The Lived Experiences with Traumatic Brain Injury

A Qualitative Study: Eastern Washington Assessment

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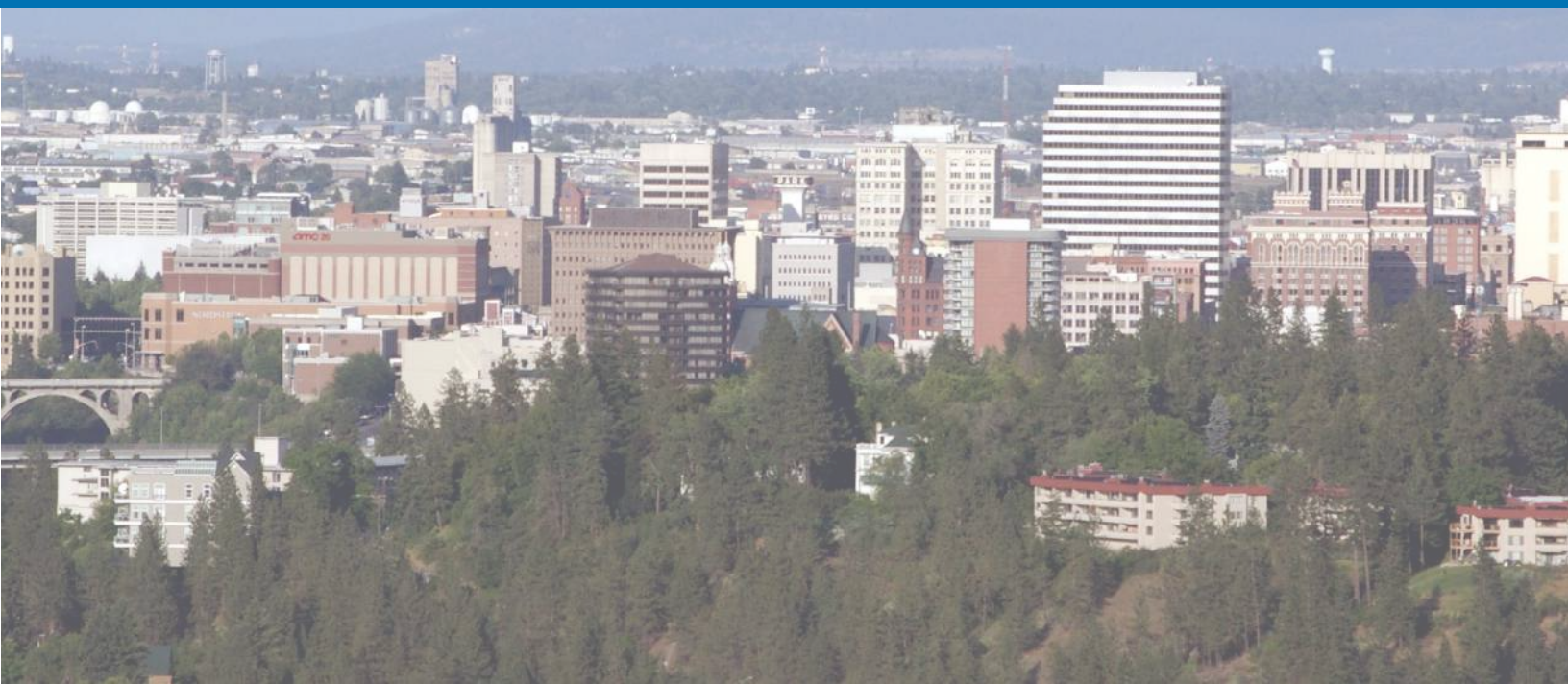

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Study Overview

Project Purpose

The following needs assessment is based on qualitative data collected to investigate life after a Traumatic Brain Injury (TBI), basic brain functionality with regards to a TBI, and the impacts a TBI can have on psychosocial, behavioral, and personality functionality in everyday life.

Respondents

436 individuals with a Traumatic Brain Injury responded to the online questionnaire or completed the in-person interview.

209 of the 436 individuals were recruited from Eastern Washington.

Traumatic Brain Injury (TBI) can have far reaching implications in the areas of emotion, language, sensation, and cognition. Significant alterations in these areas of an individual's life can affect their ability to work, maintain healthy interpersonal relationships, and perform instrumental daily activities of living (IADL). Since outcome data relating to these types of injuries are being used to inform policy decisions, treatment options, service provision, and the allocation of health-care resources, it's vital that research informs decision-makers regarding the holistic health-related life satisfaction following an acquired disability to ensure accuracy and merit.

The caveat to conceptualizing the lives of individuals with a TBI is that the influencing factors vary tremendously. Individuals can experience issues like memory loss, speech problems, chronic pain, reoccurring visual distortions, paralysis, seizures, affective mood disturbances, and slower than average cognitive processing to name only a few. The scope of problems that occur post-TBI are so broad that standard TBI rehabilitation practices may not be adequate to address these issues in their entirety, leaving many individuals adrift and without necessary support.

The following project is based out of Eastern Washington University with the intention of acquiring a holistic appraisal of life with a TBI. Our purpose is to identify major concepts and themes. The fundamental premise of this project is to shed light on the dynamics of change to better guide professionals, patients, and other relevant populations for their betterment, where possible.

The Questionnaire

Respondents were primarily recruited through the Brain Injury Association of America and the TBI Survivors Network, both of which are 501(c)(3) non-profit organizations.

Brain Injury Waikato, a Non-Governmental Organization (NGO), based out of Hamilton, New Zealand also recruited several respondents for this study. The following table details the basic demographic profiles for the overall study.

Sample (N = 436)	*n (%)*
Age (Mean/SD)	43.3 (13.6)
Minimum	18
Maximum	74
Gender	
Male	214 (49%)
Female	219 (51%)
Current Marital Status	
Single	91 (21%)
Married	147 (34%)
Long-Term Relationship	47 (11%)
Divorced or Widowed	49 (11%)
Other (Engaged/Seperated/Co-Habitation)	102 (23%)
Current Occupational Status	
Employed Part-Time	51 (12%)
Employed Full-Time	92 (21%)
Unemployed	249 (57%)
Self-Employed	38 (9%)
Student	0 (0%)
Retired	6 (1%)

Assessment and Categories

The questionnaire/interview consists of 80 multiple-choice and short-answer questions across 9 sections. Individuals were asked to respond to 144 separate items within those 80 questions.

In addition, respondents were asked to complete basic demographic information including their age, gender, and ethnicity. Multiple-choice questions regarding their marital, occupational, and income statuses, both pre-injury and post-injury, were also part of the demographic inquiry.

The bulk of the assessment included short-answer questions across nine assessment categories.

- Subjective Experiences
- Resource Allotment, Awareness, and Medical Treatment
- Brain Injury Rehabilitation and Recovery
- Independent Living
- Symptomology and Treatment Access
- Personality and Behavioral Characteristics
- Neurocognitive Abilities
- Identity Attributes
- Perceptions and Social Support

The Assessment

Assessment Category	*Example Question*
Subjective Experiences	*Describe any adjustments you made to your daily life after your initial brain injury rehabilitation? For example, consistent use of a wheelchair, issues with wheelchair maintenance, regular seizure medication, regular neurocognitive therapy, changes in interpersonal relationships (i.e. divorce/separation), etc.*
Resource Allotment, Awareness, and Medical Treatment	*If you received emergent-care or no-care at all after your Traumatic Brain Injury, please describe the reason why?*
Brain Injury Rehabilitation and Recovery	*Describe a beneficial aspect of your brain injury rehabilitation? For example, therapy, medications, social support, etc.*
Independent Living	*What obstacles have you overcome in your daily life since your Traumatic Brain Injury?*
Symptomology and Treatment Access	*Since your Traumatic Brain Injury (TBI), have you experienced symptoms that have diminished and returned with time? For example, memory problems that were initially present post-TBI, which then disappeared, only to return again after a period of weeks, months, or years.*
Personality and Behavioral Characteristics	*Have you experienced personality and behavioral changes since your Traumatic Brain Injury? If so, please briefly describe the changes.*
Neurocognitive Abilities	*If applicable, describe any memory impairments? For example, problems recalling memories from before your traumatic brain injury, problems recalling information post-TBI, impairment of memory when experiencing anxiety, etc.*
Identity Attributes	*Has your sense of identity ("who you are") changed since your Traumatic Brain Injury? If so, how?*
Perceptions and Social Support	*Identify and describe a positive relationship that has formed since your Traumatic Brain Injury? For example, dating someone new, starting a new job, joining support groups, and/or re-connecting with family.*

EASTERN WASHINGTON ASSESSMENT

Overview

Within the aforementioned study, 209 of the 436 respondents were recruited from Eastern Washington. Using NVivo 11 Pro, an open coding analysis was performed to identify and categorize the data, subsequently identifying major themes.

Data for this assessment has been solely based on individuals recruited from Eastern Washington that include the counties of Spokane, Whitman, Pend Oreille, Stevens, Ferry, Lincoln, Adams, Franklin, Walla Walla, Garfield, Asotin, Benton, Grant, Douglas, Okanogan, Chelan, Kittitas, Yakima, and Klickitat. These two tables highlight basic demographic information of those respondents included within this assessment.

Sample (N = 209)	*n (%)*
Age (Mean/SD)	53.4 (12.6)
Minimum	36
Maximum	74
Gender	
Male	112 (54%)
Female	97 (46%)

Current Marital Status	*Pre-Injury n(%)*	*Post-Injury n(%)*
Single	54 (26%)	45 (21%)
Married	88 (42%)	85 (41%)
Long-Term Relationship	34 (16%)	30 (14%)
Divorced or Widowed	28 (13%)	33 (16%)
Other (Engaged/Separated/Co-Habitation)	5 (3%)	16 (8%)

CAUSES AND CONTRIBUTING FACTORS

Of our respondents, an overwhelming majority of individuals acquired their injury via a ***Motor Vehicle Accident***. An even distribution occurred among the other causes of ***Struck By/Against*** and ***Fall***.

Other causes included Anoxic Brain Injury, Fetal Alcohol Syndrome, Perinatal Illness, and Perinatal Hypoxia, which were also reported evenly with the previous two. ***Assault*** and ***Self-Harm*** (attempted suicide) were also reported in a handful of incidents

There were several causal factors that factored into the occurrence of the aforementioned events. Of the causal factors, the most significant was ***Alcohol***. The consumption of alcohol was directly involved in the incidence of 36% of the ***Motor Vehicle Accidents*** cited above, while a ***Lack of Seatbelt*** were reported in 9% of those incidents.

Military Service contributed to 18% of the overall incidents, excluding ***Self-Harm*** and ***Other***. While ***Caused by Another*** and ***Playing Sports*** were reported in 9% of the ***Struck By/Against*** and ***Assault*** incidents respectively.

Sample (N = 209)	*n (%)*
Age at Time of Injury (Mean/SD)	34.2 (18.54)
Minimum	8
Maximum	64
Cause of Brain Injury	
Motor Vehicle Accident	102 (49%)
Struck By/Against	30 (14%)
Fall	29 (14%)
Assault	17 (8%)
Self-Harm	1 (0.49%)
Other	30 (14%)

Causal Factor	*Example of Incidence*
Alcohol	*"I was drinking with a buddy. We then decided to drive a couple blocks to visit our girlfriends. It was his car and I was the passenger, we then crashed into a tree."*
Lack of Seatbelt	*"I was involved in a car accident. I was a passenger who was not wearing a seatbelt. My wife lost control of the car, and spun into a ditch which ejected me out the back glass 30 feet onto the street head first. My skull was broken in two places, and severely fractured it in a third. The fracture actually saved my life because it allowed my brain to swell."*
Military Service	*"Hit in Iraq by #2 Mamba doing High Risk Security ops."*
Caused by Another	*"I was beaten up by a guy or bunch of guys...no idea....I was raped, beaten, and kicked. Had a broken eye socket bone, cracked head bone, separated shoulder, broken ribs, and a dislocated jaw."*
Playing Sports	*"I was struck by a softball while I was running to second base. An opposing player threw a ball (estimated to be between 60-70 mph) and it hit the right side of my head (no helmet), knocking me down."*

Causal Theme	*Example of Incidence*
Repeated Concussive Injuries	*"I have had more than six significant concussions that I always recovered from or nearly completely recovered from within days to months. But in 2010, I had a massive bike wreck, flew in the air, and landed my full body weight onto the back of my head. I had on a helmet, and the back part was compressed and also split all the way through. The wreck was me crashing into another cyclist who had signaled to make a turn but did not ever turn. The one in 2010 was my 4th."*
	"I am a survivor of multiple concussions. 19 hits from 2008 to 2015. Hitting steel hanging lamp, collided with a horse's head, 2 x 6 barn beams, stair landing, canopy door slammed on me, wind closing car door on me, many more mostly around my farm. My head loves beams. Beams win."

