The Effects of Traumatic Experiences on Identity Among People with Expressive Language Disorders

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THE EFFECTS OF TRAUMATIC EXPERIENCES ON IDENTITY AMONG PEOPLE WITH EXPRESSIVE LANGUAGE DISORDERS

By

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ABSTRACT

This study aims to address the lack of standardized measurement of the effects of trauma on identity. Waterman’s (2020) theory, taxonomy, and Trauma Impacts on Identity Functioning Scales were used to evaluate the effects of traumatic brain injury on identity. TBI survivors compared their sense of identity from pre-to-post TBI. Data collection consisted of 2 interviews and participants were compensated with $60 gift cards. Participants ($N = 15, M_{age} = 52.67$) were recruited from several language disorder groups. In terms of identity functioning post-brain injury, participant reports of their experiences varied quite a bit from identity loss to a strengthened identity. There was a significant increase in identity distress from pre- to post-brain injury as well. Time since trauma was not significantly correlated with identity functioning nor with identity distress change scores. This suggests the need for future research to determine which factors influence whether and why survivors’ experience post-traumatic identity disruption and/or growth, as it appears that time alone is not sufficient.

Keywords: Traumatic Brain Injury, Stroke, Aphasia, Identity Functioning, Identity Distress
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LIST OF ACRONYMS OR ABBREVIATIONS

Acquired Brain Injury: ABI
Analysis of Variance: ANOVA
Identity Distress Survey: IDS
Institutional Review Board: IRB
Multivariate Analysis of Variance: MANOVA
Post-Stroke Depression: PSD
Repeated Measures Analysis of Variance: RMANOVA
Traumatic Brain Injury: TBI
Trauma Impact on Identity Functioning Scales: TIIFS
Traumatic Brain Injuries, Stroke, Aphasia, and Identity

Traumatic brain injuries (TBI), specifically acquired brain injuries (ABI), not only result in a wide range of physical impairments but also can lead to an array of cognitive impairments and personality changes. One common traumatic experience in the form of a brain injury is a stroke. A common byproduct of stroke is an aphasia. Experiencing trauma, such as surviving a stroke and suffering an aphasia, may lead to changes in self-concept (Ellis-Hill & Horn, 2000), and therefore may also have an impact on identity functioning.

Along with the cognitive and personality changes that may be obvious after a TBI, such as depression and mood changes (Ellis-Hill & Horn, 2000), significant changes in the survivors’ identity may emerge. Differences in the person’s self-definition may include their goals, roles, values, and beliefs. This identity change results from reduced abilities and limitations following a brain injury (Tyerman & Humphrey, 1984). According to Waterman (2020), identity changes occur in a number of ways, including identity disruption, stagnation, or positive growth. As of yet, there is only limited research on the effects of aphasia on identity functioning (Shadden, 2005; Shadden & Agan, 2004). TBIs in general have been found to impact identity. Because aphasia is a particular type of TBI, it follows that an aphasia may be a predictor in identity functioning, but this has not yet been the focus of investigation.
Associations Between Identity and Traumatic Brain Injuries/Strokes

A stroke is characterized by a sudden loss of oxygenated blood to portions of the brain resulting in diffuse areas of brain damage as well as physical and neurocognitive sequelae. In a cross-sectional study by Ellis-Hill and Horn (2000), 26 stroke survivors and 26 hospital volunteers (non-stroke controls) completed multiple surveys measuring their anxiety, depression, and activity levels, as well as their past and present self-concept. Self-concept was also assessed using the Head Injury Semantic Differential Scale (Tyerman & Humphrey, 1984). The study investigated how a stroke survivor’s self-concept changed post-injury. Although this study did not measure identity, it demonstrated that traumatic brain injuries impact multiple parts of the self, including self-concept. Ellis-Hill and Horn found that, in comparison to the control group, stroke survivors reported higher levels of anxiety and depression, and lower levels of activity. Stroke survivors viewed themselves as more dependent and less capable, in control, confident, active, and satisfied/interested. The self-concept domains that did not change from their premorbid selves included friendliness, calmness, caring, and hopefulness. In addition, physical ability did not have an effect on the survivors’ self-concept. Although it was expected that self-concept would become more negative over time for stroke survivors, this result varied from one stroke survivor to another. Some reported mild negative changes in self-concept and others indicated much more drastic negative changes. As expected, the control groups’ self-concept remained stable over time.

The present study consists of people with aphasia. Stroke is a common cause of aphasia. Thus, we expect our sample to have similar self-concept changes as those in Ellis-Hill and Horn’s (2000) study. Although Ellis-Hill and Horn’s study looked at self-concept, it did not investigate linkages to identity, which is a related but a separate construct.
Tyerman and Humphrey (1984) measured self-concept in patients with a severe head injury. In their study, 25 participants completed multiple intelligence and memory tests. In addition, they completed interviews measuring anxiety, depression, self-concept, comparisons among past, present, and future selves, and the common problems experienced post-TBI. The researchers found that 84% of the participants reported their lifestyles were altered by their severe head injuries. Participants reported lack of mobility, reduced physical and psychological skills, personality changes, social life disruption, and limited leisure opportunities. Feeling as if they were a different person post-TBI was also reported by 72% of the sample. The participants reported negative, neutral, and positive changes. The negative changes included bitterness, frustration, irritability, depression, and dependency. The positive changes included maturity, appreciativeness, understanding, and responsibility; such changes represent posttraumatic growth. The neutral changes included being more serious and cautious. Of the participants, 64% had significant psychological disturbances indicated by their responses on the Leeds Scale of Anxiety and Depression (Snaith et al., 1976). More than half of the participants’ scores (60%) were in the clinically depressed range. It is important to note that happy or positive emotions are located in the left hemisphere and sad or negative emotions are located in the right hemisphere (Davidson & Begley, 2013). For people with aphasia, a condition almost always caused by a left hemisphere infarct, a middle cerebral artery stroke impacts the happy or positive emotions. Thus, stroke survivors of left hemisphere infarcts may experience depression because of the effect of the left hemisphere infarct (Code & Herrmann, 2003). Tyerman and Humphrey (1984) also found that 44% of the survivors scored as clinically anxious. Of the head injury survivors, 56% indicated feeling tense or wound-up, 52% reported feeling miserable or sad, 44% reported feeling a loss of interest in things, and 28% indicated that their lives were not worth living.
Tyerman and Humphrey (1984) also found that level of dependency, opinion of what others thought of them, and level of activity, were the things most affected. The domain that seemed to be the least affected was long-term goals (reports of believing they were able to make a life for themselves). Furthermore, 28% of the sample reported not feeling like a whole person, while 32% reported they felt troublesome to others. In addition, 40% reported feeling pitied by others, 32% indicated they believe others stare at them, and 36% reported feeling they were inferior to others. Lastly, almost half of the sample reported they would always be less capable than before their injury. However, 88% indicated they would be independent and make their own way in the world, and 80% reported that they could live a normal life while being physically disabled. They expected positive changes in their selves in the future, and viewed themselves more positively than they viewed others with a similar head injury.

