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Philadelphia College of Osteopathic Medicine Department of Psychology

AN EXPLORATION OF SOCIAL CONNECTEDNESS AS A PREDICTOR OF QUALITY OF LIFE IN ABI SURVIVORS

By Jennifer Oyekanmi, MS, MS

Submitted in Partial Fulfillment of the Requirements for the Degree of

Doctor of Psychology

December, 2015



PHILADELPHIA COLLEGE OF OSTEOPATHIC MEDICINE DEPARTMENT OF PSYCHOLOGY

Dissertation Approval

This is to certify that the thesis presented to us by Jennifer Oyekanmi on the 9th day of December, 2015, in partial fulfillment of the requirements for the degree of Doctor of Psychology, has been examined and is acceptable in both scholarship and literary quality.

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Dedication

First I would like to begin by dedicating this dissertation and all that it entails and represents to my loving father Aaron Irvin who unfortunately did not live to see its completion. It is because of my parent's love and encouragement that I chose to begin this journey of pursuing my dream of becoming a psychologist. Despite not being here in the flesh, I know that he is Godly proud and smiling down from heaven on me. His strength in the face of his illness was a testament to me of the resiliency of the human spirit and that we should be grateful for the gift of life.



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This dissertation would not have come to fruition without the assistance from several important individuals in my life. I would like to begin by thanking God, who with his grace and mercy has allowed me to come this far in this journey of life by faith. I would also like to express my deepest gratitude to the PCOM faculty particularly Dr. Zahn, Dr. Felgoise, and Dr. DiTommaso that provided continued support and believed in my ability to continue and succeed in this program. Your words of encouragement, guidance, and constructive criticisms helped me in more ways than one continue to strive to move forward in this program

Dr. Zahn has been an advisor, dissertation chair, and a mentor throughout my career at PCOM. His knowledge of working with the brain injured population, constant encouragement, and quick wit have helped immensely going through my highs and lows during this program. He allowed me significant time to grieve the loss of my father and was there to push me when it was time to prepare for my proposal. His unwavering commitment to my success and completion of this program has been a driving force to my continued pursuit of this degree. Also many warm thanks to Dr. Lindgren at Bancroft Neurorehab who not only assisted as a member of my dissertation committee but granted use of the outcome database and was a mentor throughout this whole dissertation process.

Additionally, I would be remiss if I did not thank the host of friends and family that provided an ear for my frustrations, comfort when I felt it was too hard to continue, and helped read and edit many papers along the way. Special thanks to my mother, who pushed me and prayed for me throughout this journey. As a child, my mother's sincere hope was that I would



use my head strong nature to achieve greatness in life and contribute something positive to society. It is awesome to see how the prayers of the righteous avail much as I come to the end of this incredible road towards achieving my dreams.

Finally, I thank my husband who has provided calm in many storms, love and care, and quiet support as we have traveled this journey together. We met right at the beginning of my starting this program and without his presence I am quite sure that I would have lost hope many times along the way. My husband has wiped my tears, gave a shoulder to cry on and always told me "It will be well" along the way. My husband's unrelenting faith in my abilities pushed me to make it to the end of this amazing passage in my life.



Abstract

Research on quality of life in ABI survivors has focused on four domains: psychological, physical, social, and cognitive (Upadhyay, 2007). Social relationships, in particular, can help ABI survivors more effectively cope with changes in their lives, help maintain a healthy outlook, and can help with seeking further understanding of the consequences of sustaining a ABI (Hibbard et al, 2002). The current study sought to examine if social connectedness is predictive of quality of life in ABI survivors. Participants were 71 individuals who have sustained a ABI and who currently or in the past participated in a long term rehabilitation program. The study utilized data from a previously collected outcome data set of ABI survivors participating in a residential and/ or outpatient brain injury rehabilitation program located in Southern New Jersey. Results from the study indicated that the Participation subscale and total QoL on the WHOQoL-BREF were positively correlated. The total MPAI-IV score as not significantly correlated with total WHOQoL-BREF despite being close to significance, p=.063. Due to having a smaller sample, there was not sufficient enough of power to reach significance. Additionally, the Participation subscale and Social Relationships subscale were negatively correlated indicating that both subscales were indicative of measuring the quality of social connectedness. Overall, it was found that social relationships accounted for 36 % of the variance in total QoL when compared to several other variables found in the research including age at time of injury, time since injury, relationship status, and current age. Strengths, limitations, potential implications, and explanations of the study's outcomes are also explored.