Reports of other causal factors varied greatly; however, there was a recurrent theme of repeated injuries with **no reported intervention** after the initial incident.

INITIAL EFFECTS AND MEDICAL ACCESS

The majority of our respondents spent 1-12 **months** (38.66%) in an acute-care setting, while the rest spent 1-4 **weeks** (20.17%), 1-7 **days** (13.45%), and 1-24 **hours** (10.08%) in that setting.

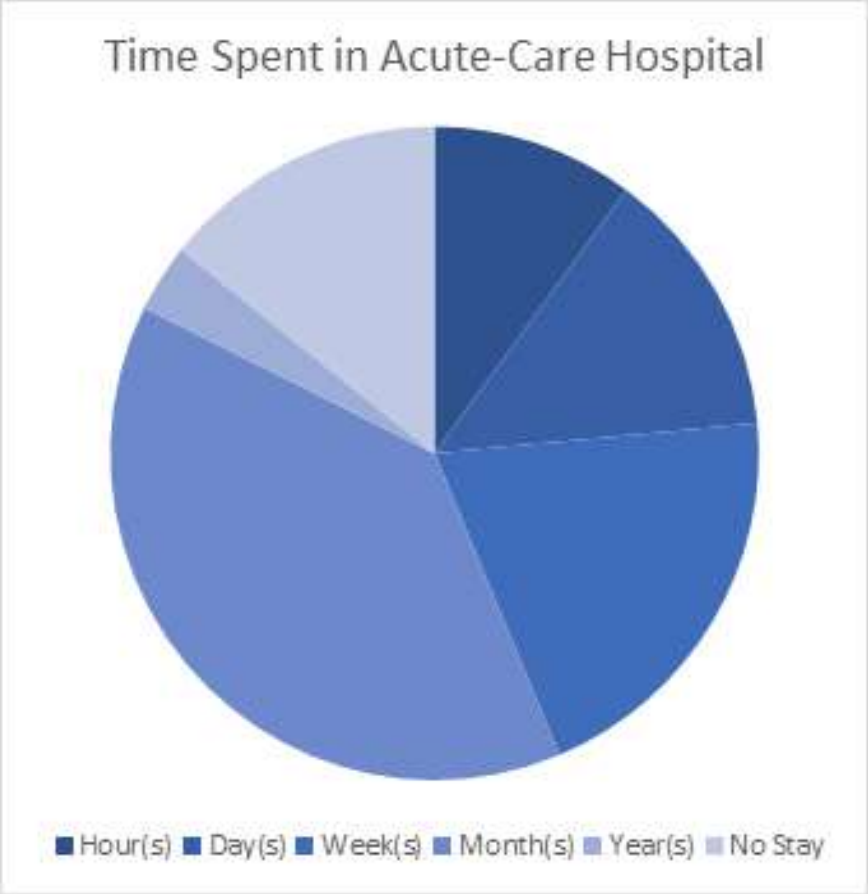
In addition, a small group of individuals reported staying **over a year** in an acute-care setting (3.36%), while a significant portion of respondents reported having never received any acute care (14.29%).

Of those that did not receive any acute-care, the following themes were predominantly present:

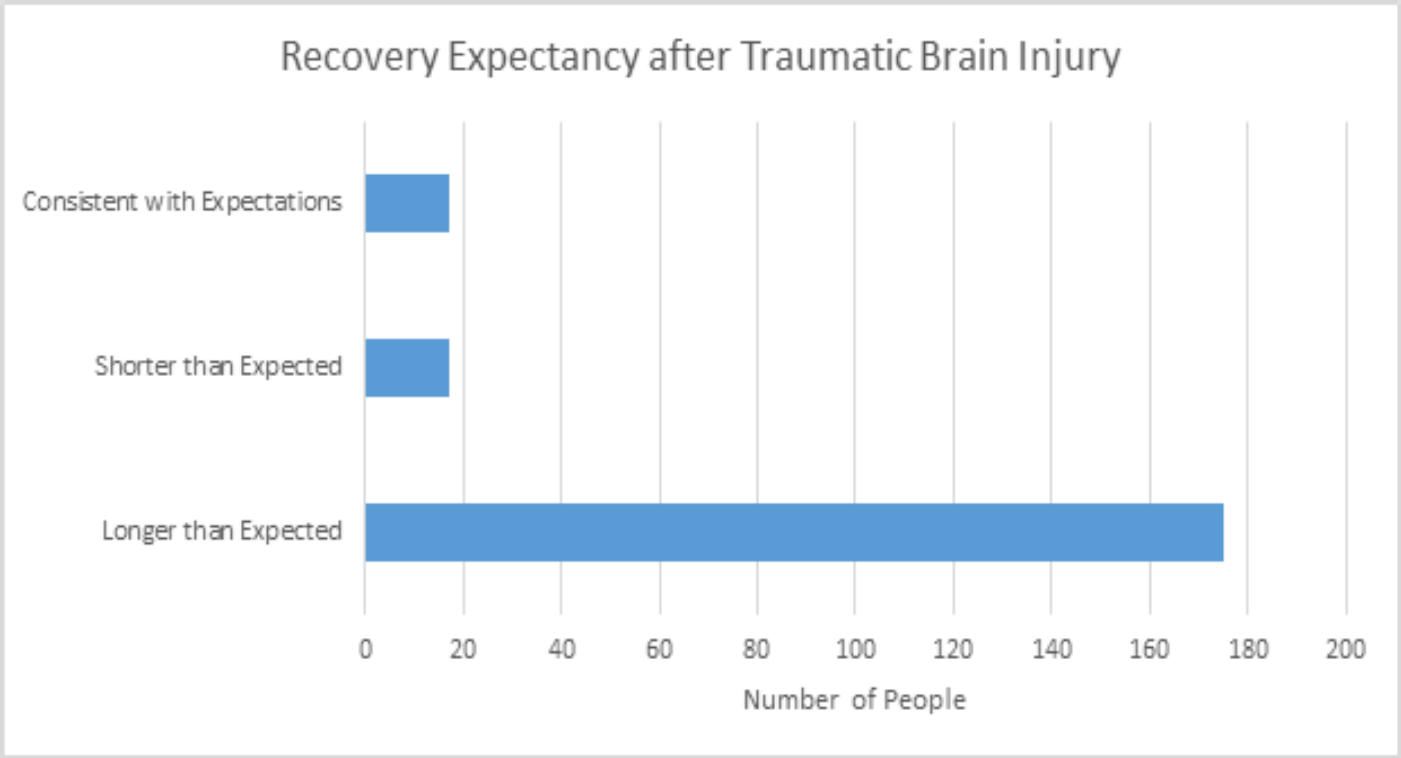
- Lack of Familiarity with Brain Injury
- Subtle Symptom Presentation
- Lack of Medical Insurance

On the part of the medical staff at the time of the injury, as reported by the respondents, the following themes were predominantly present:

- Misdiagnosis of Injury
- Misconception of Brain Injury Lasting Effect



Both of the aforementioned themes are linked with a reported lack of familiarity and understanding with regards to presentation of a Traumatic Brain Injury. Furthermore, this notion is compounded with the relative expectancy of recovery after such an injury.



The vast majority regarded their recovery process to be much longer than initially expected, either due to a misconception of the recovery process or a frustration with their lack of overall abilities.

Time till Recovery	*Reported Examples*
Longer than Expected	*"Longer. I was told at the beginning that we should know how I am doing two years out. But two years out, I was still in therapy and having terrible headaches. That's when my depression kicked into high gear."*
	"Much longer. I thought I would get better but I'm a different person now and there are so many limitations, medications to take, and lasting problems."
	"I took about six months until I was back to normal. That doesn't seem like very long, but when you're in a wheelchair struggling with your umpteenth OT task, each day is an eternity. Also, never knowing exactly how much you will get back, and no one else knowing either, but still working so hard, that makes it feel even longer. Being a life-long overachiever, I was constantly frustrated with how long my brain injury recovery was taking. There were many moments I cried simply at the frustration of, what's taking so long??"

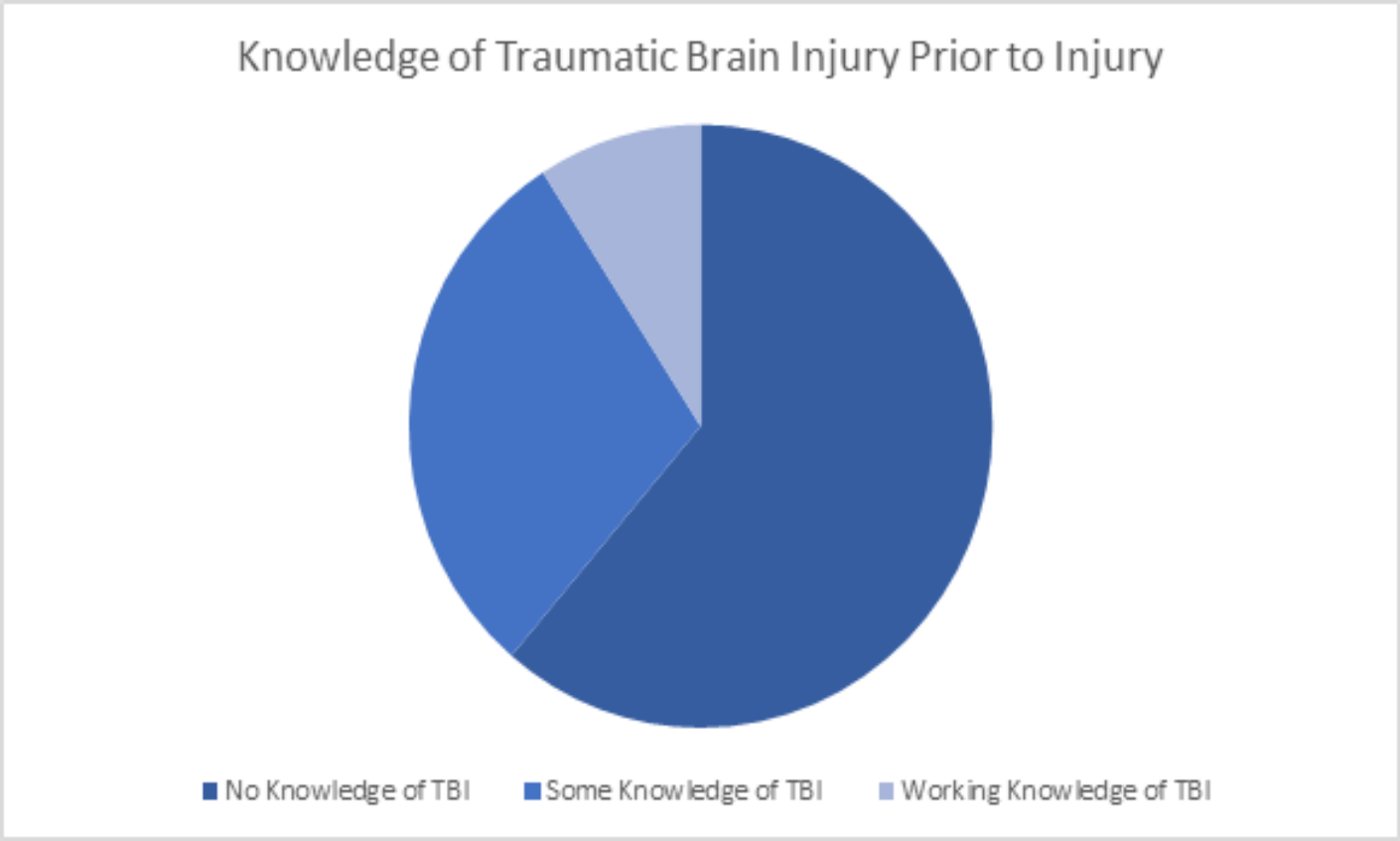
RESOURCE ACCESS AFTER A TBI

Both awareness and knowledge with regards to Traumatic Brain Injury is problematic. Several respondents, even those with extensive medical backgrounds, reported little to no awareness of any conceptualization of a Traumatic Brain Injury prior to their injury. Several of these injuries occurred within the last 10 years.

