I just don't have any communication or integration with people. But then I'm comparing myself to, as someone pointed out, "Well man you wasn't livin a normal life" you were like this (*gesturing with hands to group*) what we are doing now. And that just shut down. It's gone. It took me a long time. It still does.

SW discusses how he hesitated in responding to this question because he was quite social with students as a professor. He first indicates a feeling of loss noting, "it's gone;" in reference to that life style. However he immediately follows that comment with, "It took me a long time. It still does." suggesting he is in the process of acceptance but perhaps still in a limbo-like state between loss and moving forward.

This state of being caught between pre and post injury self can be seen when SW discusses his fixation with researching TBI. In the excerpt below, shortly after referencing the Dalai Lama's engagement in neurological research, he reflects about a constant need to research TBI.

Excerpt 15: Learning To Cope

SW: I didn't know that. (pause) I'm learning to cope. I'm learning day to day to day and I'm not trying to sound cutesy.
 SR: Mmm hmmm. No, no yeah.
 SW: But, I am constantly thinking about TBI...
 JE: Yeah
 SW: and I sit at my computer and I don't know if it's my background and what I did, research and write, but I was constantly researching, looking up, trying to understand trying to grasp. Placing myself... Oh, I got that one I know that one (*pointing/gesturing*) I know that. Without framing myself in something that's not me. You know that projection.

The language "framing myself" and "projection" appear to indicate SW is still struggling with accepting what this injury means for him. He discusses the need to constantly research and philosophically analyze his condition but still appears to be at a loss as to where to place himself. Perhaps his fixation with brain injury research limits him to a degree because it

keeps him in this perpetual state of grappling. Ultimately obsessing with his injury becomes a challenge that prevents him from moving past the injury.

Coping Strategies.

Each focus group revealed strategies that participants have utilized to cope with the effects of their injury. Humor was a way participants could openly share their experiences and reactions to their injury. Each participant used humor to relate to one another and supplement their descriptions. Even subjects more emotionally laden, such as struggles with health care or the traumatic incident itself, were often interjected with jokes and sarcastic remarks.

Excerpt 16: Health Insurance Humor

JE: (sighs) I'm just signing up for another health insurance plan cause in the past I've had various... you know, pretty good luck I think, but I got a notice that they are not going to be honoring my plan anymore here. So... (*chuckles*)

SR: Yeah

JE: It's like yesterday get on a computer and figure out another plan that works. (*laughs*)

JB: Kate is going through the same thing.

JE: Seriously?

JB: With Blue Cross, yeah...

JE: Yeah, yeah mine's Blue Cross. It's ridiculous. It's like all I want to do is go see my regular doctor and have brain surgery every now and then (*JE opens hands and laughs; SR laughs*) So yeah, so...

As shown by JE's comments, and there were many more like these from all participants, jokes made were often at the expense of the participant's own injury. Humor in general was used throughout. For instance, SW in discussing his accident first refers to himself as "beautifully bald." It is possible humor could be a coping mechanism in which these individuals are deflecting effects of living with a TBI. It is also possible humor indicates that our participants have come to terms with their injury, as it has been several years since the initial onset (Table 1). Therefore, the use of humor may also suggest a level of acceptance of their injury and the experiences that come with it.

This ability to relate to one another with the use of humor carried over into the second focus group. For instance, consider the interchange between all the participants below.

Excerpt 17: Pity Humor

<p>JE: Yeah SW: That's not good JE: Yeah, no pity parties allowed SW: I'm only gonna have 12 guinness (<i>all laugh</i>) JB: That's a lot of Guinness's right there! JE: Yeah, I can't imagine. SW: I'm kidding... it was only 8! (<i>JE laughs</i>)</p>

The subject is self-pity, but it is discussed between injections of lighthearted remarks. Not only does humor appear to be safe way for our participants to address some of their deeper struggles, it also becomes a strategy that enables each participant to build with rapport with one another. One participant can make a joke about brain injury and that is acceptable because all share that experience.