Keywords: ABI, social connectedness, quality of life



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Chapter One: Introduction

Statement of the Problem.

Acquired brain injury (ABI) has become a global public health problem that occurs in 1.4 million people in the population annually (Langlois, Rutland-Brown, & Wald, 2006). Causes of ABI varies including falls, motor vehicle accidents, assaults or being struck by an object, sports injuries, and blast injuries among military personnel (Langlois et al, 2006). As a result of these injuries, individuals encounter physical, behavioral, and cognitive deficits that typically result in loss of employment, and affect their social relationships, mood, and quality of life. Individuals who sustain a ABI go through many changes that can alter their relationships with others.

Programs designed to treat this population have had difficulty addressing the complex disabilities caused by ABI and helping individuals reintegrate back into communities (Finnie & Blumbergs, 2002). Difficulties that can occur in conducting treatment research with this population include accounting for the different types of injury, injury severity, and accompanying executive functioning deficits (Heegaard & Biros, 2007).

Despite the increase in research on the impact of acquired brain injury, limited knowledge still exists on its far-reaching effects on an individual's cognitive and emotional functioning. Current research about ABI indicates that many individual report changes in their quality of life (QoL) as a result of the impairments incurred from their injury. Researchers have determined that improvement in physical, cognitive, and functional ability does not always correlate with improved QoL (Cicerone & Azulay, 2007). One factor, improved social functioning, can help ABI survivors gain acceptance by peers, family, and assist in building new relationships (Struchen, Pappadis, Sander, Burrows, & Myszka, 2011). To comprehend the



impact of ABI on quality of life and social functioning, it is important to examine the types of injury, neuropsychological and psychological impairments, and the connection between social functioning and QoL in this population.

The cognitive, emotional, and physical impairments that occur as a result of a ABI significantly impact emotional and social functioning. ABI-associated deficits can impact an individual's social cognition, which inhibits their ability to accurately interpret social interactions. Quality of life (QoL) describes an individual's overall functioning including physical, emotional, and social domains. One main facet of QoL is an individual's social relationships and perceived satisfaction with them. Research indicates that ABI survivors often report being socially isolated (Bombardier et al, 2010). Social isolation has been linked to increased incidence of depression, anxiety, and decreased life satisfaction (Bombardier et al, 2010). Having strong social and community ties has been linked with having an improved QoL post-injury (Bedard et al, 2003; Hammond et al, 2004). Many ABI survivors require hospitalization to achieve medical stability to prepare for reintegration back into the community. Once stable, they can spend several months in physical and cognitive rehabilitation.

Long-term cognitive impairments associated with sustaining a ABI can affect many areas of functioning including social connectedness. Deficits such as slowed processing speed, impaired short term and long term memory, and decreased executive functioning capabilities can affect an individual's ability to complete activities of daily living and limit self-awareness. Other post-injury sequelae include posttraumatic amnesia, change in mental status, focal neurological deficit, or a combination of these impairments (Silver, McAllister, & Arciniegas, 2009).

Individuals with jobs requiring sustained attention and concentration may be unable to return to



their previous level of productivity (Langlois et al, 2006). This can result in financial complications, as disability reimbursement may not compare to previous earnings. Without adequate income, those with ABI may have difficulty managing health-related costs that have accumulated as a result of the injury.