- *"Before this one in 2010, yes. I studied them a good bit in speech therapy school and had an internship at a brain injury rehab facility. However, I managed to get out of grad school not at all understanding what a concussion was. We briefly touched on how mTBI can sometimes affect people seriously, but it was like one article, in one class. I had no clue that some people with a concussion could need rehab. But my first serious concussion was as a 10-year-old, and of course I didn't know anything about it and neither did my parents who did not take me to the doctor."*

- *"Nothing, except emergency care as an EMT. If they had a head injury they needed to go to the hospital and get checked out. Besides that, I had no idea of the long-term effects and rehabilitation after a TBI."*

- *"Had a couple concussions previously, none of the effects lasted more than a couple weeks. Was familiar with brain injury due to working in health care, but I did not know the full extent of what could occur."*

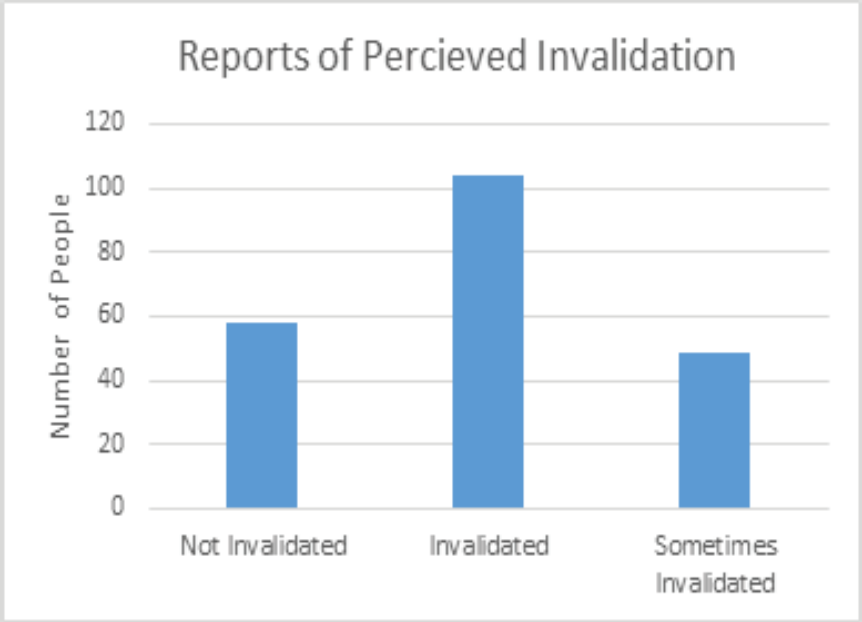


Lack of knowledge regarding Traumatic Brain Injury can preclude an individual from seeking proper medical care and subsequent rehabilitation, where needed. Based on these reports, knowledge and awareness among the public and the medical community is a fundamental barrier to resource access in Eastern Washington.

ISSUES DURING AND AFTER REHABILITATION

One of the fundamental influencing factors on an individual during and just after rehabilitation is the ***Perceived Invalidation of Self***. *It can be described as the perceived disregard for the subjective experience and autonomy of the individual.*

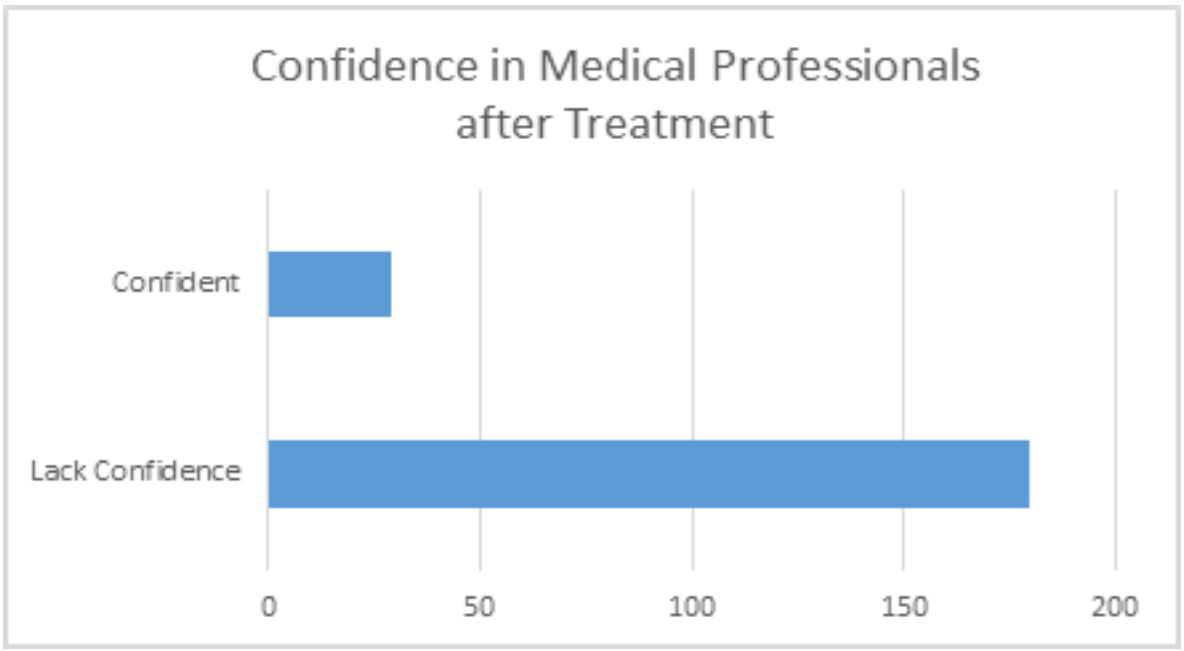
Self-reported invalidation by both rehabilitation specialists and the public have been reported as a factor that facilitates additional stress for individuals after a Traumatic Brain Injury.



Factor	*Reported Examples*
Perceived Invalidation by Rehabilitation Specialists	*"Cog rehab with the speech therapist. She would tell me my complaints weren't real. I saw her chart notes, and she often put a spin on things that were unreal like saying I was communicating "effectively" when I was sobbing and yelling at her. She would not work on my perseveration or habit of talking nonstop to strangers. She only wanted to do that annoying pencil tapping ATP. She said she'd call my boyfriend to coach him in home practice, and she didn't. She did a lot of things that were very dismissive, she talked too fast, and she took credit for things if I ever had a useful idea. Nearly every minute of cog rehab was terrible."*
	"My speech therapy...my paperwork said I was legally blind yet the doctor kept handing me things to read to him, like I could read the stuff at all. I couldn't even see him in front of me most days."
Perceived Invalidation by the General Public	*"It's more that I feel that I have to justify myself and explain to everyone that I was in an accident. I apologize for being slower, not being able to bike longer, it's as if I want them to know that this isn't really me. I worked hard to downplay my injury, which sometimes hurts me because people forget or don't believe that it's really that bad."*
	"Yes. All the time. But, it is part of the territory. Don't you know, TBI persons are supposed to be drooling at a nursing station drugged to not be a "problem? You may tell them of a limitation, but people do not understand the length, width or depth of the limitation. I don't fault them as long as when reminded, they re-think and respond accordingly. The other side of the coin is we TBI persons must be accountable for our actions."

The effects of this invalidation can lead to systematic issues for the individual.

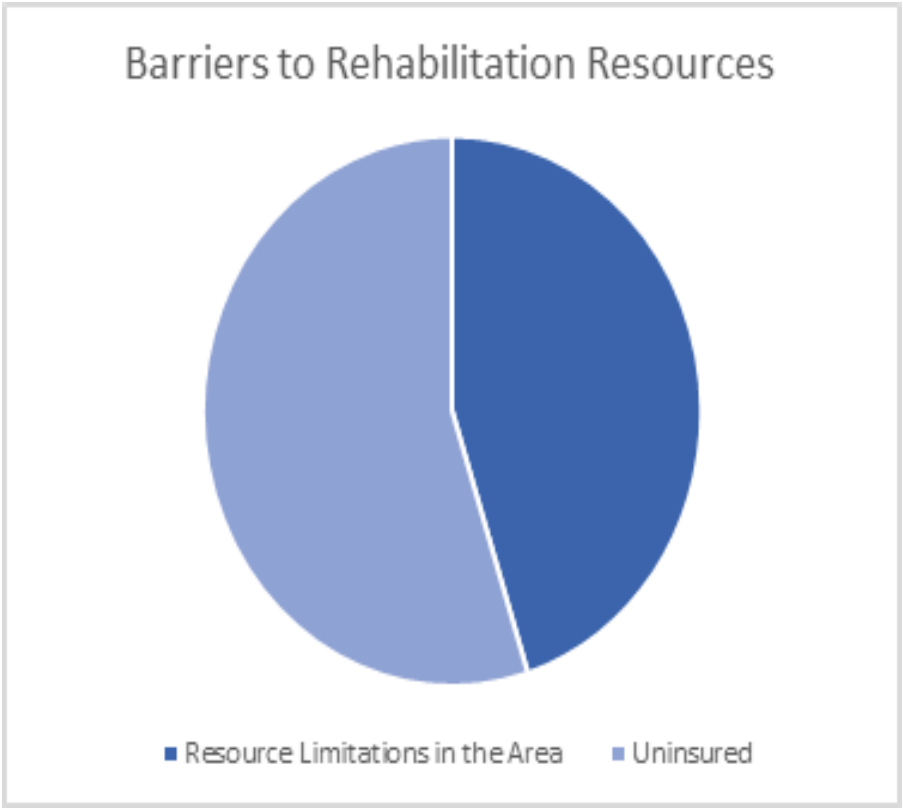
Of those that experienced invalidation, overall 61.8% reported an increase in stress that lead to a lack of confidence in medical professionals. Furthermore, increases in stress lead to higher incidences of self-isolation and subsequent signs of depression.



The central issue with invalidation during rehabilitation is that it discourages the individual from seeking/asking for help and continuing to move forward toward a positive outcome post-TBI.

Another fundamental issue with regards to rehabilitation is the length of treatment and continued support. 24.4% of respondents have reported that rehabilitation treatments either did not address all their needs or was too short, either due to insurance cutoffs or lack of resources in their area.

Compounding this was a relative lack of access to continued support after rehabilitation.



Of the issues not addressed during rehabilitation, these themes were the most prominent:

Themes of Issues Not Addressed	*Reported Example*
Social and Cultural Integration	*"The social-cultural stigma/assumption that a person with a BI is incompetent, needs pity, and belongs drooling at the nursing station."*
Specific Rehabilitation Treatments	*"Not all issues were addressed. I had speech difficulties that were not treated enough and hearing/processing difficulties that took years to address."*
Emotional Support and Stability	*"My life has been put on hold due to a circumstance out of my control, and that tears me apart in a multitude of ways. I was days away from finishing training at work, and now it's been over 6 months since I've worked. I feel more isolated from my friends and support structure, financially drained, and like my goals for continuing my education is all but out of my reach. I just want my life back."*
Advocacy	*"Lack of advocacy. Doctors don't understand that I am not capable of various things (memory problems etc.) and therefore are unhelpful in assisting me or providing guidance to family members so they can advocate for me."*

OBSTACLES AND ADJUSTMENTS AFTER A TBI

Daily Living Adversities: These are the regularly occurring issues that actively hamper progression toward satisfactory life experiences. The following list represents the categories of adversity that our respondents have the most difficulty managing.