**Impacts of Aphasia**

Aphasia can result from acquired brain injury, such as a stroke. An aphasia is a language disorder that encompasses a wide range of communication impairments. Various types of aphasias include Broca’s Aphasia which results in difficulties with speech output, and Anomic Aphasia which is marked by word finding difficulties. Wernicke’s Aphasia is characterized by non-coherent fluent speech. Global Aphasia involves an inability to produce or comprehend speech (National Aphasia Association, 2017). According to the National Aphasia Association (2016), 750,000 Americans have a stroke each year, and currently there are approximately two million people with aphasia in the United States. Laures-Gore and colleagues (2016) reported that at least one-third of stroke survivors experience post-stroke depression (PSD), and that this number might be much higher due to the inaccuracies of diagnosing PSD. The main consequence
of an aphasia involves the loss of language skills, such as the loss of expressive language, loss of receptive language, or both.

Relationships with others are a large part of a person’s identity, and communication forms the base of these relationships. Therefore, the language deficits following an aphasia may impact the person’s ability to communicate and affect their ability to perform the roles that are part of their identity (Taubner et al., 2020). Lam and Wodchis (2010) reported that people with aphasia have a larger decrease in quality of life compared to patients with cancer and Alzheimer’s disease. People with aphasia experience self-perception changes, such identity changes are inevitable after developing an aphasic disorder (Corsten et al., 2015). One reason for these changes in self-perception includes findings that many people with aphasia view themselves as incompetent (Dorze et al., 2013). Corsten and colleagues (2015) explain that identity renegotiation is impaired by the deficits in language skills. They reported finding four main themes in regard to identity and aphasia: agency (the degree of responsibility the patients take for their life course), control (the amount of control they have over their life events), disease concept (the people with aphasias’ emotional responses and cognitive responses to their disorder), and doing things (engaging in meaningful activity).

Trauma and Identity

Identity refers to an individual’s roles, goals, and values that give their life a direction and purpose (Berman, 2016). Individuals may re-evaluate these roles, goals, and values after experiencing trauma (Berman et al., 2020). Identity distress refers to the negative feelings that come from struggling to resolve identity problems (Berman et al., 2004). Our identities contribute to the way we live our lives and plan our futures (Erikson, 1959, 1968). However, according to Berman (2016), a traumatic event can greatly disrupt the way an individual lives
and plans their future. For example, for someone who defines their identity in terms of their life roles, the death of a close family member will cause reevaluation of self and roles. In a sample of Chinese adults who lost their only child, Zheng and Lawson (2015) found that the loss impacted their collective identity. In China, 76,000 Chinese parents lose their only child each year. These parents are known as “shiduers.” Family is a central part of Chinese culture and being a parent contributes to identities. Not only does losing an only child impact identity, but it also leads to most shiduers forming a collective identity with other shiduers. Sandole and Auerback (2013) conducted a qualitative study with 30 female survivors of the Rwandan genocide. During the 1994 genocide, sexual violence against women was used as a war instrument. In a content analysis of interviews with Rwandan genocide survivors, three themes emerged. The first theme is the civilized self, which explains that the Rwandan women identified with many roles other than being a Tutsi (ethnic group residing in Rwanda), such as a mother, daughter, and sister. The second construct is the survivor self. Within this construct, the Rwandan survivors described that their world during the genocide did not contain the norms they lived with before the genocide. For example, the Rwandan women thought they could rely on family and the church for safety, but these assumptions did not hold true. In addition, these women endured severe long-term sexual assault, life-threatening encounters, and the loss of their entire families. While surviving, the women were only viewed with a Tutsi identity and all other role identities were removed (i.e., mom, classmate, Christian, etc.). The third construct was the aftermath self. After the genocide, the Rwandan women were unable to return to the self they were before the genocide and reported feeling alone with no support. Not surprisingly, the researchers found that trauma-induced identity transformations occurred among this sample. Although a stroke is not the same as the trauma experienced in the previous examples, we may see similar identity changes in the
stroke survivors with resulting aphasia as they also experienced identity changes post-trauma. Berman (2016) explains that identity, particularly how an individual views their self-efficacy, can either aid in the recovery from a traumatic event or hinder the individual’s recovery. Trauma can also be integrated into one’s identity. Robinaugh and McNally (2011) found that a traumatic event can be a turning point in one’s life as well as a way for an individual to form expectations about their future. Identity distress has previously been linked to trauma (Ertorer, 2014; Merrill et al., 2015). Berman and colleagues (2020) suggest that people use certain factors, such as beliefs about the world, religion, and politics, to put trauma into perspective. This perspective makes the trauma harder to endure (posttraumatic stress) or easier to endure (posttraumatic growth). In addition, trauma can be a defining moment in an individual’s life, from which they either perceive themselves as a victim or a survivor (Berman, 2016; Morris et al., 2010).

**Waterman’s taxonomy**

Waterman (2020) describes nine trajectories identity functioning can take in the aftermath of trauma:

1. **Identity resilience**- when the individual survives a traumatic event, and the trauma does not affect their established identity. These individuals do have effects of trauma, but these do not include identity effects. Individuals who have identity resilience maintain their identity commitments pre-and post-traumatic event.