In many instances, ABI survivors can develop co-occurring health and physical conditions that affect their quality of life and social relationships. Physical impairments can include ataxia, aphasia, and poor balance and mobility. Further complications of a ABI are the development of other serious medical disorders such as epilepsy, insomnia, dizziness, and neurological deficits related to cell death and trauma. Health concerns affect an individual's ability to work, interpersonal relationships, and overall functioning (Langlois et al, 2006). Structural damage can occur to major brain areas such as the prefrontal cortex and limbic system that can alter an individual's personality, physical functioning, and emotional well-being. Changes in personality and affect regulation related to neurological damage can alter an individual's ability to perceive and understand their social interactions. Impaired social cognition skills have been linked to decrease in frequency and quality of social contacts and relationships (Langlois et al, 2006).

Common psychiatric symptoms that can present post-injury include aggression, psychosis, sleep disorders, depression, and anxiety. In their study of depression prevalence rates of those with ABI, Bombardier et al (2010) found that 297 of 559 patients (53.1%) met criteria for MDD at least once in their first year post injury. In another study examining prevalence rates, Jorge, et al (2004) observed that 33% of patients were diagnosed with MDD after the 1st year post injury, while 76.7% reported comorbid anxiety and 56.7% demonstrated aggressive



behaviors. In addition to depression and anxiety, ABI survivors may experience post-traumatic stress disorder after their injury, impairing their psychosocial functioning and quality of life (Bombardier et al, 2010). Research has indicated that social isolation has been a major contributing factor to the development of these psychiatric disorders (Bombardier et al, 2010). Currently there are limited empirically supported treatments for psychiatric disorders for individuals with ABI (Bombardier et al, 2010; Hammond, Hart, Bushnik, Corrigan, & Sasser, 2004). Group therapy and support groups are gaining empirical support, but further research is needed to determine what treatments are most efficacious in treating this population (Bedard et al, 2003).

Current research has focused on how executive functioning and physical deficits impact quality of life, however, factors impacting social functioning and their relationship with quality of life have yet to be explored. Further research is needed to understand what factors of social functioning impact QoL in ABI survivors and the impact strong social ties can have in improving life satisfaction.

Purpose the study.

Given the importance of social connectedness and the possible issues people with ABI can have in the social domain, the purpose of the current study will be to examine if social connectedness is predictive of quality of life in ABI survivors. More specifically, this study will investigate if social connectedness, as measured by the Mayo-Portland Adaptability Inventory-4 (Malec, 2005), will predict scores on the World Health Organization Quality of Life-BREF. This will be observed in a sample of patients who have sustained a ABI and who currently or in the past participated in a long term rehabilitation program.



Chapter 2: Literature Review

Construct of Quality of Life in ABI.

Definition.

Quality of life is a multidimensional construct comprised of an individual's psychological well-being, health, and social factors. This construct has developed over the past 20-25 years in the medical field, especially among the surgical specialties, where it was found that medical patient's emotional and mental state impacted their progress in treatment (Berger, Leven, Pirente, Boullion, & Neugebauer, 1999). In the 1970's, this observation began to cause a shift in the medical field to begin to focus on how the patient is feeling, rather than the doctor's perception of the how the patient should be feeling.

The construct of QoL still was poorly defined at this time and it was recommended to design measures that could clearly articulate the factors that influenced it (Berger, Leven, Pirente, Boullion, & Neugebauer, 1999). Several measures were created to begin to assess QoL, but it was still unclear when it was necessary to assess for it among medical patients. Initial measures were too long and used complicated medical language that interfered with obtaining accurate QoL information about the patient. Recent measures, such as WHOQoL, have gained empirical support through analysis of their psychometric properties (WHOQOL, 1994).

Factors of QoL in ABI survivors.