- Neurological Symptoms (29%): Effective management and coping of neurological symptoms has been reported one of the most significant barriers to the relative ease of living daily. Of those symptoms, the following are reported as the most significant:

  - ◊ Chronic Neuro-Fatigue
  - ◊ Headaches and Migraines
  - ◊ Emotional Lability
  - ◊ Speech Production
  - ◊ Vision Disturbances
  - ◊ Working Memory Processing
  - ◊ Sensitivity to Sounds
  - ◊ Cognitive Disorientation

- Physical/Mobility Issues (23%): The ability to effectively transport one's self from home to work or another location with relative ease. This includes access to mobility aids and automobiles, which can be problematic in the rural areas of Eastern Washington. Of the issues reported, these are the most significant:

  - ◊ Ease of Access to Public Transport
  - ◊ Access to Mobility Aids (i.e. Wheelchairs, Canes, etc.)
  - ◊ Driving Independently
  - ◊ Walking Independently

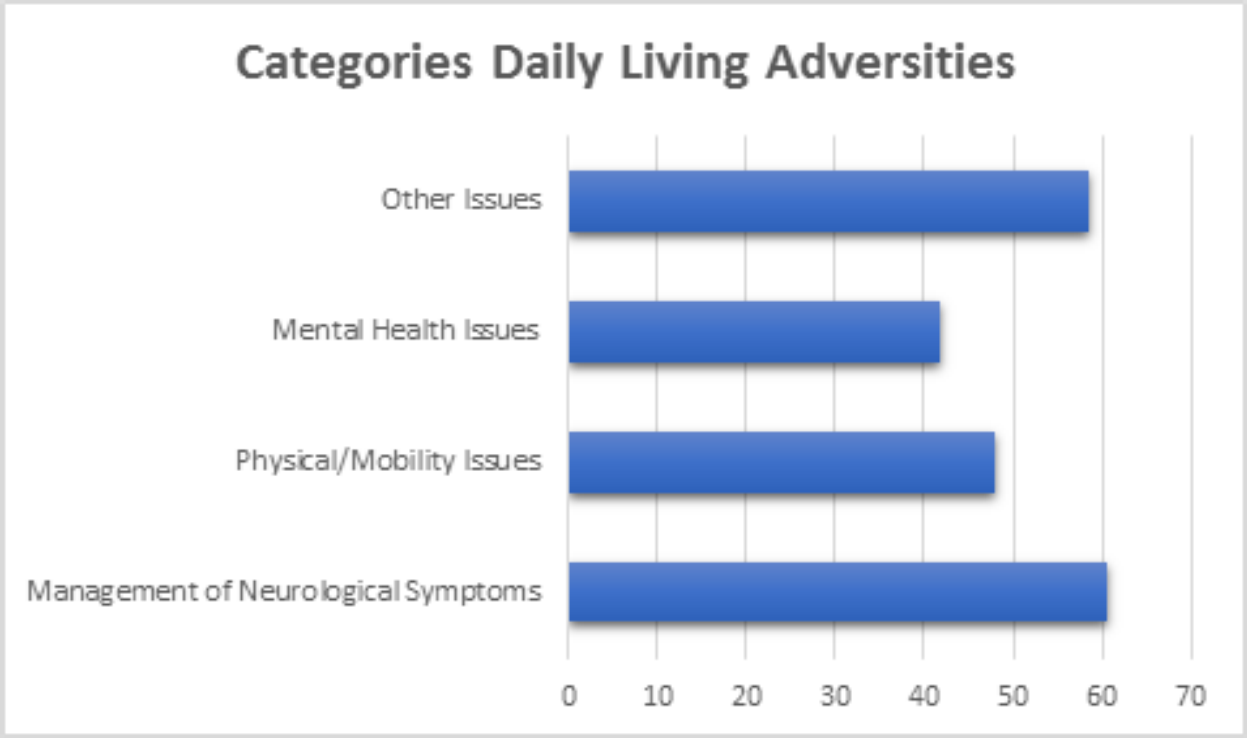
- Mental Health Issues (20%): Vulnerability to mental health issues is prominent within this population creating unnecessary barriers, especially anxiety and depression (see Mental Health Issues Post-Injury) The mental health issues in question thereby allow for a vulnerability toward the following:

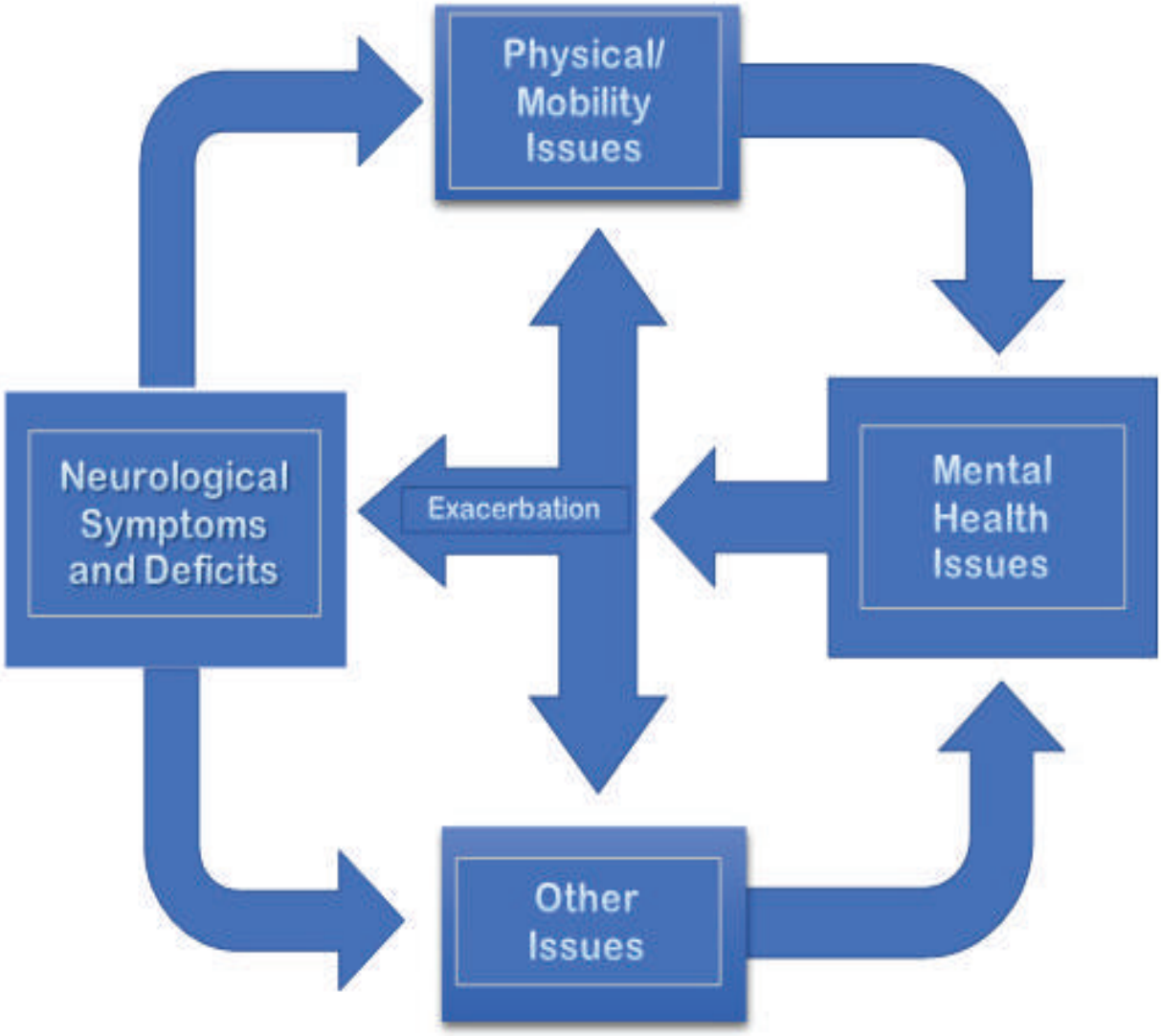
  - ◊ Self-Isolation
  - ◊ Depression
  - ◊ Suicidal Ideation
  - ◊ Overt Frustration
  - ◊ Avoidant Behavior
  - ◊ Self-Shaming
  - ◊ Anxiety
  - ◊ Ruminating Thoughts and Feelings
  - ◊ Emotional Outbursts
  - ◊ Lack of Motivation Toward Goal-Seeking

- Other Issues (28%): The category of "Other Issues" includes a variety of adversities that significantly affect daily quality of life, but do not singularly fit into the above categories.

  - ◊ Financial Burdens/Limitations
  - ◊ Intimate Relationship Dynamics
  - ◊ Management of Medications
  - ◊ Completing Education
  - ◊ Social Encounters/Relations
  - ◊ Employment Barriers (*see Employment Issues*)
  - ◊ Social Stigma of Brain-Injury/Disability
  - ◊ Identity Re-Formation
  - ◊ Familial Tension
  - ◊ Organization Issues

The overarching issue among the following adversities is **Independent Living.**





The excess stress that runs in tandem with daily life slows the ability to function with the pace and expectations of traditional society. Thus, one could argue that the Mis-Management of Neurological Symptoms precludes an individual to the worsening of both Physical Mobility and the Other Issues thereby facilitating the exacerbation of Mental Health Issues that otherwise might not be as prominent, which further exacerbates the former two and creating a vicious cycle.

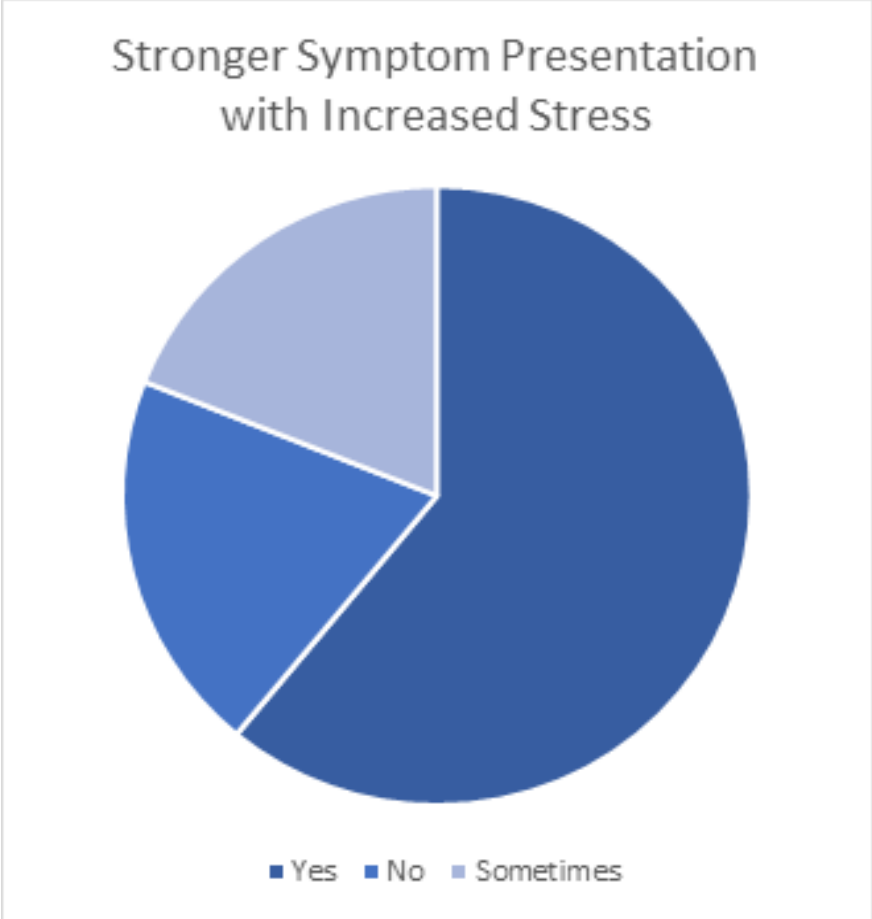
Symptoms that Interfere with IADLs: Instrumental Activities of Daily Living (IADLs) are essential components that facilitate independent living. However, as the cycle of exacerbation continues (i.e. increased levels of stress) symptom presentation is shown to become stronger.