2. **Identity affirmation**- when an individual’s identity commitments are reinforced or strengthened by the traumatic event. For example, a religious person may become more religious after their TBI.

3. **Identity delay**- when the person’s identity roles are delayed due to the individual being unable to continue their identity-related plans post traumatic event. For example, an
individual whose plans are postponed after their TBI; the trauma had an economic impact (i.e., job loss, hospital bills, etc.) such that certain goals of theirs have been delayed until they regain their financial footing.

4. **Identity threat**- when the traumatic event leads the person to question their identity. For example, an individual who can no longer work post-trauma, and is now questioning their purpose in life and who they are.

5. **Identity loss**- when the traumatic event leads to the person losing part of their identity. For example, if a parent survives a TBI but can no longer take care of their child, they lose the part of their identity that is being a parent.

6. **Identity alteration**- when an individual alters part of their roles according to their new abilities to maintain a modified version of that part of their identity. For example, if a person with a TBI can no longer run their business, but they can still work at their business. They are changing part of their identity that is their role in their career.

7. **Identity replacement**- when an individual develops new identity elements that are not related to those previously held. For example, if a person with a TBI can no longer run their business, so their new career becomes being a stay-at-home parent. They replaced the part of their identity that was their career.

8. **Trauma-shaped identity**- when a radical change in the individual’s identity emerges that would not have occurred without the occurrence of the traumatic event. For example, a TBI survivor may become an activist for other TBI survivors or start fundraisers to raise money for TBI survivors.
9. **Trauma-centered identity**- when the traumatic event becomes the most important aspect of the individual’s identity. Here, all aspects of their identity have been affected by the traumatic event. All aspects of their life are consumed by and oriented around their TBI.

Waterman also explains three effects of trauma on different domains of identity concerns. The first are changes in identity-related personal priorities. Here, the individual’s identity elements change in level of importance resulting in either post-traumatic growth, increasing their overall level of basic functioning, or impairments to the individual’s level of functioning.

Secondly, changes in identity coherence may occur. This involves the degree to which various elements of an individual’s identity are inter-related. The last effect of trauma on identity is the breadth of disruptive identity impacts, which includes the number of identity domains that were impacted by the traumatic event. The last aim of the current study is to classify the participants’ trajectory according to this taxonomy. Specifically, we aim to find the commonalities and differences in the participants’ identity functioning following a traumatic event.

**Rationale**

As Berman (2016) pointed out, there is evidence that identity development and trauma affect each other; however, there is a lack of standardization in measuring the effect of trauma on identity. The aim of this thesis was to change this lack of standardized measurement by using Waterman’s (2020) theory, taxonomy, and Trauma Impacts on Identity Functioning Scales, to evaluate the effects of TBI on identity more systematically. The purpose of this study was to examine the effects of traumatic brain injury on identity. Toward this endeavor, TBI survivors’ recollections of their sense of identity before they acquired a TBI were compared with their current sense of identity (post-TBI). In addition, identity domains were assessed to determine which were the most affected by the survivors’ TBI and which were the least affected. Lastly, the
survivors’ trajectories were classified using Waterman’s taxonomy, comparing commonalities and differences, and testing several of his assumptions in regard to the effects of trauma on identity.

**Hypothesis 1:** TBI survivors’ identity functioning as measured by the Traumatic Impact on Identity Functioning Scale would be significantly better before the trauma than after the trauma.

**Hypothesis 2:** Any changes in ratings of importance from pre- to post-trauma for the domains of personal relationship with a romantic partner and personal relationship with a close friend would depend on whether the patient remained in a relationship with a spouse or friend. If they did not remain in a relationship, the identity domain may be less important to them post trauma. However, if the relationship loss becomes a focus of obsessive concern, it may increase in importance. If they did remain in a relationship, the identity domain would be more important to them post trauma.

**Hypothesis 3:** Survivor ratings of importance would indicate a significant increase in importance from pre-to post-trauma for the domains of religion or spirituality, and philosophy of life.

**Hypothesis 4:** Survivor ratings of importance would indicate a significant decrease in importance from pre-to post-trauma for the domains of work, job, or career; hobbies, sports, or leisure time activities; role as a parent or caregiver to another person; physical health; mental health; and community involvement, volunteer activities, or community service activities. We predicted a decrease because they may be unable to do these things. However, they may find new activities in the same domain to replace them, thus we asked open-ended questions to investigate this possibility.
Hypothesis 5: Waterman’s taxonomy of developmental impacts of trauma on identity were grouped into 3 categories: Positive impact (identity resilience, identity affirmation, threat to restoration, loss to alteration, loss to replacement), Negative impact (identity delay/stuck, continuing threat, threat to loss, identity loss), and In transition (identity delay/moving, threat to exploration, loss to exploration). It was predicted that there would be a significant difference in time since trauma for the three groups such that those in the positive impact group would have the longest average time since trauma; those in the negative impact would have the least time since trauma; and those in the Transition group would be in between the other two groups. Trauma centered identity could be positive or negative depending on coping. Therefore, no specific hypotheses were made, and separate analyses are exploratory in nature.

No change is expected for survivor ratings of importance from pre-to post-trauma for ethnic or racial identification, immigrant status, politics or views on specific social issues, gender, and sexuality. This was examined separately, and analyses are exploratory in nature. However, the importance of sexuality may change if the stroke affects the romantic relationship or sexual functioning.
METHOD

Participants

Participants included 15 stroke survivors recruited from various aphasia rehabilitation programs in the Central Florida area, as well as various social media sites for people with aphasia. Some of these groups were Aphasia Family, Feeling Aphasia, Aphasia Choir, Aphasia House, and Communications Disorders Clinic. The mean age of the participants was 52.67 years with a standard deviation of 11.06. The sample included 8 females and 7 males, of which, 53.3% were White, 33.3% were Black, 6.7% were Hispanic, and 6.7% were Mixed/Other. Education breakdown included 26.7% with a Master’s degree, 20% with a Bachelor’s degree, 20% with a High School Diploma/GED, 13.3% who completed some college but did obtain a degree, 6.7% who did not finish high school, 6.7% who had an Associate’s degree, and 6.7% who had a Doctoral degree. The time since they acquired an expressive language disorder ranged from 2 to 21 years ago ($M = 7.33, SD = 5.73$). The participants mostly (93%) had diagnoses of Aphasia.