Three main factors were proposed by Ganotti (1993) related to QoL in ABI survivors: neurological disturbance, emotional/personal attitudes towards injury, and social consequences. Changes in personality and cognitive deficits can further complicate assessing for QoL in this



population. Additionally, self-report measures are generally used to assess QoL even though they can be difficult to complete for ABI survivors with various functional impairments (Martin-Hernz, Zatzik, & McMahon, 2012). Another complication with self-report measures is they require a level of self-awareness that some ABI survivors may not have. Specific measures for QoL in ABI survivors are limited, although measures such as the World Health Organization Quality of Life Measure-BREF (WHOQoL-BREF) have demonstrated validity (Berger, Leven, Pirente, Boullion, & Neugebauer, 1999).

Eichenbaum, Deluca, Lindgren, and Brownsberger (2012) examined if the QoL domains on the WHOQoL-BREF (physical, psychological, social relationships, and environment) were significantly related to rehabilitation outcomes (ability, adjustment, and participation). These measures were completed by interdisciplinary team members with a population of ABI survivors in a residential/ and or outpatient brain injury rehabilitation program, Bancroft, in Southern New Jersey. Results from their study indicated that there was not a significant relationship between the scores on the MPAI-IV and WHOQol-BREF. One limitation they noted was that interpersonal relationship satisfaction could have influenced scores as it is a MPAI change score on the measure. A similar study conducted at Bancroft, Halpern, Deluca, Eichenbaum, Lindgren, and Haggerty (2013) examined correlates of rehabilitation outcomes including age, time since injury, and time since admission to Bancroft's Brain Injury Services with MPAI-IV total score that measures an individual's functioning. The Participation subscale on the MPAI-IV, that addresses psychosocial functioning, had a statistically significant relationship with years since injury. This indicated that time since injury predicted a decrease in community participation while adjustment and participant abilities were maintained and were not significantly correlated with time since injury. Further research is still needed into understanding the influence of factors of participation such as engagement in the community, quality of social relationships, and perception of community support.

Social Connection.

Definition.

Social connectedness fuels the basic needs of social behavior. Biocca et al (2001) stated that connectedness relates to a sense of social presence that involves psychological engagement with another person. The fundamental need to develop and foster relationships gives individuals a sense of belonging and identity. Another important factor in social connectedness is social awareness, or being cognizant of social norms and practices. In ABI survivors, impairment in self-awareness and emotional regulation severely impinges their ability to sustain meaningful social relationships (Biocca et al, 2001).

Connection between social connection and OoL.

Social adjustment difficulties and isolation are strongly connected to QoL in ABI survivors (Anderson et al, 2009). Improved social functioning, one of the domains of QoL, can help ABI survivors reintegrate back into their lives post-injury (Struchen, Pappadis, Sander, Burrows, & Myszka, 2011). Conversely, inability to effectively communicate socially can lead to low self-esteem, loneliness, and social isolation. These factors can decrease opportunities for social interactions, which can adversely affect QoL (Struchen, Pappadis, Sander, Burrows, & Myszka, 2011). Having social and family supports is essential for patients that are adjusting to the post injury emotional, cognitive, and physical changes.



In a study by Steadman-Pare, Colantonio, Ratcliff, Chase, and Vernich (2001), the authors examined factors that affect perceived QoL in a sample of 275 patients who had sustained moderate to severe ABI that were interviewed up to 8-24 years post injury. Participants included 191 males and 81 female patients that ranged in age from 23-84 years old. The participants were discharged from a rehabilitation hospital and were given the self-rated Quality of Life Scale. In addition to the factors of participation in work and leisure, overall health, mental health, participants also rated having emotional support from peers as significant in their perceived QoL. A multivariate linear regression analysis indicated that the availability of social support was significantly associated with QoL. Analyses further demonstrated that females rated QoL higher than males.

In another study by Kreuter, Dahloff, and Siosteen (1998), 92 ABI survivors and 167 spinal cord injury (SCI) patients were compared to a control group of 264 individuals from the general population to assess the quality of their partner relationships, functioning, mood and global quality of life. The median ages for SCI persons was 33 years (range 19 to 79 years), ABI persons 40 years (range 20 to 70 years), and controls 31 years (range 19 to 79 years). The age of injury for the SCI group was 14-76 years old and for the ABI group was 16 to 56 years old.