All participants also identify a support system as being crucial to coping with the side effects of their injury. JE and JB highlight their appreciation for others in the pre volunteering focus group. JE gives credit to a close friend who “really helps take care of things” now that she frequently experiences extreme fatigue. JB explains that support groups specific to brain injury were beneficial.

Excerpt 18: Support Groups

<p>JB: I started to get into support groups. The Brainstormers, at the Wellness center, which met every, once a month... and then meeting Katy um my friend she was I was the first person that she met with another Traumatic Brain Injury. We became friends and then started coming to the Mind Matters. So definitely these groups, I really love these groups.</p>

In the post-focus group discussion, there was less mention of the need for help or support from others (other than the driving assistance previously discussed). When help or support arose in the discussion participants were on the giving end rather than the receiving

end. Consider this excerpt where SW discusses his attempt to find a volunteer experience that was a good fit for him.

Excerpt 19: Something That We Can Do

SW: I kept thinking there's something in adult and higher education that we can do to help people that are going through what we are going through (referring to individuals with TBI) and what I am going through and people there. And I wrested and I wrested with it. And one of my colleagues is in Instructional Technology. This is basically teaching with computers and I kept hounding him, help me think of something. You know, there is something there we can do.

SW identified struggles with finding an appropriate volunteer organization, but rather than dwell on those struggles and fall into a state of helplessness continued to brainstorm ideas on his own. SW was not content with any opportunity. He was convinced there was something he could do help others like himself and, propelled by that desire, he refused to give up.

Achievements.

In the first focus group achievements are not emphasized. SW is the only participant who appears to acknowledge specific accomplishments. He frequently discusses his academic success as well as his upcoming nomination for Professor Emeritus. However, in the second focus group all participants, not just SW, note a sense of purpose and accomplishment as a direct result of the volunteer experience.

SW credits his volunteer experience as helping him to attain a semblance of his post injury self. He explains immediately after the injury, "you kind of feel like everything has just been stripped from you," suggesting a lost sense of identity. However, when discussing the impact of the volunteer experience he notes, "I kinda feel, damn your worth something still." He used words such as "sense of purpose" and claims the experience itself, "made me feel like I was kind [sic] back." It appears that, for SW, the volunteer experience allowed him to reclaim a sense of self that he thought was lost post injury.

JE discusses how serving others with her abilities, such as donating her time to read, would give her a sense of enjoyment and, perhaps, fulfillment in life.

Excerpt 20: Sharing Abilities

SR: I'm gonna backtrack a little just because we only have a few more minutes left but JE so for you, did you feel like doing that video highlight any of your abilities or, at all? or not? I mean I'm not...

JE: Well it's kind of funny because right before I thought, well, you know, I used to work for 10 years and I had several jobs that I didn't enjoy and just not. I mean I got to use my skills but I didn't like being in the structure of that.

SR: Right.

JE: And, and so I've been thinking, like 5 years ago about well what could I do that would be, you know, have some kind of value and I just thought and I like to read a lot and I like to read to people and I thought a friend of mind started to do a thing online were he reads and then you can hire him to read for you.

SR: Huh, okay.

JE: And he reads his books and stuff and I thought that sounded like a really good idea because I think people understand me pretty well.

While she does not note a profound sense of "I'm back" specific to her volunteer experience, like SW, she does point to a desire find meaning in sharing her abilities with others. As demonstrated by the quote below, JE strives to achieve a sense of purpose through engagements in something "bigger" than her self.

Excerpt 21: Next Steps

JE: So there's a kinda, a kind of what now where like I know there's something I could be doing and be like bigger than me.

JB: I know, I hear what your saying.

JE: Yeah

JB: Like, like I'm trying to get involved with ASU in the Disability Services Department.

JE: Excellent

JB: Or the Communication Disorders department. Something like that.