Measures

A demographic questionnaire was used to collect data on age, sex, education, ethnicity, year TBI occurred, time since TBI, and type of TBI.

The Trauma Impact on Identity Functioning Scales (TIIFS; Waterman, 2020) is a 69-item survey that measures the impact a specific traumatic experience has on an individual’s goals, values, beliefs, and activities (identity domains) and how that may have changed from the trauma. The TIIFS also includes a survey flow that permits questioning for certain responses, such as a significant increase or decrease in the level of importance of one domain from pre-to
post-trauma. For the current study, the TIIFS was shortened and revised with images to aid in the TBI survivors’ understanding of the questions being asked. The first part of the TIIFS measures level of importance from pre-to-post trauma for 15 domains: work/career, religion/spirituality, philosophy of life, personal relationship with romantic partner, personal relationship with closest friend, ethnic/racial identification, immigrant status, hobbies/leisure time activities, role as a parent of caregiver, politics, gender, sexuality, physical health, mental health, and community involvement. The items are rated on a scale of 1-not at all important to 5-extremely important. In the current study, this scale had an alpha of .84 at time 1 and .65 at time 2. The second part of the TIIFS is a 9-item questionnaire that measures how participants’ feel about their sense of identity. The items are rated on a scale of 1-not at all true to 5-extremely true. Example items are “my identity was clear and unambiguous before my brain injury,” and “I felt very positively about my identity.” In the current study, this scale had an alpha of .90 at time 1 and .96 at time 2. The TIIFS also categorized the participants into one of Waterman’s identity functioning categories based on his taxonomy previously described.

The Identity Distress Survey (IDS; Berman et al., 2004) measures overall identity discomfort. It consists of 7 items that measure distress, worry, or discomfort over the following issues (domains): long-term goals, career choice, friendships, sexual orientation and behavior, religion, values or beliefs, and group loyalties. This survey uses a 5-point scale ranging from 1-none at all to 5-very severely. Berman and colleagues (2004) reported the test re-test reliability to be .82, with the Average Distress Subscale internal consistency to be .84. In the current study, the Cronbach’s alpha was .84 for time 1 and .85 for time 2.

All measures in the survey battery were modified using picture visuals and minimal wording to make the survey easier to understand for participants with deficits, including aphasias. This is
another reason the interviewing component was essential to this study in order to ensure that the brief survey instructions were explained by a professional who is familiar with working with people with aphasia.

Procedure

The current project was approved by The University of Central Florida’s Institutional Review Board (IRB). Participants with expressive language disorders were recruited from several aphasia rehabilitation programs and social media support groups. The measures were put into Qualtrics format. Participants met individually with the researcher via zoom during which the researcher read the questions to the participants in order to maximize participant understanding of the question. Data collection occurred throughout two sessions. Participants were compensated with a $60 gift card after completing both interviews.
RESULTS / ANALYTIC STRATEGY

Preliminary and Descriptive Analyses

In terms of identity functioning post-brain injury, 33.3% of participants were categorized as experiencing an identity development delay, but moving forward, 26.7% had developed a trauma-centered identity, 13.3% experienced a loss of identity but were trying to restore it, 13.3% questioned their previous identity but were exploring new directions and purpose, 6.7% questioned their previous identity but did not change, and 6.7% reported that their identity became even stronger after the TBI.

Descriptive statistics for both measures are shown in Table 1. A bivariate correlation was conducted to reveal significant correlations between age with identity distress time 1 and identity clarity time 2 (See Table 2 for a correlation matrix of all study variables). A 2 (gender) by 3 (ethnicity) Multivariate Analysis of Variance (MANOVA) revealed significant gender differences for identity distress time 1 ($F_{(1, 9)} = 17.10, p = .003$). Males indicated having higher levels of identity distress at time 1 ($M = 1.94, SD = .72$) than females ($M = 1.07, SD = .12$). The MANOVA also revealed significant ethnicity differences for identity clarity time 1 ($F_{(2, 9)} = 7.80, p = .011$). An LSD post hoc analysis revealed that Mixed/Other ethnicity significantly differed from Black individuals ($M_{difference} = 1.48, p = .003$) and White individuals ($M_{difference} = 1.19, p = .008$). White and Black individuals both scored significantly higher than Mixed/Other individuals. No other gender or ethnicity differences were found.

Main Analyses

Hypothesis 1 (Participants’ identity functioning as measured by the Traumatic Impact on Identity Functioning Scale will be significantly better before the trauma than after the trauma)
was tested via paired samples t-test. Although the means for identity functioning followed the expected pattern, the resulting equation was not significant ($t(14) = 1.73, p = .106$). The sample had a higher mean at time 1 ($M = 4.41$) than at time 2 ($M = 3.93$).

Hypothesis 2 (Any changes in ratings of importance from pre-to post-trauma for the domains of personal relationship with a romantic partner and personal relationship with a close friend will depend on whether the participant remained in a relationship with a spouse or friend. If they did not remain in a relationship, the identity domain will be less important to them post trauma. If they did remain in a relationship, the identity domain will be more important to them post trauma) was tested via a $2 \times 2 \times 2$ repeated measures analysis of variance (RMANOVA), with time (pre/post) as the repeated measure factor, relationship status (change/no change) and sex (male/female) as the fixed factors, with importance ratings on the domain of personal relationships as the dependent measure. No significant differences were found for romantic relationship. Hypothesis 2 was partially supported as ratings of importance of their relationship with their closest friend from pre-to post trauma interacted with whether they stayed in the relationship with their closest friend post-trauma ($F(1, 3) = 40.50, p = .008$, Wilks’ Lambda = .069). Those who lost their friend rated the pre-trauma quality of that relationship as significantly higher than those that kept their friend; but on post-trauma rating, those that kept their friend reported a significant increase in friendship quality, whereas those that lost the friendship reported a significant decrease (See Figure 1).