Approximately half of each group in the study was currently in a relationship with a stable partner at the time and the relationships had been established post-injury. Both the ABI and SCI participants did not differ in education or perceived QOL or distress. In assessing their perceived QoL, the SCI group differed significantly from the control group whereas the ABI group and control were similar in QoL. In all three groups in the study, participants who were single had significantly lower ratings on the global Qol ratings in comparison to participants that were in stable partner relationships. In both the ABI and SCI groups, having a high level of physical and

social independence were positive determinants of perceived QoL (Kreuter, Dahloff, & Siosteen, 1998). Results indicated that established social relationships are a strong predictor of QoL in the general and ABI population

Additionally, a similar study by Webb, Wrigley, and Fine (1995) examined perceived QoL by examining the effects of effects of demographic, psychosocial, physical, and rehabilitation variables on quality of life 2 years after hospital discharge. Study participants were 18 years old and above, had been recently discharged from the hospital within the past 3 days, and were residing and had been injured in Alabama. The study was comprised of a total of 293 persons that were also eligible for the study but 186 were available for the 24 month follow-up survey. They found that QoL as measured by the Life Satisfaction Scale was higher in individuals who had more family support 2 years post injury. A supportive family was hypothesized to contribute to increased functional independence and ability to return to work (Webb, Wrigley, & Fine, 1995). Overall life satisfaction was also found to be attributed to perception of satisfaction with an individual's family and support system (Warren, Wrigley, Yoels, & Fine, 1996).

A relatively recent longitudinal study by Tomberg, Toomela, Ennok, and Tikk (2007) examined how coping, social support, perceived QoL, and life perception change in a sample of thirty-one patients with ABI who were first investigated on average 2.3 years after injury and were prospectively followed on average 5.7 years later. This study was conducted in Estonia and the participants consisted of 85 Estonian-speaking persons (69 men and 16 women) who had suffered a ABI between December 1996 and June 1998. The participants education level varied including fourteen patients (47%) with a basic education (9 years or less), 11 (33%) had



secondary education (12 years) and six (20%) had higher education. Participants had either sustained a moderate to severe ABI. The information collected from participants was gathered through personal and semi-structured interview. The data collected included functional status and health complaints, as well as life activities and social functioning (leisure activities, social contacts, family relationships and occupational status). Participants reported that their perceived health QoL and participation in work did not improve, but there was an increase in seeking positive social supports and community engagement.

Similar outcomes have been found in research conducted with children who have sustained a ABI. Yeates, Walz, Taylor, Stancin, and Wade (2010) study sought to determine what impact the family environment had on post-injury psychosocial outcomes. Participants were recruited from consecutive admissions to three tertiary children's hospitals in the Midwestern region of the United States. The children ranged in age from 3 to 6 years old and had sustained blunt trauma requiring an overnight admission to the hospital, with a Glasgow Coma Scale of <15. A Glasgow coma scale score <15 would indicate a change in neurological status or evidence of abnormalities on a computed tomography (CT) scan or MRI. The study included a total of 206 children (23 severe ABI, 64 complicated-mild/moderate ABI, and 119 orthopedic injuries) and their caregivers. In the initial assessment phase, caregivers completed retrospective ratings of their parenting style pre-injury and their general family functioning. A home visit was conducted to assess the quality of the home environment. The authors measured family environment by examining parenting style, overall family functioning, and quality of the home environment. The psychosocial outcomes were assessed using measures that examined behavioral adjustment, adaptive functioning, and social competence.



Outcomes from the measures indicated that family environment accounted for significant variance in psychosocial outcomes with children. Family environment independently predicted behavioral adjustment and social competence across all treatment groups. The family's overall functioning also served as an indicator of better behavioral adjustment after 18 months postinjury. These results were consistent with prior research that family environment and support can help with social competence and improvement in post-injury overall QoL (Yeates, Walz, Taylor, Stancin, & Wade, 2010).