JB highlights this quest for purpose, first acknowledging JE's like minded sentiments, and then explaining how he desired to pursue work, or volunteering, that engaged him with students. For both JE and JB volunteering may have encouraged that need to serve others using their abilities.

In addition to desires to achieve a sense of purpose through acts of service, a common thread throughout the participant's discussion is the language used to express authority. All participants project a sense of expertise about a particular subject. For instance JE provides SW and JB with specific instructions on how to use the VocaliD program. JB describes in detail how to use a computer program JAWS to navigate his computer and utilize all elements on his desktop and online, despite being blind. SW describes the specifics of the robot, MAX (the subject of the grant proposal he was involved in), and how MAX assists people with TBI. All participants take ownership of these subjects and explain these concepts to the group as if he/she is a specialist on the subject. This may suggest that volunteering has prompted a sense of mastery in which the participant can confidently take ownership of his/her abilities.

All participants acknowledge volunteering as a meaningful achievement.

Excerpt 22: Volunteering as a Positive Experience

<p>SR: It taught you patience (<i>reiterating JB's previous comment</i>). Anyone else learn anything negative or positive about, from the experience? Patience, JB: Yeah, I mean come on, I can't get mad at these people, I'm volunteering SR: Right (<i>All laugh</i>) JB: So... SR: That's what I do too...no just kidding (<i>JE laughs and JB smiles</i>) But, anything anyone else or JE: No, I'm glad that we had the opportunity...I would do it again in a heartbeat. SW: Yeah, and if somebody were to ask me, that God forbid just suffered at TBI and I would say you know ASU called me and wanted to know if I would, I would say "yeah man" SR: So you would recommend this to somebody else? SW: Yeah girl! SR: Who had a TBI? To do volunteering? JE: Absolutely JB: Yeah, definitely. It gets your out, especially if you go somewhere, I think it gets your out of your (gesturing with arms around head) self.</p>

Not only were all participants unanimously positive about the experience but also recommended volunteering for other individuals with TBI. For JB, volunteering is a useful

activity that assists individuals in “getting out of your self.” Volunteering becomes a method to avoid the slippery slope of learned helplessness.

Discussion

Possibilities Juxtaposed with Limitations

Both focus groups discuss strong emotions associated with deficits that accompany their injury. In the first focus group JB and SW perseverate on difficulties overcoming anger outbursts and how these incidents are a continuous burden. The focus appears to be on their inadequacies. However, in the second focus group, the predominate emotion expressed is fear and all participants addressed fear in the context of anticipating future events related to purposeful activity. While fear associated with anticipation and anxiety is not a positive emotion, it may suggest that the participants were drawn from a passive state by the act of volunteering. Rather than give in to a state of self-deprecation, the participants discuss a desire to be productive, which did incite negative emotions of fear and anticipation, but also motivated participants to grapple with their limitations rather than simply dwell on those deficits. The expression of anticipatory fear indicates the participants were moving toward a state that Muenchberger, Kendall, and Neal (2008) described as tentative balance: navigating between their past loss and limited self confidence (contraction) and moving towards a personal journey of goals and decision making (expansion). While this limbo like state may feel unsettling, it often is an essential part of accepting the injury, and may help the individual become liberated from the loss associated with TBI (Fraas & Calvert, 2009). The fact that these anticipatory feelings are drawn out of activities that are of service to others suggests that these experiences are something worth participating in. Participants were still willing to participate and pursue activities of service despite experience with this emotion.

Volunteering then became a medium much like Muenchberger, Kendall, and Neal (2008) recommend that permitted new possibilities while still allowing a space to question and grapple with their abilities and limitations.