Hypothesis 3 (Participant ratings of importance will indicate a significant increase in importance from pre-to post-trauma for the domains of religion or spirituality, and philosophy of life) was tested via a $2 \times 2$ repeated measures analysis of variance (RMANOVA), with time (pre/post) as the repeated measure factor and sex (male/female) as the fixed factor with
importance ratings of the three domains as the dependent measures. The resulting equation was not significant for religion \((F(1, 13) = 4.25, p = .060, \text{ Wilks’ Lambda} = .754)\) or philosophy of life \((F(1, 13) = 4.18, p = .062, \text{ Wilks’ Lambda} = .757)\). The pattern showed that males increased their ratings of importance from pre \((M = 3.57)\) to post \((M = 3.71)\) trauma for religion, while females showed a decrease in their ratings of importance from pre \((M = 4.00)\) to post \((M = 3.38)\) trauma for religion. The same pattern was found for philosophy of life, with males increasing their ratings from a mean of 3.86 to 4.29 and females decreasing their ratings from 4.50 to 3.50.

Hypothesis 4 (Participant ratings of importance will indicate a significant decrease in importance from pre-to post-trauma for the domains of work, job, or career; hobbies, sports, or leisure time activities; role as a parent or caregiver to another person; physical health; mental health; and community involvement, volunteer activities, or community service activities) was tested via a 2 X 2 repeated measures analysis of variance (RMANOVA) with time (pre/post) as the repeated measure factor and sex (male/female) as the fixed factor with domain ratings of importance as the dependent measure. The change from pre-to-post ratings of importance for work was significant \((F(1, 13) = 17.47, p = .001, \text{ Wilks’ Lambda} = .427)\), indicating that participants reported their career played a more important role in their identity pre-trauma than post-trauma. There was no interaction with gender \((F(1, 13) = 2.43, p = .143, \text{ Wilks’ Lambda} = .843)\). The males’ ratings of importance decreased from a mean of 4.43 to 3.29 and the females’ ratings decreased from 4.63 to 2.13. The resulting equations were not significant for hobbies, caregivers, physical health, mental health, or community. See table 3 for the means for pre and post trauma by gender.

Hypothesis 5 (There will be a significant difference in time since trauma with those who reported a positive impact of trauma on identity having the longest average time since trauma,
those who reported a negative impact of trauma on identity having the least time since trauma, and those “in transition” will be in between the other two groups) was assessed by first, grouping participants based on Waterman’s taxonomy of developmental impacts of trauma on identity into 3 categories: Positive impact (identity resilience, identity affirmation, threat to restoration, loss to alteration, loss to replacement), Negative impact (identity delay/stuck, continuing threat, threat to loss, identity loss), and In transition (identity delay/moving, threat to exploration, loss to exploration). Then, a ONEWAY ANOVA was conducted with the 3 groups as the fixed factor and time since trauma as the dependent measure. Trauma centered identity could be positive or negative depending on coping. Therefore, no specific hypotheses were made, and separate analyses were exploratory in nature. Four participants were categorized into the trauma centered identity category. Two of those four participants were placed in the negative impact category and two were placed in the positive impact category. These placements were based on their explanations of their identity changes. Two participants indicated a negative impact of trauma on their identity, seven participants indicated they were in transition, and six indicated a positive impact. The ONEWAY ANOVA was not significant ($F(2, 12) = 1.13, p = .356$).

As expected, no significant differences were found for ratings of importance from pre-to post-trauma for ethnic or racial identification, immigrant status, politics or views on specific social issues, gender, and sexuality.
DISCUSSION

Main Findings

Although identity functioning was not significantly better at time 1 than time 2 as we predicted in hypothesis 1, the pattern showed that participants did report having higher levels of identity functioning at time 1. This pattern did not reach significance. It is possible that we did not have a large enough sample size to produce the power needed for this pattern to become significant. It is important for future research to investigate changes in identity functioning of stroke survivors with a larger sample.

Despite our predictions, no significant differences were found in the domain of romantic relationships. However, there was an interaction for relationship with closest friend and status of relationship with closest friend from pre-to-post trauma. Participants reported various reasons for their change in importance for romantic relationship: “It is hard to find someone, because I can't communicate. I think different than most people, my perspective is different,” “relationship is stronger now than it was before. Support system. I was tirelessly working. Mental, physical, and spiritual part of identity are now on track,” and “before the disorder, I was with my partner but now we do not understand each other anymore.” Similarly, participants reported the following as explanations for changes in importance for their relationships with their closest friend: “I share aphasia connections with my closest friend,” “friends slowly started to exit life after stroke. Now I have a support group and they have become close friends because they had stroke and aphasia and can relate to me. They are better friends, true friends,” and “all of my friends were from work and now none of them talk to me. Only one person still talks to me, but I have no close friends. Everybody loved me and now nobody knows or cares who I am.” As Ellis-Hill and Horn
(2000) found that self-concept varies from one stroke survivor to another, it could also be true that perceptions of relationships may vary from one stroke survivor to another.

An interesting finding, although not reaching a level of statistical significance, is that males showed an increase of importance from pre-to-post trauma for religion and philosophy of life, while females showed a decrease in importance. Future research is needed to replicate the current study to determine if this trend would reach significance with a larger sample size. When asked about their change in ratings of importance for religion, some responded saying religion is what saved them: “I think that God saved me because there is no other reason I'm here. Even though I was married when I had a stroke, he wasn't there, I was all by myself and that was scary, and my worst fear was dying alone and God was there for me. I had 95% chance of dying and God saved me,” while others highlighted that they were unable to participate in religion the way they did pre-trauma: “Because I didn't go to church after [my stroke] and I used to go every Sunday but it took me a long time to go back because of my mobility and I didn't want to go to church, I had to fortify myself and get my mind right before I could go to church again.” For philosophy of life, some reported a completely new outlook on life: “I almost lost my life, life is short. I wasted too much time on the people that didn't make me happy,” “I was thinking you have to deal with whatever comes your way and give yourself a break if something is askew, don't beat yourself up but keep going and never give up,” “I died for two minutes so now I try to live my life as if it was gonna end tomorrow. I'm not scared of dying anymore,” while others reported no change to their philosophy of life post-trauma: “I am the same person as before.”