Post-traumatic growth (PTG) is another way to evaluate an individual's QoL post-injury. It is defined as "the positive effects that result from a traumatic event" (Powell, Gilson, & Collin, 2012). Powell, Gilson, and Collin (2012) wanted to examine what factors influence post-traumatic growth 11 and 13 years post-injury. Participants were recruited from the Reading Head Injury Clinic register in Reading, United Kingdom (1994-1996) who participated in a prior study. Participants included 21 of the original 26 participants in the initial study, which included 19 males and 2 females, with an average age of 42.8 years old. The participants' injury severity was measured by the criteria from the Medical Disability Society, which included the Glasgow Coma Scale (GCS) and post-traumatic amnesia. Several measures were administered that assessed for post-traumatic growth and other factors that influence it, such as spiritual beliefs, perception of social support, and potential for depression/ and or anxiety.

Their study found several important factors that influence post-traumatic growth.

Participants identified that having a sense of personal meaning/ and or purpose in life, current life satisfaction, social support, stable post-injury relationships, spirituality, and employment were correlated with their PTG. Individuals with higher post-traumatic growth demonstrated the ability to establish new relationships, ability to work, and having a spiritual beliefs. Specific



comments made by individuals who reported higher PTG included the important of family/children and they were future oriented.

Another international study found similar outcomes regarding QoL in ABI survivors. A study conducted by Sukraeny, Songwathana, and Sae-Sia (2014) conducted in Indonesia sought to examine what factors influence QoL in Indonesian survivors of ABI. Participants were recruited from Dr. Kariadi Hospital that were admitted to the neurosurgical unit from 2011 through 2012. Participants had been diagnosed with a mild to severe ABI, age 18-65 years old, and had been discharged at least 1 month from the hospital. From the hospital, researchers were able to recruit 103 patients that were administered the Quality of Life after Acquired brain injury (QOLIBRI) instrument that consists of 4 domains: cognition, self, daily life and autonomy, and social relationship scales.

The social relationships domain consisted of satisfaction with family members, partner, sex life, and attitudes towards others. Results indicated that individuals who rated high on the social relationship domain had higher satisfaction with their social supports. These results were consistent with other studies that had demonstrated that social support is positively related with QoL (Steadman-Pare, Colantonio, Ratcliff, Chase, & Vernich, 2001; Tomberg et al., 2007).

Social support and quality of social relationships has shown to improve overall life satisfaction in various studies; however, there is still a lack of recent studies with larger sample sizes to assess how strong this connection is. Additionally, integrating a social component into treatment programs could potentially increase symptom improvement from a variety of deficits that can result from ABI.

Background on ABI.



Scope of Problem and Definitions.

The Head Injury Interdisciplinary Special Interest Group of the American Congress of Rehabilitation Medicine (2011) defines a brain injury, "by a traumatically induced physiologic disruption of brain function, as manifested by one of the following: any period of loss of consciousness (LOC), any loss of memory for events immediately before or after the accident, any alteration in mental state at the time of the accident, focal neurologic deficits, which may or may not be transient"(p.1). There are three categories of ABI that are categorized by the Glasgow Coma Scale (GCS) and other criteria. The Glasgow Coma Scale assesses an individual's severity of injury by examining their motor, eye opening, and verbal response within 48 hours of sustaining a head injury (Dawodu, 2011). This scale allows doctors to assess the amount of damage and to begin to formulate a plan of treatment for the patient.