Compensation for Deficits

In the first focus group, fatigue was addressed in the context of a crippling side effect that limited the participant's ability to participate in activities. Both JE and SW placed themselves as passive respondents to fatigue, much like the participants in Cloute, Mitchell and Yate's study (2008) who described themselves in "pattern[s] of passive positioning," at mercy to their symptoms (p.663). Fatigue continued to be discussed in the second focus group, but more specifically in the context of socialization. In fact, the participants discussed how each believed the social aspect of volunteering was one that would insight feelings of exhaustion. Instead of allowing the accompanying exhaustion to prevent them from volunteering, participants took an active role in compensating for their deficits by choosing to volunteer from home. While this did not help encourage socialization, participants did not discontinue the project because of the socialization aspect. Instead all used avoidance of social fatigue as a strategy to complete their project. This may suggest volunteering was important enough to pursue, despite undertaking a new, and perhaps uncomfortable role of active positioning. Rather than be limited by fatigue, participants found a way to succeed in spite of it.

The recognition of the importance of volunteering coinciding with avoidance of socialization appears to have played a role in the participant's awareness of their social limitations. All participants choose to volunteer from home, which acted as an unintentional control. All participants also increased in their LCQ scores (Table 3 reveals changes ranging

in a 4 -10 point increase) indicating a greater perceived communication inability. Perhaps, then, participants were not as aware of their socialization limitations, until placed in a position in which he/she needed to compensate for those deficits. Volunteering ultimately may serve as an avenue to help participants both recognize and compensate for their communication limitations.

Interestingly, despite the cognitive demands of each volunteer experience (Table 2), no participant identified fatigue in relation to volunteering experience. A study out of the New York Academy of Medicine found that volunteering actually improved an individual's perceived strength and energy (Barron, Tan, Yu, Song, McGill & Fried, 2009); which suggests that, for the participants in our study, volunteering became a motivating rather than tiresome activity. Perhaps it was the motivating factor of volunteering that initially encouraged compensation.

Productivity

All participants not only unanimously identified the volunteering experience, as positive, but it also appeared to be an avenue that encouraged autonomy. In the first focus group, all participants identified a good support network as a key factor to coping with the consequences of their injury, whether that network be family members, friends, or support groups. In the second focus group, however, discussion of support shifted from the need to be recipients to the desire to be benefactors. All participants addressed a strong desire to be of service to others and sought to find a meaningful avenue (i.e., volunteering or work) to provide that service. This shift in focus suggests that volunteering helped our participants pursue a fundamental desire identified by many individuals with TBI according to Douglas (2010, p.198); that is to simply “do something useful.”

That sense of productivity and usefulness appeared to be a predominate outcome of the volunteering experience when considering the participants' discussion of achievements. In the first focus group achievements were rarely discussed, with the exception of SW who predominantly mentioned his past academic accomplishments. However, in the second focus group, not only are accomplishments discussed, but these accomplishments appear to be a direct result of the volunteer experience. SW identified a sense of reclaiming who he once was as the volunteering experience allowed him to feel as if he was, "worth something still." Both JB and SW identified specific abilities highlighted through the volunteer experience and expressed a desire to serve others with those abilities. The language of the participants also appeared to be influenced by this new sense of purpose, derived from service to others. In the second focus group all participants used language that displayed authority and presented a demeanor of expertise when discussing their volunteer experience. This presentation of expertise suggests that qualities of confidence, knowledge, and authority are positive attributes that are a direct result of engaging in experiences deemed purposeful. This reaffirms Ylvisaker's and Feeney's (2000) conclusion that a positive sense of self correlates with meaningful activities in the TBI population. Finding purpose in productivity through volunteering thus creates an environment where the participants can positively view themselves and their abilities.