Ratings of importance for career differed significantly from pre-to-post trauma, but with no interaction with gender. Both males and females showed a decrease in ratings of importance in regard to their career from pre-to-post trauma. Many participants explained their pre-trauma
career, and how they are unable to continue with that career post-trauma: “I had an awesome job before but when I had the stroke, and I can’t talk to people like before, I lost my job. Because I was an office manager and a human resources assistant so I talked to people all the time and now I can’t do that,” “I had the same job for 30 years and now I cannot work,” “I lost my job because I couldn't talk so I couldn't be a professor. I was proud of myself before my stroke. Now nobody knows who I am, and I thought I would be a popular professor by now.” The participants’ responses indicated that the stroke survivors were significantly impacted by their inability to return to their career post-trauma. Taubner and colleagues (2020) found that difficulties with communication skills following an aphasia affects their ability to perform the roles that are part of their identity. It appears as though our findings support Taubner and colleagues’ findings, specifically in regard to career, as we see that language impairments were the main reason participants could not return to work and lost that part of their identity.

Although there were no significant differences for pre-to-post ratings of importance for hobbies, caregivers, physical health, mental health, or community, participants still seemed to be negatively impacted by changes in these areas of their lives. In terms of hobbies, participants reported that: “Before the stroke I used to do Yoga every day and horseback riding every Friday. After the stroke I am missing part of my skull over my temporal lobe, so it is no longer safe to be around horses. I miss being able to be around horses, they make me so happy. I don't have any real hobbies now. Before my stroke I didn't watch TV and all I do now is watch TV and have post-stroke fatigue. I watch YouTube and watch other people living their lives but cannot go live my own life like that anymore,” and “I used to walk, I used to go to the gym, I used to garden, the only thing I did at that time [after stroke] was look at people doing stuff that I used to do.”
Participants had similar things to say about their changes in caregiver status: “Before I had the stroke, my kids would come to me for help, and now they don't because I don't know that much stuff anymore. They don't ask my opinion on anything or help anymore which is a bummer,” and “nowadays I can't be able to handle many things like before” whereas others reported finding a new role as a caregiver: “Larger role in it now. Helping out nephews, giving my guidance, life goals, and educating girls on technology, feeling confident, high energy, insight.” One explanation for why some participants reported a decrease in importance in caregiver status from pre-to-post trauma could be that stroke survivors view themselves as more dependent, less capable, and less in control (Ellis-Hill & Horn, 2000).

Physical health elicited various responses from the participants: “I think my physical health was important before because I used to exercise with friends and now I don't,” “I used to sit in a chair all day for 12 hours, I didn't do anything else, now I do 10,000 steps a day, I bike some, I mess around with the dogs and horses, clean horse stalls, etc.,” “I had to learn how to do things with one side of my body, I had to learn my limitations until I got strong enough to do more things. It was awful,” and “I could drive, I can't do that now. I live upstairs, I could run upstairs before; now I have to hold on to rails and I can't walk far or fast. So, everything just went down.” Ellis-Hill and Horn (2000) also found that physical health was not a significant predictor of changes in self-concept, and it appears as though physical health is not a predictor of changes in identity functioning either. In addition, Tyerman and Humphrey (1984) found that the majority of their participants reported their lifestyles were altered by their head injuries due to things such as a lack of mobility and reduced physical skills.

Although there were no significant differences in ratings of importance for mental health from pre-to-post trauma, it is evident that some participants struggled with their mental health
post-trauma: “Because I have permanent brain damage, my aphasia, my language center is permanently affected, and I have higher anxiety and higher depression now. I try to keep myself more positive.” We expected participants to report difficulties with mental wellbeing post-trauma, as Ellis-Hill and Horn (2000) found that stroke survivors reported higher levels of depression, higher levels of anxiety, and lower levels of activity, all of which we found while reviewing qualitative data on mental health and physical health. In addition, Tyerman and Humphrey (1984) reported that the majority of their participants reported being clinically depressed post-trauma, and just under half of the participants reported being clinically anxious.

Community involvement from pre-to-post stroke varied for participants: “I was a member and leader and now a days I am no longer a member and the leader was changed,” “it is zero because I was in a low income area trying to get services for the people there and once I had my stroke I didn't get back to them because it took me over a year to gain my speaking abilities back so I didn't go back because it was time loss,” “I would volunteer at foster care organizations. Now I can't physically do that stuff anymore,” “before stroke, I wasn't involved in much. I am involved in a lot of activities and support groups, and I run a support group online.” Despite the lack of significance in our quantitative data for various areas of importance for pre-to-post stroke, it is evident from the qualitative data that TBI survivors are experiencing a wide range of changes in these areas of their lives. It is important for future research to further investigate these domains to determine which factors are predictors for positive or negative change from pre-to-post trauma for each identity domain. Tyerman and Humphrey (1984) reported that participants with head injuries experienced lifestyle changes in relation to their social lives being disrupted, as well as having limited leisure opportunities post-trauma.
Ellis-Hill and Horn (2000) reported that results varied from stroke survivor to stroke survivor in terms of how their self-concept changed post-stroke. It appears as though identity changes post-trauma also vary from one TBI survivor to another, which may explain why not all of our hypotheses reached significance, but the patterns seemed to follow our predictions. It is important for future research to further investigate how various domains of identity change from pre-to-post TBI and determine the intensity of such changes. Identity changes have important clinical implications in regard to treating TBI survivors in a therapy setting, and it is essential for therapists to understand the various changes that occur within a survivor from pre-to-post TBI, and how these changes impact their daily functioning.