The Glasgow Coma Scale scores range from 1 through 15, (motor 1-6, verbal 1-5, and eye movement 1-4), which addresses an individual's visual, motor, and speech functioning (Dawodu, 2011). For a score of 1, an individual has either no responsiveness either verbally, by opening their eyes, and is unable to make any movements. A score of 2 indicates that an individual will open their eyes and move in response to painful stimuli, and will produce incomprehensible sounds. For a score of 3, the individual is uttering inappropriate words, will open eyes in response to a voice, and has abnormal flexion in response to painful stimuli. An individual with a score of 4 is more alert and able to open eyes spontaneously but is still disoriented. For a score of 5, the individual can converse normally and can localize painful stimuli. A score of 6 indicates an individual who is fully alert and responsive to all stimuli. The scores are summed among these domains to determine an overall score that ranges from 3 (deep



coma) to 15 (fully awake person). Individuals with lower GCS scores are more likely to have more severe brain damage that affects their overall cognitive, emotional, and physical functioning (Dawodu, 2011).

Head injuries have been treated since the time of Hippocrates, who described trephination and neurosurgery techniques in his early writings (Heegaard & Biros, 2007). The most common causes of acquired brain injury in early human history were assaults (Heegaard & Biros, 2007). Current research indicates that 1.1 million patients are evaluated in emergency rooms for ABI and are most commonly caused by motor vehicle-associated injuries (Heegaard & Brios, 2007). The typical peak ages of those who sustain a ABI are young people in the 15-24 age range and a smaller peak occurs with children ages 5 and younger (Heegaard & Brios, 2007). Individuals in these age groups typically suffer damage to their still developing prefrontal cortex, which is the area of the brain that controls executive functioning, decision making, and problem solving (Baalen, Maas, Ribbers, Bergen, & Stam, 2003). This age cohort is often at risk for impulsive or risk-tasking behavior, which potentially explains why they put themselves in situations where they are susceptible to injury.

Injury Categories.

ABIs are described by three main categories that include mild, moderate, and severe. A mild ABI requires longer than a 48 hour hospitalization, a GCS score greater than 12, absence of abnormality on a computed tomography (CT) scan, and no operative lesions. The individual may experience post-traumatic amnesia, which can last up to an hour after the injury (Mayo Clinic, 2013). A moderate ABI is categorized by a loss of consciousness that can range from 1 to 24 hours and can cause bleeding, axonal shearing, and bruising that can cause long term changes to



the brain (Mayo Clinic, 2013). Individuals who have sustained a ABI will have abnormal brain imaging results that indicate which brain areas were affected by the injury. A severe ABI results in coma or loss of consciousness, for more than 24 hours post injury and abnormal brain imaging results.

Severe ABIs can further be classified into sub-categories that indicate the level and length of consciousness. One category is *coma*, which is a state of unconsciousness where an individual cannot be awakened. Some individuals will report having some awareness during a coma state but are not able to communicate with their environment (Northeastern University, 2010). A *vegetative state* is a form of a coma, but the individual lacks awareness of their environment. A *persistent vegetative state*, can last at least over one month time period. Lastly, a *minimally responsive state* is categorized by an individual who is neither in a coma or vegetative state, and is intermittently responsive to their environment (Northeastern University, 2010). Severity and location of injury in the brain is important to consider when examining the deficits that each individual presents with.

Mechanism of Injury.

There are two primary types of brain injury: closed head injury (CHI) and penetrating head injury (PHI). Each of these injury types can produce different functional outcomes in individuals. Closed head injuries occur when acceleration or decelerations, typically found in motor vehicle accidents, cause diffuse injury and contusions (Baalen, Odding, Maas, Ribbers, Berger, & Stam, 2003). Additionally, closed head injuries typically result in a contra-coup brain injury. In a closed head injury, the initial impact is the coup injury caused by some form of blunt force. The coup injury typically causes the brain to shift forward causing damage to the frontal



region of the cortex, which is similar to a whiplash effect. When a contra-coup injury takes place, the cortex is shifted to the back of the skull causing other diffuse damage to the cortex. One hypothesis for why this occurs is that upon impact, the denser cerebrospinal fluid (CSF) moves to the injury site causing the brain to displace in the opposite direction (Drew & Drew, 2004). In closed head injuries where the contra-coup injury is more severe than the coup injury, it is generally a result of the initial movement of the brain to the contra-coup location. Other potential factors that can affect these injuries include tumor, vascular, anoxic events, and blast injury. When this occurs, it is typically causes more severe brain contusion (Drew & Drew, 2004).