Challenges remain

In the first focus group identity was discussed as a day-to-day challenge that was consistently reshaped by new emotions and cognitive deficits stemming from their injury. Participants discussed an existential crisis that occurred immediately post injury; in which acceptance of the self is equated to navigating an alternative reality. This sensation echoes

Lubusko and colleagues' (1994) and Lubinski's (1995) discussion of "learned helplessness" in which individual's altered engagement with the world ultimately created the perception that one was a stranger to one's own wants and needs. Volunteering did not eliminate that sense of questioning, and the participants still struggled with feelings of lost control and limited agency. For instance, both JB and SW continued to discuss their frustration with their memory deficits and reported a need to interrupt a conversation the instant a thought surfaces, despite the social inappropriateness. Independence also remained a challenge for the participants. JB highlighted this lack of agency when discussing his inability to drive. He explained that driving provides independence and the inability to drive creates inevitable limitations. Despite uncovering the opportunity to serve others, physical deficits either limited his type of volunteer service or required him to seek assistance from others for transportation. He strives to be independent but remains "always depending" (Excerpt 10). SW, though less overtly, still alluded to the need to "wrestle" with his sense of self and JE still described activities in her life in terms of fatigue. It is essential to recognize that volunteering is not an expatiated solution to creating a positive identity; challenges with control and agency remained.

Volunteering is a Stepping Stone.

While volunteering did not alleviate every component that interferes with positive identity construction, it did appear to assist participants in beginning the process. As Fraas and Calvert (2009) pinpoint in their study, acceptance of the loss associate with TBI takes many years to accept and requires both flexibility and adaptation. Therefore progress towards positive identity construction is a slow process that may show signs in subtle and less apparent forms. For instance, declines in F1 scores across participants in the BIGI indicate all

participants reported less perceived grief than prior to the volunteer experience. In a study on grief and self-awareness following TBI, Carroll and Coetzer (2011) found that perceived grief correlates with perceived identity change. Individuals with the greatest change in self-concept post injury are more likely to report problems adjusting and expressing a negative self-image (Carroll & Coetzer, 2011). Therefore a decline in indications of grief post injury may indicate progress, however slight that might be, towards positive identity construction for all participants. The drop in HADS depression scores for SW also may convey improved self-concept. Carroll and Coetzer also found that the more individuals were aware of their loss post injury, the greater their depression level. Therefore, a drop of 6 points placing SW at a normal depression level may suggest SW was gradually moving towards accepting his deficits rather than dwelling on a constant awareness of his loss. Though the changes in survey scores may not reveal a dramatic change in identity, the change in scores implies a correlating, though slight, change in improved self-image.

In addition to the surveys, the language used by the participants in the second focus group also points to small steps towards the development in positive identity construction. Following volunteering, all participants provided detailed information about a particular subject and utilized language that emphasized knowledge and expertise. Participants were able to adopt an authoritative role, suggesting the experience of volunteering heightens confidence. Volunteering encouraged our participants to take ownership of their abilities which suggests a shift in identity; instead of being defined by their limitations the participants are asserting his or herself as “expert” because of the abilities highlighted by the volunteer experience. The participants’ confident expression of inside knowledge may

suggest the participants have subtly begun to see and define themselves by new possibilities, rather than maintain a narrow definition of the self based on their perceived limitations.

Reclaiming The Self

In the focus group, participants also provided evidence that volunteering incited a progression to reclaim the self. Every participant, following the volunteer activity, expressed a desire to continue engaging in purposeful activity. For SW, this was engagement in research: he explicitly states that it was his volunteer experience that encouraged this action and consequently reaffirmed his sense of self worth. SW's positive mood appeared to derive from a sense of achievement much like participants in Ylvisaker and colleagues' (2008) study; however, for JE and JB the pursuit for purpose went beyond affirmation of their abilities. JE described the need to share her abilities with others to accomplish something bigger than her self. JB expressed a strong desire to share his insights with college students rather than take the form of work or volunteering. Fraas and Calvert (2009) found that individuals who engage in activities that assisted others felt empowered, and, for JE and JB, service to others is fundamental. Perhaps altruism is the key component to self-fulfillment. This returns to Harré and Van Langenhove's (1999) theory of identity. If positioning oneself is dependent on the constant fluctuation with the "other" then individuals who have lost the self can reclaim identify through negotiating new relationships by altruistic means. Volunteering is selfless service by nature, and therefore an ideal environment to foster that altruism, which appeared subsequently necessary for the participants to reclaim the self.