Of our respondents, 61% reported worsening symptoms under the condition of increased levels of stress, which both hamper and in some instances completely interfere with the execution of IADLs.

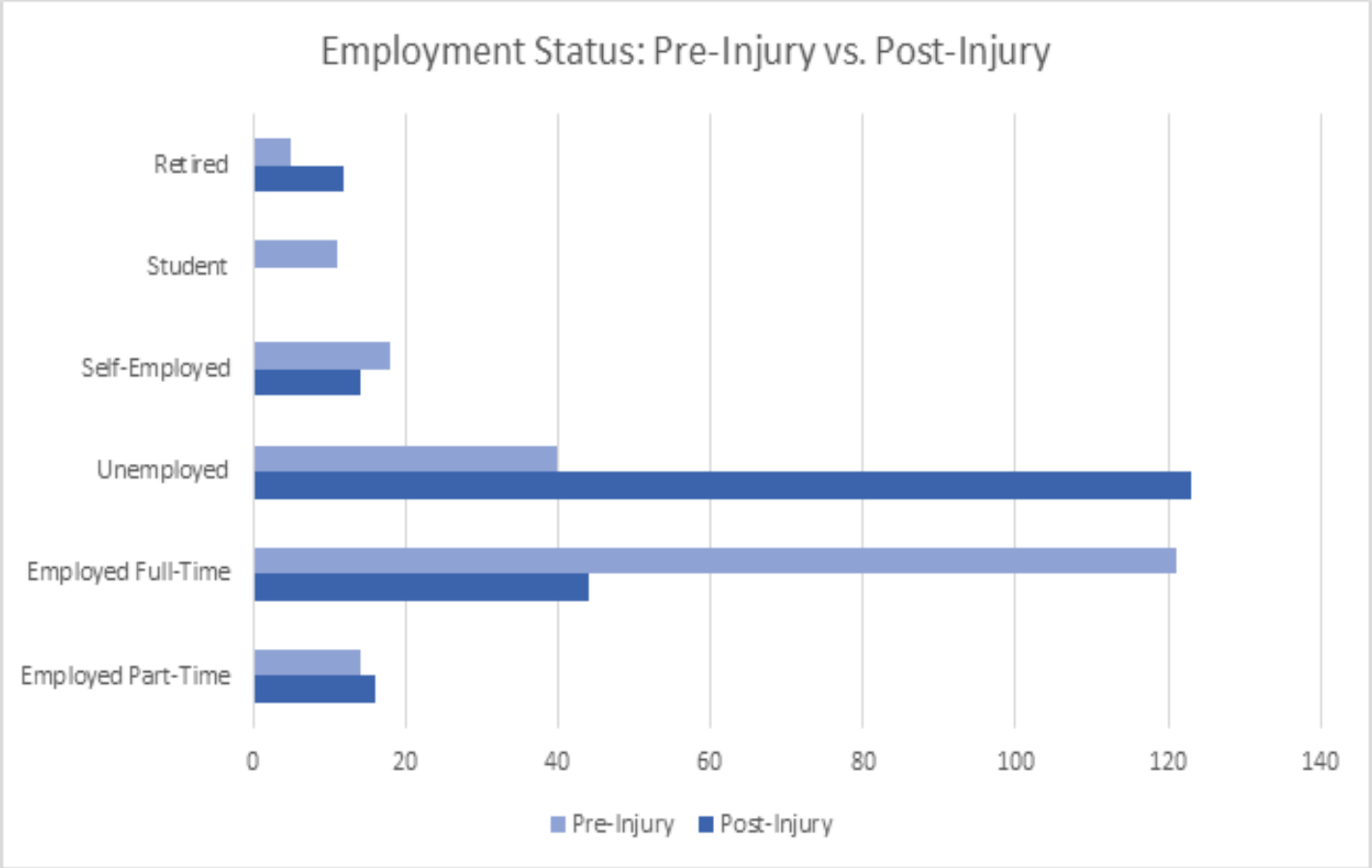
The 19% of respondents that reported only "Sometimes" experiencing exacerbated symptoms state that it occurs only in certain environments like large public venues that offer the opportunity to become overwhelmed or scrutinized for their behavior. The 20% of respondents that reported "No" exacerbation of symptoms due to stress stated that they had effective coping strategies to deal with stress under a variety of conditions.

The following is a list of deficits and symptoms that are significantly exacerbated under the conditions of increased levels of stress.

- Attention, Filtering, & Focusing
- Keeping Organized
- Decision-Making
- Balance & Coordination
- Sensitivity to Sounds
- Chronic pain
- Memory Impairments
- Depression & Anxiety
- Disruption of Sleep/Wake Cycles
- Lack of Motivation
- Agitation and/or Irritability
- Impulsivity
- Light sensitivity



Employment Issues: Employment barriers are one of the most significant factors that contribute to adversity in an individual's life after a Traumatic Brain Injury.

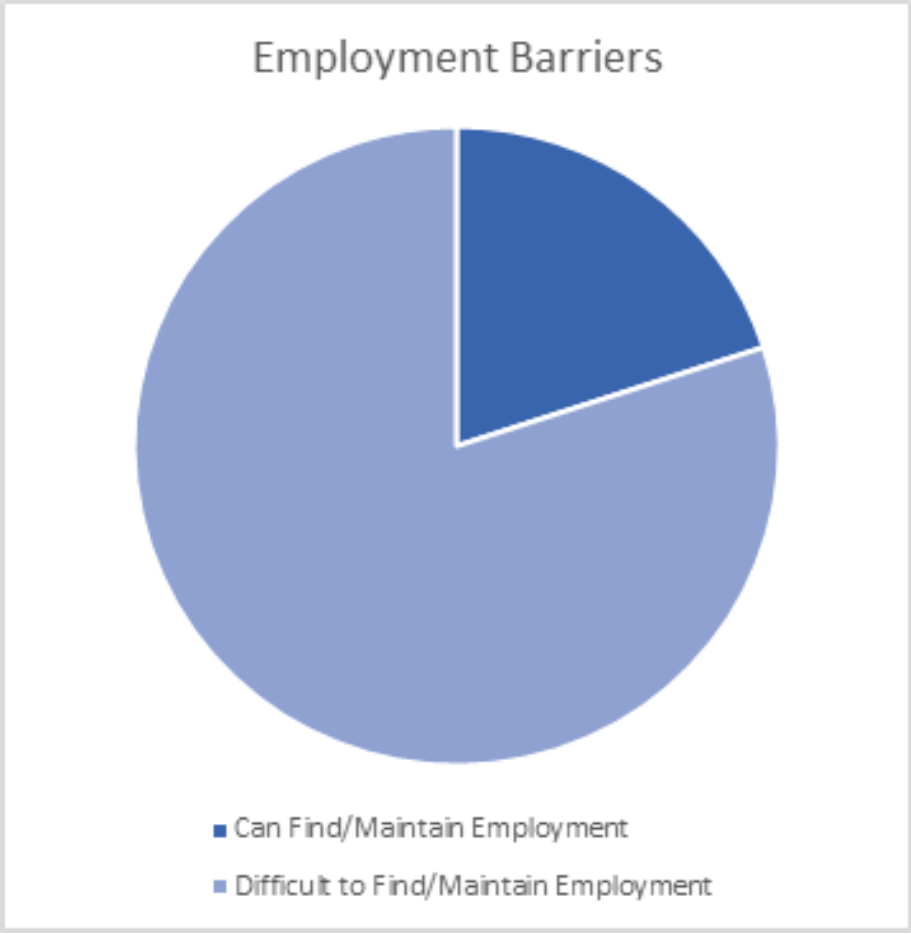


As the graphical representation highlights, 58% of our respondents were employed in full-time positions at a variety of private sector corporations/agencies prior to their injury. However, 59% of our respondents are now unemployed as a direct result of their injury and receive their income through some type of governmental assistance program (i.e. SSI, Welfare, etc), worker's compensation, or their own personal savings account (i.e. 401K).

Those that were formally students at either a university or community college reported being unable to keep a sufficient pace with their former studies or found that there were insufficient accommodations available to them.

18% of our respondent's post-injury were either forced to retire, found adequate part-time employment, or devised a way to supplement their income through a hobby/family business.

Out of 209 respondents, 80% have reported that it is difficult for them to either find or maintain employment post-injury. This includes those that are unemployed, self-employed, employed part-time, and are currently retired from employment (forcibly or otherwise). The other 20% have reported relative stability in their employment and can maintain it with relative ease.



Employment Issue	*Reported Example*
Difficult to Find/Maintain Employment **<u>Contributing Factors</u>**: • Severity of Neurological Symptoms • Geographical Location (i.e. rural areas) • Un-supportive Employers • Lack of Social Support Network • Lack of Access to Transportation • Physical/Visible Signs of Disability • Energy Draining Employment Position • Resource Limitations • Pre-Injury Skills Lost • Perceived Discrimination • Lack of Access to Education	*"I have had to leave full-time teaching and then found part-time teaching too difficult, so I am now a 1 to 1 tutor."*
	"It's nearly impossible to do a successful interview with slurred speech, a right arm that doesn't work too well, and wobbly walking."
	"There is no significant public transportation in our area. We are so rural, even pizzas are never delivered to our area."
	"Still in the process of trying to get energy to get back to work. It's been 2 years since the injury and I've worked myself up to 3x a week, 7 hour shifts at an internship."
	"I have a great many challenges that are directly due to my TBI. I am unable to transport myself to a job for example. I need to rely on family to take me to and from anywhere I need to go."
	"I am on state disability and am not allowed to have a job or I lose my retirement permanently."
Can Find/Maintain Employment **<u>Contributing Factors</u>**: • Supportive Employers • Adequate Accommodations • Acceptance by Co-Workers/Employer • Access to Education • Opportunities to Change Career Paths	*"My employer has been great, they have helped with my rehab and accommodated the changes I need to improve each day."*
	"I'm lucky to return to my same job in healthcare clinic setting. I have great coworkers who are always there to support me. I am never afraid to say if I cannot do something or need to leave."
	"It has been difficult doing my old job but I received tremendous support from my employer who eased me back into my duties."
	"I went through a massage therapy program a few years after my injury & became a certified massage therapist. I'm not so great at remembering all the muscle names but I go by touch mainly and I do great like that. All my clients are always extremely happy."

PSYCHOLOGICAL WELL-BEING AFTER TBI

Personality and Behavioral Issues: Our respondents have reported significant alterations that functionally changed both their personalities and behaviors, yet the outcome of these changes are not exclusively positive or negative. However, there are consistent reports of a lack of resiliency to unexpected changes, emotional volatility, and an extreme brain fatigue from average levels of exertions and involvement when dealing with language or numerical efforts. In addition, individuals report experiencing a type of existetialism that heightens both positive and negative emotions that are conferred on their subsequent actions.