Limitations and Future Directions

One limitation of our study was the ability to communicate via Zoom for the clinical interviews. Although the interviewer had professional experience and training on how to communicate with people with aphasia, it is possible that some participants did not fully understand the concepts that were being asked, which could have altered their self-report ratings. Future research could benefit from reconducting this study post-pandemic when data collection can be done in person and communication efforts can be improved. In addition, future research could benefit from including a measure of comprehension prior to conducting the interviews. This leads to the second limitation, our findings are based on self-report, and it is possible that the self-reports of the TBI survivors are not fully accurate. Future research could further investigate this topic by getting additional reports from family and friends of the TBI survivor to further evaluate which domains of identity are impacted post-TBI.

The biggest limitation to our study was our sample size. Despite receiving a grant and offering participants a $60 gift card to participate, recruitment was still difficult. This could be
due to the current times (Coronavirus pandemic). Prospective participants may not have wanted to participate in person, and were unable to participate online. Future research would greatly benefit from replicating our study with a much larger sample size to determine if the patterns we found become significant.

Interestingly, time since trauma was not significantly correlated with identity functioning nor identity distress change scores. This suggests the need for future research to determine which factors influence whether and why survivors’ experience post traumatic identity disruption and/or growth, as it appears that time alone is not sufficient.
APPENDIX A: IRB APPROVAL LETTER
June 17, 2021

Dear Bailey Wagaman:

On 6/17/2021, the IRB determined the following submission to be human subjects research that is exempt from regulation:

<table>
<thead>
<tr>
<th>Type of Review:</th>
<th>Initial Study, Category 2(ii)</th>
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<tbody>
<tr>
<td>Title:</td>
<td>Identity changes due to trauma</td>
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<tr>
<td>Investigator:</td>
<td>Bailey Wagaman</td>
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<tr>
<td>IRB ID:</td>
<td>STUDY00002999</td>
</tr>
<tr>
<td>Funding:</td>
<td>Name: Learning Institute for Elders at UCF</td>
</tr>
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<td>Grant ID:</td>
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Documents Reviewed:  
- Form 251 Identity changes due to trauma.pdf, Category: Faculty Research Approval;  
- Email script, Category: Recruitment Materials;  
- HRP-254-TBI and Identity.pdf, Category: Consent Form;  
- HRP-255-TBI and Identity.docx, Category: IRB Protocol;  
- Phone script, Category: Recruitment Materials;  
- Recruitment message.docx, Category: Recruitment Materials;  
- Survey_TBI and Identity.docx, Category: Survey / Questionnaire;  
- WagamanLtr2021 (1).docx, Category: Sponsor Attachment

This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made, and there are questions about whether these changes affect the exempt status of the human research, please submit a modification request to the IRB. Guidance on submitting Modifications and Administrative Check-in are detailed in the Investigator Manual (HRP-103), which can be found by navigating to the IRB Library within the IRB system. When you have completed your research, please submit a Study Closure request so that IRB records will be accurate.

If you have any questions, please contact the UCF IRB at 407-823-2901 or irb@ucf.edu. Please include your project title and IRB number in all correspondence with this office.

Sincerely,

Katie Kligore  
Designated Reviewer
APPENDIX B: DEMOGRAPHIC QUESTIONNAIRE
PARTICIPANT NUMBER:

AGE: Type your age

SEX: Indicate your gender
  • Male
  • Female
  • Transgender
  • Non-Binary
  • Other (explain):__________________________

EDUCATION: What is your highest level of education?

ETHNICITY: Select the ethnic/racial identifier that best describes you:
  • White, non-Hispanic
  • Black, non-Hispanic
  • Hispanic or Latino/a
  • Asian or Pacific Islander
  • Native American or Alaskan Native
  • Mixed ethnicity or Other (Specify):______________________

How long ago was your brain injury?________
APPENDIX C: TRAUMATIC IMPACT ON IDENTITY FUNCTIONING SCALES
In this survey we will ask about your “Identity” and how it might have changed from before your brain injury and currently.

Your identity involves the roles, goals, and values that give your life a sense of direction and purpose.

Identity =

Roles

Goals

Values/ Beliefs
TIIF

How important was each of these things to your sense of identity BEFORE your brain injury.

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A. Your work, job, or career

B. Your religion or spirituality

C. Your philosophy of life

D. Your personal relationship with a romantic partner
E. Your personal relationship with your closest friend

F. Your ethnic or racial identification

G. Your immigrant status

H. Your hobbies, sports, or leisure time activities

I. Your role as a parent or caregiver to another person
J. Your politics or views on specific social issue

K. Your gender

L. Your sexuality

M. Your physical health

N. Your mental health
O. Your community involvement, volunteer activities, or community service activities
For the following questions, think about how you felt about your sense of identity BEFORE your brain injury.

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</table>

12. My identity was clear and unambiguous before my brain injury.

13. I felt very positively about my identity.

14. My identity provided me with a sense of meaning in my life then.

15. My identity was an important part of who I was then.
16. My identity was a source of personal satisfaction in my life then.

17. My identity was central to how I thought about myself then.

18. My identity seemed to relate to most things I was doing at the time.

19. I spent a great deal of time then engaging in activities relating to my identity.

20. I believed my identity would remain pretty much the same in the years ahead.
Now, CURRENTLY, how important is each of these things to your sense of identity:

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A. Your work, job, or career

B. Your religion or spirituality

C. Your philosophy of life

D. Your personal relationship with a romantic partner
E. Your personal relationship with your closest friend

F. Your ethnic or racial identification

G. Your immigrant status

H. Your hobbies, sports, or leisure time activities

I. Your role as a parent or caregiver to another person

J. Your politics or views on specific social issue
K. Your gender

L. Your sexuality

M. Your physical health

N. Your mental health

O. Your community involvement, volunteer activities, or community service activities
For the following statements, think about the way you CURRENTLY feel about your sense of identity.

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18. My identity seemed to relate to most things I was doing at the time.

19. I spent a great deal of time then engaging in activities relating to my identity.
20. I believed my identity would remain pretty much the same in the years ahead.