Limitations and Future Directions

As there is a limited amount of published research specific to TBI and volunteering additional studies with larger sample sizes will be necessary to reach more definite

conclusions. While a small sample size provides insights unique to the individual, as was the case with this study, the greatest weakness is the inability to generalize these insights to a larger population of individuals with TBI.

Another challenge with this study stems from the procedural format of analyzing information from focus groups and self-rated surveys. While one's own perception of self is critical to identity construction, one must acknowledge that an individual could be overly confident or overly critical in his/her responses, which may influence results. For instance, JE less overtly discussed her challenges with VocaliD and appeared to minimize her difficulties, specifically in regards to learning to use and setup the program. This inability to accurately recognize limitations is not uncommon with a right-sided brain injury (Heilman & Valenstein, 2011). Utilizing a focus group and self-rated survey's is an effective method to obtain access to participants' authentic and complex perspective on an experience; however, at the caveat that participants may not have an accurate awareness of their limitations and abilities, a common deficit for individuals with TBI (Bach & David, 2006). Future studies may wish to incorporate insight from individuals close to the participant (i.e., family members, friends, caregivers) to provide an alternative approach to analyzing the impacts of volunteering. While the participants in this study provided useful insights on how volunteering may improve the quality of life for individuals with TBI, many questions remain. For instance, does volunteering from home have the same impact as a traditional on site experience? Future studies could undertake a comparative study between specific types of volunteering in relation to their impact on identity construction. Researchers may also wish to investigate how volunteering may benefit other populations with communication impairments.

Clinical Implications

This study also provides useful implications for clinician's seeking additional methods to assist clients in achieving their cognition and communication goals. Not only is positive identity construction essential to one's ability to successfully interact with the world (Harré & Van Langenhove, 1999; Tirado & Gálvez, 2007), but targeting identity construction is a key facet of evidence-based practice, often overlooked, which is identifying the specific needs of the individualized client (Roulstone, 2011). This study suggests volunteering as one avenue that may begin to address the difficulties associated with reclaiming identity following brain injury. Should engagement in volunteering be appropriate for a client, the clinician may wish to assist him/her with elements that were difficult for this study's participants. It is advisable that the clinicians work directly with the client in researching an appropriate organization and scheduling the volunteer experience. Volunteering may not be an appropriate method for all clients, but, for some, it may be a stepping-stone in a long process of beginning to reclaim a more positive sense of self.

The participants in this study also identified challenges specific to the volunteering experience, which have implications for clinical practice. Both SW and JE discuss difficulties initially connecting with an organization despite receiving materials and information on contacting local agencies (Appendix B). This highlights a key limitation in volunteering as many individuals with TBI struggle with planning and organization due to damage in the frontal lobe (Heilman & Valenstein, 2011). Were other individuals with TBI to engage in volunteering, it may be beneficial to seek out a family member, friend, or other outside party to assist with the initial enlistment.

Clinician's may also create stronger connections with clients by adapting some of the participant's strategies, for coping, into client therapy. In both focus groups, all participants used humor to discuss more emotionally laden subjects. It appears as a strategy both to discuss their injury, and also relate to one another. Each discussed traumatic events and resulting struggles and because of this mutual experience were allowed to create and acknowledge amusing qualities to the consequences of their injury. For instance, to discuss the frequencies of doctor's visits and associating difficulties with health care JE states, "It's like all I want to do is go see my regular doctor and have brain surgery every now and then" (Excerpt 16). In this way humor became a medium and comfortable space where the participants could relate to one another. Humor from a psychodynamic perspective is seen as an involuntary coping mechanism defined as, "homeostatic mechanisms that reduce the disorganizing effects of sudden stress" (Vaillant, 2011 p.366). Humor is believed to be an adaptive reaction that increases an individual's ability to cope with trauma. Vaillant describes humor as one of the "fourth mature defenses" of the brain's response to stress, which has the effect of, "maximize[ing] gratification and allow[ing] relatively more conscious awareness of feelings, ideas, and their consequences" (Vaillant, 2011 p.368). He explains that humor, similar to meditation, incites the parasympathetic system, inducing calm. Therefore, humor, although a form of dissociation, became a healthy method for the participants to acknowledge and discuss traumatic events. This has implications for clinicians as humor may serve as a bridge to identify and address more delicate subjects while still building rapport with a client.