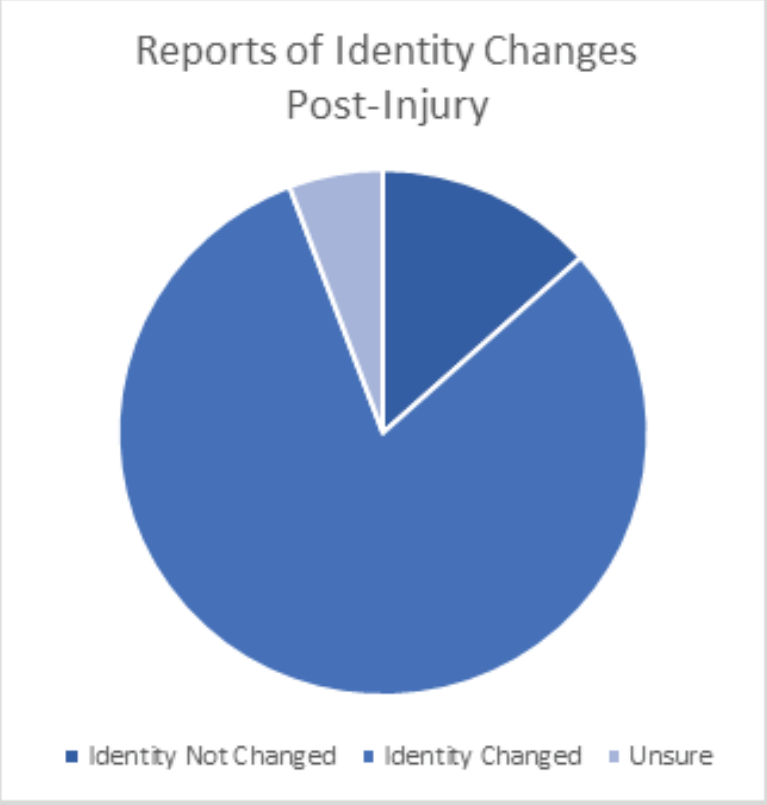
Change	*Reported Example*	*Factor(s)*	*Action(s)*
Negative	*"I am more short fused, get frustrated more easily. Before TBI, I never used to get upset by anything, I was a happy go lucky, go with the flow kind of person. Now I need to be more regimented and follow more of a schedule most of the time. If not, it is easy to get off track and tend to get frustrated."*	• Emotional Instability • Frustration • Slower Cognitive Processing	• Scheduling • Vigilance of Behaviors
Negative	*"I am more impulsive, get excited more quickly and with exaggerated actions, get angry more easily and my anger is more extreme than before. Also, I am a lot more organized and careful than before - I think everything through very carefully before doing it. I am more reserved than I was before - I struggle with small talk and prefer to interact with people that I know, rather than trying to talk to new people."*	• Impulsivity • Emotional Instability • Slower Cognitive Processing • Fear of Judgement	• Socially Reserved • Avoidant Behaviors • Highly Active Organization
Negative	*"I used to laugh and was confident in my skills. I had a good social life, a job, and looked forward to the future. Now I shun social situations, frequently stay home all day, can't hold a job, don't like noise and light. People often think I am on drugs or stupid."*	• Lack of Confidence • Social Anxiety • Neurological Symptoms • Mental Health Issues	• Self-Isolation • Self-Shaming • Avoidant Behaviors

Change	*Reported Example*	*Factor(s)*	*Action(s)*
Positive	*"As part of my recovery, I got back into wood-working to prove I could still do it. I started cooking. I started playing the guitar again. I am learning to play the piano. I opened a business with my son. I realized that this close call means that we will not live forever and better do the things that are important before we leave."*	• Optimistic Attitude • Acceptance of Injury • Social Support from Family	• Development of New Skills • Actively Engaging in New Activities • Positive Outlook Reinforced
Positive	*"Generally, I have a positive outlook on life, even in my current situation I try to focus on the fact that my life will be better in the long term and I just have to make the most of it until then."*	• Chooses to Focus on Positive Perspectives	• Rationalizes Long-Term Benefits of Positive Perspectives
Positive	*"I am happier, more content overall, more mindful and more compassionate. Much of this comes from my husband. He is a very calming influence. I do not have as much compassion for people who complain about their situation all the time. I think this comes from a near death experience. I feel grateful for every day and no matter how much it sucks I am here for the good and the bad the point is I AM HERE. I could complain about my situation, I could make a huge deal about how it has affected me and go on and on but why. No one really cares."*	• Social Support from Intimate Partner • Existential Appreciation of Life • Acceptance of Injury	• Resilient Attitude • Positive Perspective

Identity Fluctuations Post-Injury: Regardless of positive or negative personality/behavioral changes, a clear majority of our respondents reported that their sense of identity had changed in comparison to their pre-injury self. Described as the "**New Normal**", 81% of our respondents stated their sense of identity had changed as a result of the events surrounding their Traumatic Brain Injury.

Identity changes post-injury are important considerations because they include a wide range of factors that influence these vital areas:

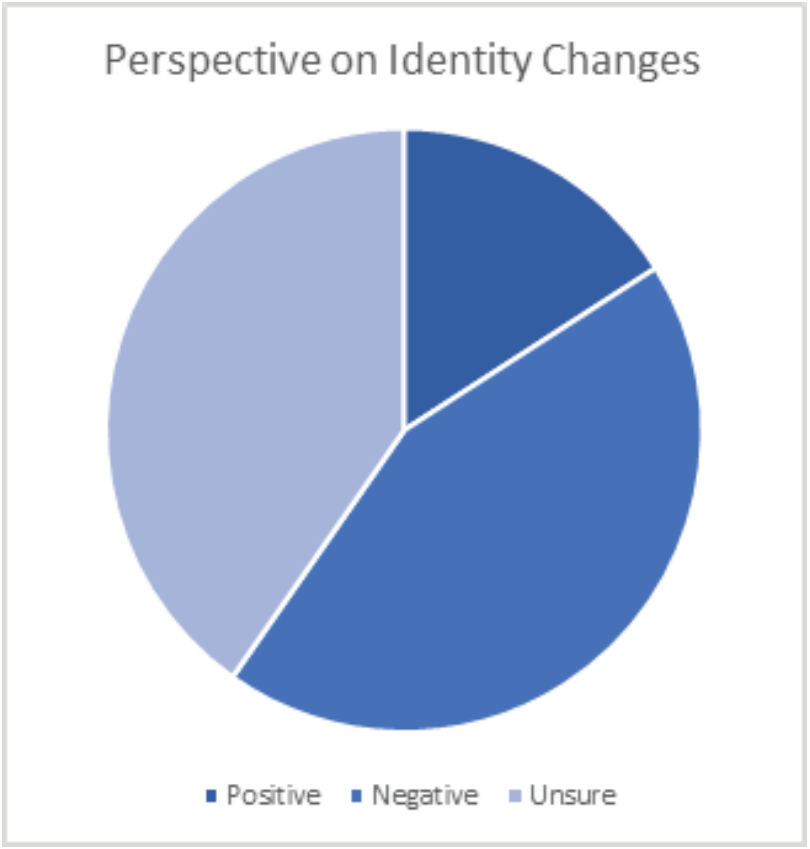
- Emotional & Mental Health
- Interpersonal & Intimate Relationships
- Motivation to Improve Post-Injury
- Acceptance of Injury



*The "**New Normal**" can be described as changes in an individual's personality, values, and perspective on the world that subsequently alters their relative interactions with both their environment and the people that reside within that environment.*

Unfortunately, many of our respondents have difficulty identifying their "**New Normal**" either due to Limited Resources in their Area or they are stuck Mourning their Pre-Injury Self.

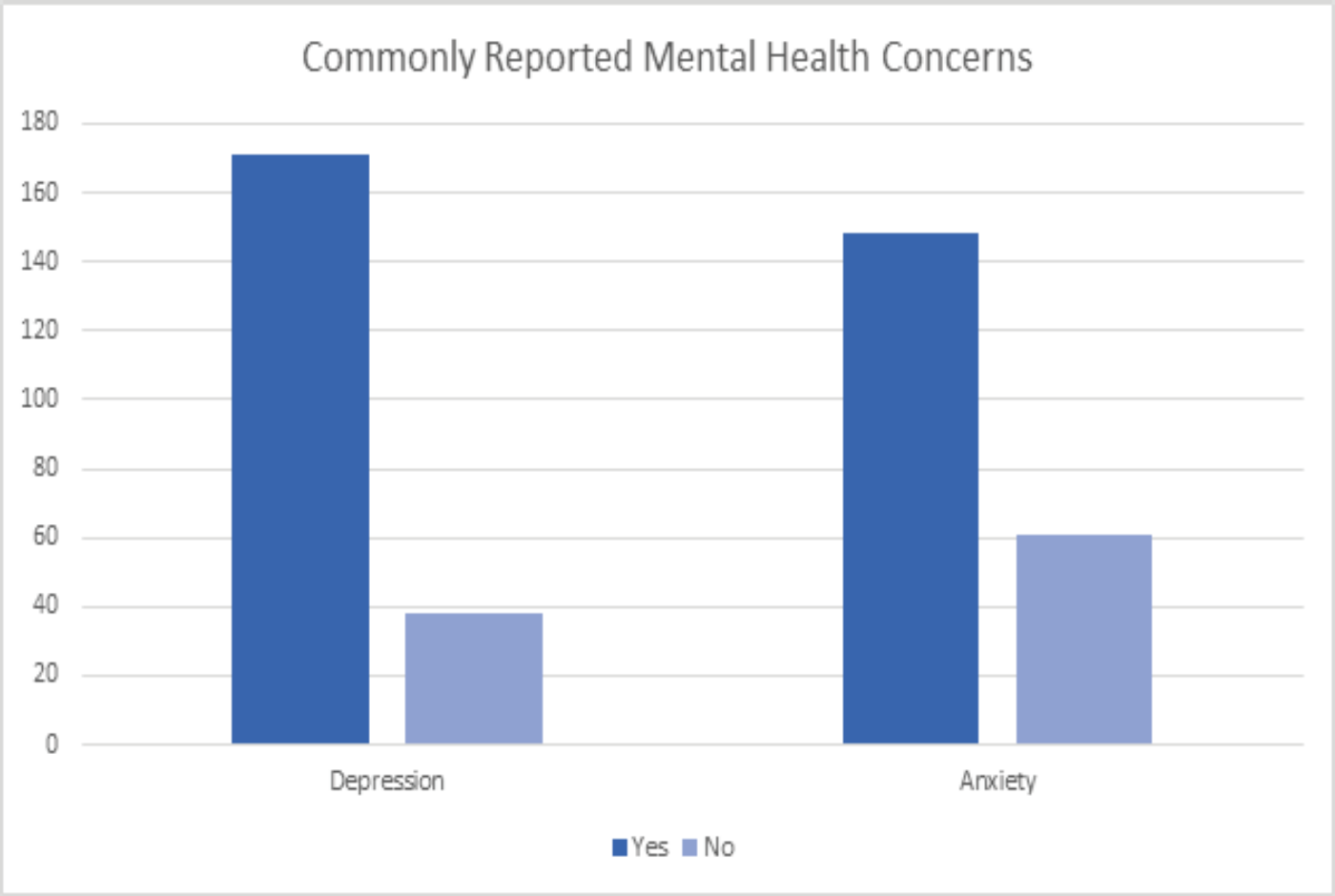
Out of the 169 (81%) respondents that reported their "Identity Changed", 44% indicated those changes were negative, while 40% stated they were unsure if the changes that occurred were either positive or negative. Only 16% of those respondents stated their identity changed for the better.