(Ask this question for each domain that changes by at least 2 points)
1. I noticed that your ratings of the importance of ______ decreased/increased quite a bit from before to currently. Can you tell me more about this?
START OF INTERVIEW SESSION 2

How do you think your identity has changed (if at all) since your brain injury?

a) It hasn’t changed  
b) It has become totally centered on my brain injury and its effects on me and the lives of others. (Scoring: Trauma-centered Identity)  
c) I felt like my identity was on hold for a while  
d) It made me wonder if my identity needed to change  
e) It made me feel like I totally lost my identity

Can you tell me more about that? __________

(Survey Flow)

If they picked (a)  
Do you feel like your identity has remained the same or become even stronger since the injury?  
   a) The same (Identity Resilience)  
   b) Even stronger (Identity Affirmation)

If they picked (b)  
   (Trauma-centered identity)

If they picked (c)  
Does it still feel like it is on hold?  
   a) Yes (identity delay/stuck)  
   b) No, I feel like it is moving forward again (identity delay/moving)
If they picked (d)
After wondering if your identity needed to change, what did you finally decide?
   (a) No, it did not need to change (threat to restoration)
   (b) I am still not sure (continuing threat)
   (c) I am working on developing a new identity (threat to exploration)
   (d) I have given up trying to establish a sense of identity (threat to loss)

If they picked (e)
After feeling like your identity was totally lost, what did you do?
   (a) I am trying to restore my previous identity (loss to alteration)
   (b) I am developing a new identity (loss to replacement)
   (c) I am exploring what I want my identity to be (loss to exploration)
   (d) I have given up trying to establish an identity (identity loss)
APPENDIX D: IDENTITY DISTRESS SURVEY
**IDS:** Please respond to these statements the way you think you would have BEFORE your brain injury. To what degree, at that time, were you upset, distressed, or worried over any of the following issues in your life?

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<tr>
<td></td>
<td>None at all</td>
<td>Mildly</td>
<td>Moderately</td>
<td>Severely</td>
<td>Very Severely</td>
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</table>

1. Long term goals? (e.g., finding a good job, being in a romantic relationship, etc.)

2. Career choice? (e.g., deciding on a trade or profession, etc.)

3. Friendships? (e.g., experiencing a loss of friends, change in friends, etc.)

4. Sexual orientation and behavior? (e.g., feeling confused about sexual preferences, intensity of sexual needs, etc.)
5. Religion? (e.g., stopped believing, changed your belief in God/religion, etc.)

6. Values or beliefs? (e.g., feeling confused about what is right or wrong, etc.)

7. Group loyalties? (e.g., belonging to a club, school group, gang, etc.)
**IDS-2:** Please respond to these statements the way you think you now feel CURRENTLY. To what degree have you recently been upset, distressed, or worried over any of the following issues in your life? (Please select the appropriate response, using the following scale).

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</table>

1. Long term goals? (e.g., finding a good job, being in a romantic relationship, etc.)

2. Career choice? (e.g., deciding on a trade or profession, etc.)

3. Friendships? (e.g., experiencing a loss of friends, change in friends, etc.)

4. Sexual orientation and behavior? (e.g., feeling confused about sexual preferences, intensity of sexual needs, etc.)
5. Religion? (e.g., stopped believing, changed your belief in God/religion, etc.)

6. Values or beliefs? (e.g., feeling confused about what is right or wrong, etc.)

7. Group loyalties? (e.g., belonging to a club, school group, gang, etc.)
APPENDIX E: TABLES AND FIGURES
Table 1: Descriptive Statistics

<table>
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<th></th>
<th>M</th>
<th>SD</th>
<th>Minimum</th>
<th>Maximum</th>
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<tbody>
<tr>
<td>Identity Distress Time 1</td>
<td>1.48</td>
<td>.66</td>
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<td>3.00</td>
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<tr>
<td>Identity Distress Time 2</td>
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<td>.92</td>
<td>1.00</td>
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<tr>
<td>Identity Clarity Time 1</td>
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<td>3.11</td>
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<tr>
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<tr>
<td>Identity Importance Time 1</td>
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<tr>
<td>Identity Importance Time 2</td>
<td>3.43</td>
<td>.57</td>
<td>2.47</td>
<td>4.60</td>
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### Table 2: Correlation Matrix for all study variables with age

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<tbody>
<tr>
<td>(1) Age</td>
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<td>-</td>
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<tr>
<td>(2) Identity Distress Time 1</td>
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<td>-</td>
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<tr>
<td>(3) Identity Distress Time 2</td>
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<td>-</td>
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<tr>
<td>(4) Identity Clarity Time 1</td>
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<td>28</td>
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<td>31</td>
<td>-</td>
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<tr>
<td>(6) Identity Importance Time 1</td>
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<td>-20</td>
<td>15</td>
<td>38</td>
<td>49</td>
<td>-</td>
</tr>
<tr>
<td>(7) Identity Importance Time 2</td>
<td>40</td>
<td>-32</td>
<td>-53*</td>
<td>-07</td>
<td>60*</td>
<td>63</td>
</tr>
</tbody>
</table>

Note: *$p < .05$
Table 3: Means at time 1 and time 2 by gender

<table>
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<th>Time 1</th>
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<th>Time 2</th>
<th></th>
</tr>
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<tbody>
<tr>
<td>Hobbies</td>
<td>Male</td>
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<td>Female</td>
<td>4.00</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>3.86</td>
<td>Female</td>
<td>4.13</td>
</tr>
<tr>
<td>Role as Caregiver</td>
<td>Male</td>
<td>2.86</td>
<td>Female</td>
<td>4.13</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>2.43</td>
<td>Female</td>
<td>3.00</td>
</tr>
<tr>
<td>Physical Health</td>
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<td>3.86</td>
<td>Female</td>
<td>3.88</td>
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<tr>
<td></td>
<td>Female</td>
<td>4.29</td>
<td>Female</td>
<td>3.50</td>
</tr>
<tr>
<td>Mental Health</td>
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<td>Female</td>
<td>4.38</td>
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<tr>
<td></td>
<td>Female</td>
<td>4.14</td>
<td>Female</td>
<td>4.13</td>
</tr>
<tr>
<td>Community</td>
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<td></td>
<td>Female</td>
<td>3.57</td>
<td>Female</td>
<td>2.75</td>
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</table>
Figure 1: Interaction between pre/post ratings of importance of relationship with their closest friend and post-trauma friend status.
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