Conclusion

Volunteering did not drastically alter the participants' sense of self; however, volunteering did appear to initiate progress towards reconstructing a positive self-image. Participants continued to grapple with negotiating abilities with limitations, but were able to develop useful strategies to compensate for these deficits. All participants identified the volunteer experience as meaningful, and recommend volunteering to other individuals. The productive avenue of volunteering as well the altruistic nature of the activity appeared to be essential factors that ultimately facilitated steps towards positive identity construction. Active involvement in charitable service served to provide participants with a sense of achievement and encourage those participants to seek further opportunities to find fulfillment through sharing his/her abilities with others. Volunteering did not profoundly alter the participant's sense of self, but it appeared as a catalyst in process of reclaiming the self. While social communication abilities remained a challenge, this experience perhaps heightened self-awareness of communication deficits. Engagement in volunteering challenged participants to grapple with their limitations rather than dwell on them, which ultimately propelled them out of a helpless state of inaction. Participants appeared to value volunteering to such an extent the individuals found ways to compensate for their deficits rather than be limited by them. Volunteering did not alleviate every limitation; challenges still remained with control and agency. However, volunteering did appear to be a method to incite the complex process of reshaping a positive self, following brain injury, as revealed by changes in survey scores and authoritative language utilized in the second focus group. Ultimately volunteering becomes an avenue that can create a more positive outlook on life,

and perhaps it is the altruistic nature of volunteering that motivates individuals to continue reclaiming the self.

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Appendix B

Watauga Volunteer Service Opportunities

Organization	Focus Area	Volunteer Activities	Contact Information
Blue Ridge Conservancy	Land Conservation	Office Work, Event Planning, land protection	828-264-2511
Casting Bread Food Pantry	Meals	Stocking items, loading vehicles, Client intake	828-295-8333
F.A.R.M. Cafe	Meals	Greeter, server, Prep-cook, dishwasher, set-up, breakdown, garden spot	828-386-1000
Hospitality House of Boone	Poverty	Food Drive, Gardening, Farming	828-264-1237
Hunger and Health Coalition	Meals	Meal Prep, Thanksgiving Meal, Garden Space	828-262-0649
Samaritan's Purse	Poverty	Operation Christmas Child	828-262-1980
WAMMY Community Action, Inc.	Poverty	Office Work, Organization, Fundraising Event Planning	828-264- 2421
Watauga Habitat	Poverty	Construction, Family Selections/Support Committee, Meal Prep, Events, Office, Booth Representative	construction@wataugahabitat.org
WAMMY Community Action, Inc.	Poverty	Office Work, Organization, Fundraising Event Planning	828-264- 2421

Vita

Jillian Reynolds was born in Walnut Creek, California, to Marcia and Charlie Reynolds. She graduated from Wiesbaden High School in Wiesbaden, Germany in 2009. The following fall she entered Furman University to study English, and in May of 2013 was awarded a Bachelor of Arts degree. From May of 2013 through May of 2015 she completed two years of service for AmeriCorps VISTA working for a nonprofit in Greenville, SC. In fall of 2015 she entered the Communication Sciences and Disorders program at Appalachian State University to obtain a Masters of Science Degree. She graduated in August of 2017. She currently resides in Greenville, SC.