Areas of Influence	*Reported Examples (Negative)*
Emotional & Mental Health	*"I was laid back, loved life and people. I'm not the same person I used to be, which is very frustrating. I almost wish I couldn't remember what I used to be like so I wouldn't have anything to compare my current personality to."*
Interpersonal & Intimate Relationships	*"Completely. I was a senior manager at a Public Hospital. I was very proud of my achievements gaining a Master's Degree, working extremely hard. I was a pretty good cyclist at my age, I suffered role reversal, especially regarding my son, who now manages our finances about preparing for retirement and budgeting so that we can survive on my pension from 65. I feel judged by many people as worthless by not working, and valueless in society. I myself feel that I should be doing more. I am really a nobody - not of any significance. For a long time my daughter didn't trust me with her children (especially driving them - that nearly destroyed me)."*
Motivation to Improve Post-Injury	*"I see myself more now as an unreliable, hateful, flaky, unmotivated person."*
Acceptance of Injury	*"I don't feel like I have my own identity anymore. I'm not a nurse, caregiver, just nothing anymore."*

Areas of Influence	*Reported Examples (Positive)*
Emotional & Mental Health	*"If anything, my TBI has made me a stronger person and I refuse to be walked on or abused. I always stand up for myself more than my pre-accident days. I was always known as easy going and I still am but if challenged I will now make a stand."*
Interpersonal & Intimate Relationships	*"I feel much closer with my husband."*
Motivation to Improve Post-Injury	*"I think I'm actually more badass then I was before - I feel like the worst has happened so I'm braver to try new things."*
Acceptance of Injury	*"I now see myself as more than my cognitive skills. As a gifted student, I placed a lot on my academic abilities. I'm now MUCH more rounded."*

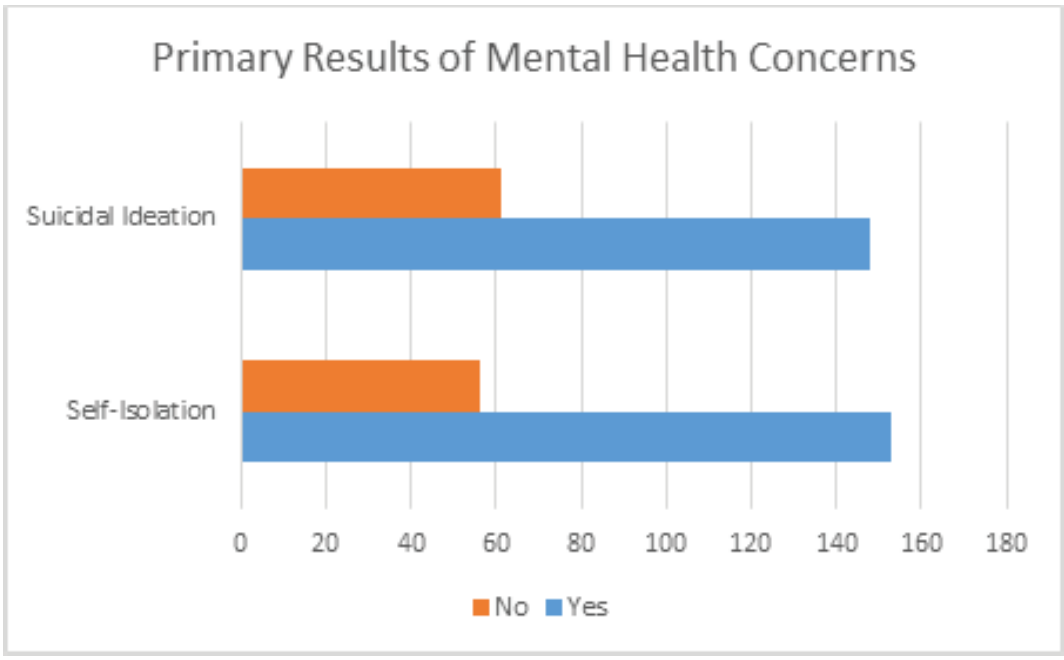
Mental Health Issues Post-Injury: Those that endure a Traumatic Brain Injury are inherently more vulnerable to mental health issues post-injury. Our respondents consistently reported that both Anxiety and Depression as being the primary mental health issues they struggle with.



Both mental health concerns are the result of struggling with the adversities that have no simple solution post-injury, these issues are further compounded by a lack of stable support both during and after rehabilitation. The prognosis is even worse if no rehabilitation or support was provided post-injury.

As detailed in previous sections, individuals that struggle to maintain their lives exhibit signs of both depression and anxiety. Of our respondents, 81% exhibit signs of depression and 71% exhibit signs of anxiety.

Beyond signs of these two mental health concerns, our respondent have directly reported co-morbid conditions like social anxiety, agoraphobia, post-traumatic stress disorder, and re-current panic attacks.



Beyond signs of these two mental health concerns, our respondent have directly reported co-morbid conditions like social anxiety, agoraphobia, post-traumatic stress disorder, and re-current panic attacks.

Consistent struggling with daily living adversities, that have no discernable solutions or end, have resulted in signs of depression and anxiety that further result in significant reports of self-isolation and suicidal ideation.

Factor	*Reported Examples*
Suicidal Ideation	*"Most of the time, after I got hurt. when I was working out of the truck stops, I was hoping a serial killer would pick me up. Got close once...but it didn't happen. It's kind of funny now. I still would like to die...but I can't find the energy to do it myself...but if I woke up dead...that would be awesome...as long as my g/f don't have to find me or see me."*
	"I'll feel anxious or worried usually several times a year that coincide with my accident/injury, anniversary/holidays, and the change of seasons. Either a fear of death or that I'm going to die, then feeling like I did die that day I was hit by the car, it's the mental cycle of living after the traumatic experience (I think) that I haven't quite gotten a handle on. When I've talked with others I see the pattern of survivor's guilt. It's not talked about much at all. I think I need to somehow work through it, to put it to rest. I'm not exactly sure yet how to deal with it."
Self-Isolation	*"I try to stay away from everyone on bad days. I feel they will see my bad days and don't know how to deal with it."*
	"Yes, I isolate myself as often as I can. But, I also yearn for a close relationship where I can just be me and enjoy companionship."

The contrast between "Good Brain Days" and "Bad Brain Days" best illustrates the subjective experiences that facilitate the aforementioned conditions.

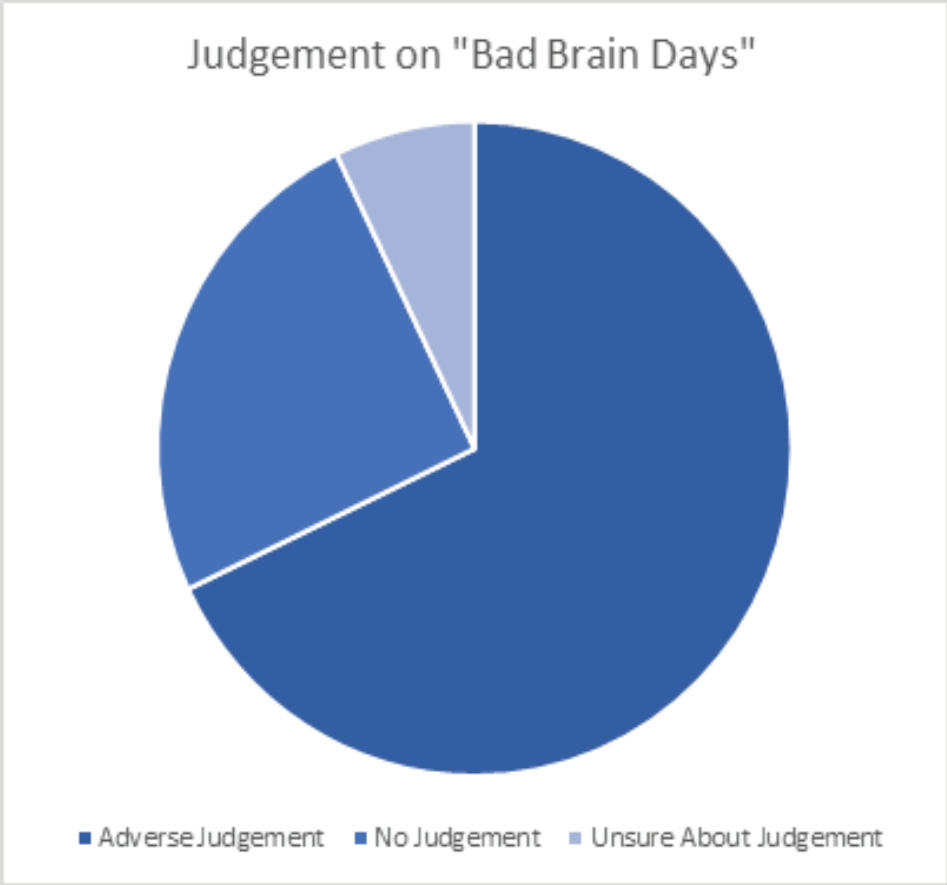
- ***Good Brain Day***: Respondents report being motivated and organized on these days. There are consistent reports of an abundance of mental energy, an ability to stay focused on daily tasks, and a lack of neurological symptom presentation.
- ***Bad Brain Day***: Respondents report a lack of motivation and an abundance of frustration in several areas of their life on these days. The frustration stems from an inability to be productive or complete daily tasks with ease either due to an exacerbation of neurological symptoms or social barriers outside their purview of control.

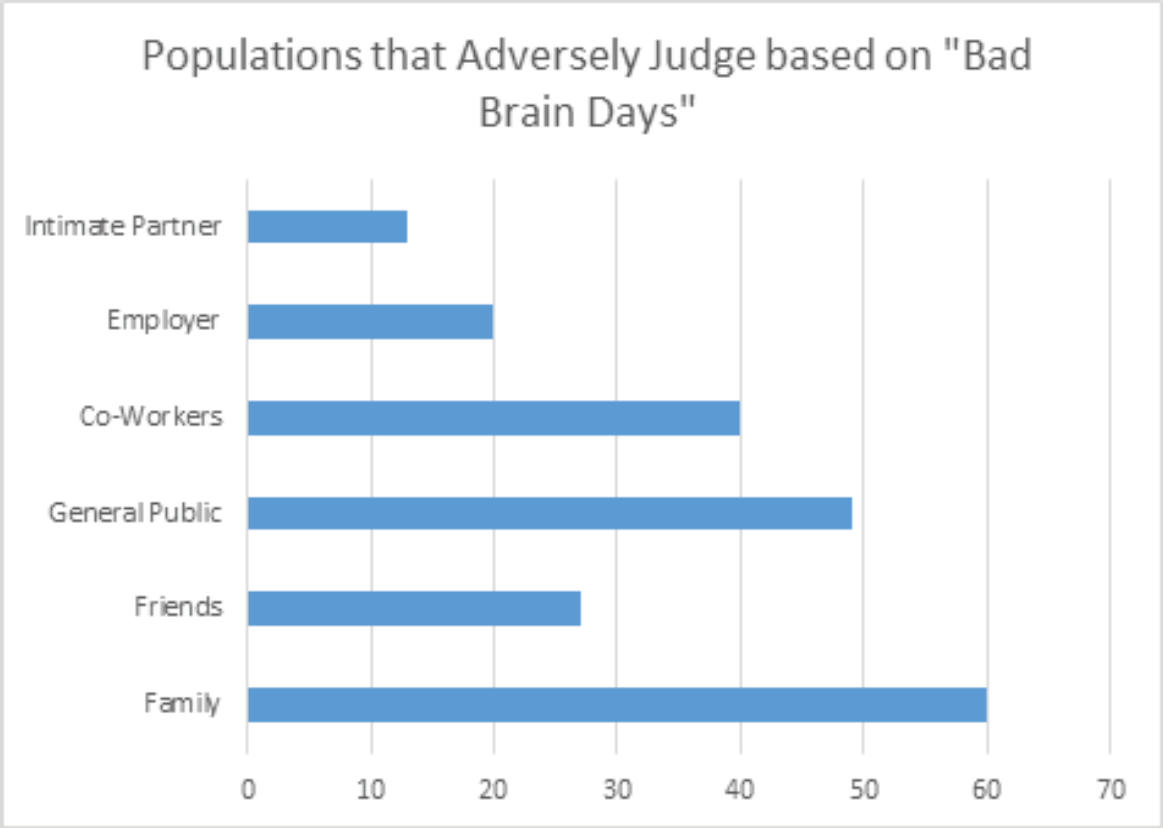
Good brain days result in an ability to keep pace with society and its expectations. However, bad brain days result in an inability to do that, thus 68% of our respondents report experiencing adverse judgement based on their bad brain days, while 7% report being unsure if anyone judges them based on these days. The 25% of respondents that report no adverse judgement on these days, also consistently report isolating themselves on these days or only being around individuals that clearly understand their condition.

The ultimate result is our respondents avoiding situations, environments, and people that they believe will adversely judge them.

Several respondents believe that the adverse judgement is due to a lack of understanding/conceptualization of Traumatic Brain Injury among the population, thus resulting in several misconceptions of their behavior.

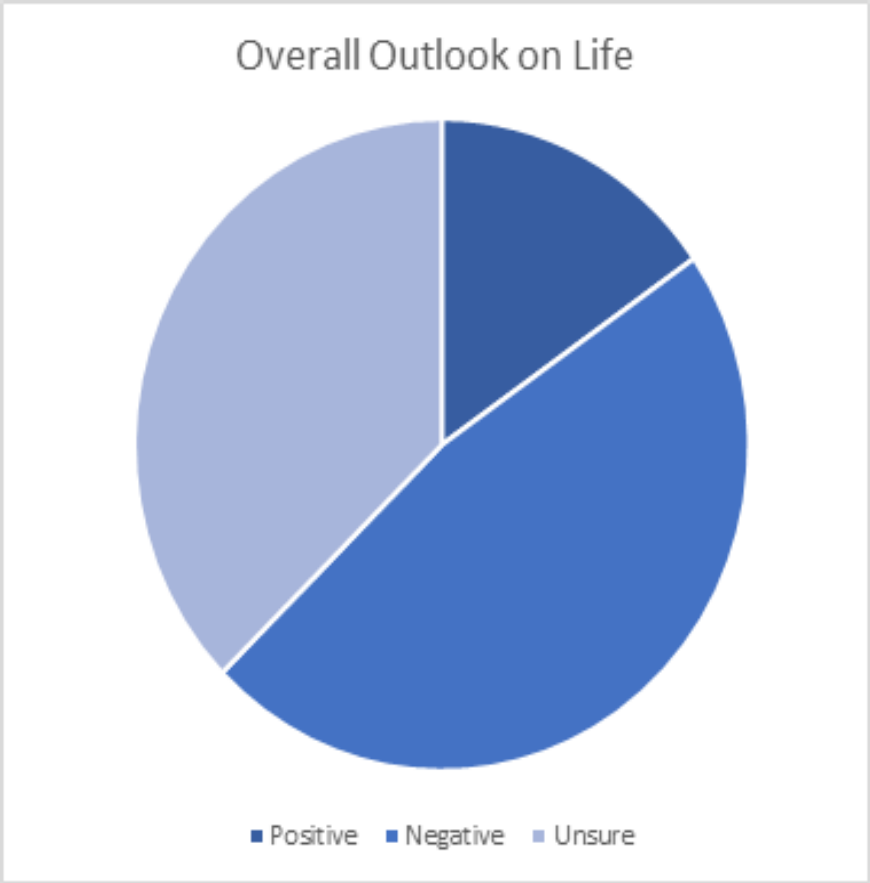
Regardless, the avoidant behavior facilitates the vulnerability toward self-isolation and anxiety that further creates possibilities for depression and suicidal ideation.





Both suicidal ideation and self-isolation are further compounded by the lack of access to adequate support post-injury. Several of our respondents live in rural regions of Eastern Washington or they are limited by the resources available to them, further complicating their ability to form new connections, seek proper medical-care, and strive for satisfactory life experiences.

47% of our respondents report a negative outlook toward their lives, however 37% report that they are unsure of their outlook. The uncertainty in our respondents suggests that they still have hope for a positive outcome, yet for now, a positive outcome is difficult envision under their current circumstances.



Effects of Social Support: Socialization is a significant issue after a Traumatic Brain Injury, with a clear majority of our respondents stating that they either find it difficult or impossible to socialize. However, social support can have a tremendous effect on an individual's life post-injury, either through group activities or some type of support group (in-person or internet-based).

- *"The Facebook groups have been a blessing. So many who only want to help. Knowing there are others like me. Being educated by a caring community is pretty cool."*
- *"Making new friends in my support groups as well as an on-line Facebook group, the bad part was losing "everything" due to the TBI."*
- *"Meeting the people at my disabled sports chapter. They gave me confidence and they make me happy when I'm up there. And, meeting my Adaptive Gym coach, he helps me at the gym doing different workouts that I'm able to do."*

The 15% of respondents that reported a positive outlook on life, were those that described a robust social support network and a lower incidence of depression and anxiety. With regards to where the support originates, 59% of our respondents report that family members provided them with the most social support, followed by friends at 26% and their intimate partners at 15%. Ultimately, social support highlights an opportunity to encourage those with a Traumatic Brain Injury that they still have autonomy and hope after their injury. As one of our respondent's states, *"I've had less suicidal ideation when I've gone on to live a new dream, gain other accomplishments, see that living with TBI doesn't have to be all loss and negativity."*.

SUMMARY AND SUGGESTIONS

When speaking of individuals after they suffer a Traumatic Brain Injury, it's important to consider all the variables. While the biological and physiological nature of the Traumatic Brain Injury are critically important, the subjective experience of the individual cannot be dismissed as irrelevant. Our research has highlighted how the subjective experience can have a deleterious effect on an individual's life in the long-term.

For example, let's say a random individual has an injury that occurred less than a year ago, due to a motor vehicle accident. In addition to having a TBI, this individual can no longer walk and uses a wheelchair to move around. The individual also requires regular rehabilitation visits, therapy, medication to control for seizures, and wheelchair maintenance. Furthermore, the individual has no support from their family and the individual's intimate relationship is slowly falling apart. Under these circumstances, what is the likelihood this individual will experience a positive outcome post-injury? There are several variables to consider, but with little social support and a tremendous amount of stress because of the injury, it's not wrong to conclude the adversity might be stronger than the person.

However, let's consider another individual. For the sake of this illustration, let's call this individual Megan Miller. Megan's injury occurred two years ago, while working. Megan formally worked for a food processing warehouse as a laborer on the warehouse floor, packaging food products. After her injury, Megan was hospitalized for several weeks, subsequently missing work. Upon going through a full regiment of rehabilitation and one-on-one therapy, Megan returned to work. As she began working again, her supervisors insinuated that she was now incompetent and incapable of doing her job by criticizing her performance, straining her professional relationships. In addition, Megan's friends and family often suggest that she is simply "wanting sympathy" when she voices her concerns over emerging symptoms related to memory and attention issues. Due to these issues, Megan quit her job and stopped speaking to her family. Since then, she has published a successful book that speaks of her experiences after her injury. Megan's husband divorced her shortly after her injury, however, she is now seriously dating another TBI survivor that she met via a local support group and they now take regularly take trips together with their two dogs. The difference with Megan, was access to necessary rehabilitation and her ability to connect with resources and social support after her injury.

We can greatly improve the prognosis of an individual after a Traumatic Brain Injury through relatively simple actions of education, advocacy, and support. With regards to Eastern Washington, the following points are worth your consideration.

- There is a lack of necessary intervention after the initial injury due to lack of education.
- Knowledge and awareness among the public and the medical community is a fundamental barrier to resource access in Eastern Washington.
- Perceived invalidation can be a serious problem because it discourages an individual from seeking/asking for help and continuing to move forward toward a positive outcome post-TBI.
- Increased levels of stress because of adversity in daily life facilitates a vicious cycle that exacerbates an individual's life post-injury.
- Consistent struggles with daily living adversities, that have no discernable solutions or end, can result in signs of depression and anxiety that further create significant reports of self-isolation and suicidal ideation.
- Social support can be a life-saver for those that are struggling.

Suggestions for the future in Eastern Washington:

- Access to a wider range of practioners.
- Connecting survivors to available resources post-injury in a timely manner.
- Creating an infrastructure of resource support based in Eastern Washington, i.e. Spokane.
- Emphasis on social support after a Traumatic Brain Injury, i.e. enhance funding for local support support groups and activities.
- Education and awareness for both TBI Survivors and the public, vital to closing the gaps in knowledge.
- Reaching out to local hospitals, colleges, and universities to create more education and awareness of Traumatic Brain Injuries for both the public and future medical providers.
- Personalized and guided life-coaching/therapy for TBI Survivors.

As we end this assessment, please consider some of the thoughts and notions from TBI Survivors:

"I was fortunate in that the severity of my injuries is not obvious to most people. The idea that I'm not obviously impaired to the naked eye does not mean I'm ok. Concussions and strokes are not over when the event or the initial trauma is over. After effects come along long after the event has occurred."

"The biggest thing isn't that you just get better one day and like a broken arm, it just heals. You never fully recover, but with time it gets more manageable as you learn ways to make adjustments."

"If I did offer advice it would be to have more follow up after the first year or two, as during the initial stages you really don't have a clear ability to understand what is happening to you. It is only after that first year or two that you have enough cognitive ability to really understand your situation. Also, the reality is that most folks that suffered a severe TBI don't recover enough to provide the needed information and advice to help others. And those that are damaged to a truly severe level aren't or can't respond enough to help others. They are simply trying to survive. Most doctors and therapist want to help but they can never truly understand what it means to suffer a TBI. Too many folks, fake it until they make it, but most of use never truly make it out. We just learn to get through it."

"Recovery takes time and effort. Clearly this was the toughest thing I had to do in my life. My injury occurred eight years ago. As I started to realize what had happened to me as I recovered, I would lament to my neurologist and neuro-psychologist that life as I knew it was over. My psychologist would snap me back to attention by saying "That was now, this is your reality now." Then he would challenge me by saying "How hard are you willing to work to get your life back? What are you willing to do to improve?" One thing that I learned was that if I didn't take an active role in recovery, my life would not get any better. In a race, it's not uncommon for me to be behind the leaders. Being behind is temporary; what makes it permanent is giving up and quitting. I am not a quitter."

"Medical professions, especially general practitioners, need more education. Patients need more support after leaving rehab. TBI causes a huge arrays of symptoms, we are a diverse group. Some need full time help and some of us work full time careers, but we all struggle to some degree. It's a huge impact on the person."

"People with TBI live under complex circumstances. I wish we didn't have to suffer so much. (Then I'm reminded suffering is optional - forgot who said that) So many people I've met fall through the cracks in various systems. Loss of self (who we knew ourselves to be is a profound experience). It's hard to be your own advocate at least in the beginning with TBI. But we are often called to be that... for those of us without dedicated family support."

"As a PhD in psychology, I mentor TBI survivors and help them return to the workforce. You should ask TBI survivors if they feel they might benefit from working with a TBI coach or mentor, especially one who is a TBI survivor and understands the challenges."

"I really wish there was clearer continual care and more information about resources"

"People think we can "heal". People, even survivors think it will go away, no more injury to our brain. Not facing the reality, it is damaged tissue, it can't be without damage."

"That all people suffer the same symptoms, and that a 'mild' TBI won't have any lasting effects."

"TBI is the most devastating experience one can go through. A highly-personalized journey through a tunnel of shit. A journey one takes on their own and one that NO one can ever truly understand. And one that I pray you Will never truly understand. All one can do is try their best every day, find peace, be respectful of others, embrace your journey and find some enjoyable moments."

"I would like to see the TBI Community to provide more information/studies on the TBI survivor journey at different stages. It would be helpful to know predictability of what at different years, etc. And I just wish someone would act like they truly care about what happens to me."

Any questions or concerns can be directed to Nick Mehrnoosh at nkmehrnoosh@eagles.ewu.edu

The overall study will still be continuing, with a further analaysis of the 436 respondents forthcoming. If you wish to learn more about the larger study or would like more information, please contact Nick Mehrnoosh at the above email address.

A special thank you to the TBI Survivors Network, Brain Injury Association of America, and Brain Injury Waikato for the efforts in recruiting individuals for this study.

Furthermore, we want to thank all the repondents that took time out of their day to participate, it is greatly appreciated.

Eastern Washington Unviersity, 2017