In a penetrating head injury, mortality rates are significantly higher and functional outcomes are poorer. In a penetrating head injury, a penetrating object, such as a bullet from a gunshot, causes localized damage. Depending on the amount of force of the object, damage can also be widespread to multiple brain regions (Baalen et al, 2003). Deficits associated with penetrating head injuries are typically physical, while in closed head injuries deficits are primary related to cognitive functioning.

Physical deficits.

Physical deficits are most easily recognized and treated when working with ABI survivors. Movement involves the coordination of several systems including the sensory, motor programming, and musculoskeletal. If any of these systems are compromised, such as in a head injury, physical disabilities can occur (Basford et al, 2008). Research studies conducted with individuals who have sustained a ABI indicate they rely more on visual input, which can lead to swaying and impaired balance when ambulating. Difficulty ambulating legs and upper



extremities has dramatic effects on an individual's ability to complete activities of daily living and job performance.

Other physical deficits that can result include inability to move the mouth for speech, swallowing difficulties, and inability to use one or more limbs. Physical and occupational therapists employ various techniques to improve and regain physical functioning (Baalen et al.,2003). Unfortunately, depending on injury severity, individuals may have to use ambulatory devices such as braces and walkers to be able to move. Use of these devices and inability to move body parts can significantly impact an individual's functioning and quality of life.

Cognitive deficits.

Cognitive impairments that occur after sustaining a ABI can affect information processing speed and memory. Animal models have shown that after a ABI there is a disruption in the storage of information in the brain that affects the ability to retrieve information from memory (Whiting, Baranova, & Hamm, 2006). Long term memory processes have found to be increasingly affected by ABI in comparison to other cognitive processes (Whiting, Baranova, & Hamm, 2006). Retrograde amnesia (RA), induced by trauma, prohibits an individual's ability to recall information already stored in memory. By using animal models, after inducing a ABI, researchers found that RA was attributed to inability to retrieve and store information (Zhou & Riccio, 1995). Other memory deficits that result from ABI include anterograde amnesia, working memory deficits, and slowed processing speed. Significant memory impairments affect an individual's ability to function on a daily basis, such as employment and interpersonal relationships.



Post-traumatic amnesia after ABI has also been linked to future intellectual impairment (Konigs, Kieviet, & Oosterlaan, 2012). Meta-analysis revealed a predictive relationship between post-traumatic amnesia and intelligence (Konings, Kieviet, & Oosterlaan, 2012). Post-traumatic amnesia has been specifically correlated with full scale intelligence, as measured by the Wechsler Intelligence scale. Mild ABI has limited impact on intelligence; however those who have severe ABI are likely to have a decreased full scale IQ score in comparison to same aged peers. Children who sustain a ABI are more likely to experience deficits that affect their ability to perform academically, vocational performance, social relationships, and mental well-being (Anderson et al, 2011).

Neuropsychological effects of ABI.

Pre-Frontal Cortex Damage.

Identifying the brain region affected by a ABI is difficult, considering that many injuries cause diffuse and focal damage. The restrictive space of the skull and tissue strain can localize in the ventral and polar frontal and lateral anterior temporal lobe regions (Fujiwara, Schwartz, Gao, Black, & Levine, 2008). Closed head injury can affect these regions from the acceleration/deceleration forces, and cause white matter atrophy and widespread axonal projections. Radiological imaging tests such as fMRI are able to label the brain injuries affected by ABI and the corresponding effects to executive and cognitive functioning (Kraus, Susmarars, Caughlin, Walker, Sweeney, & Little, 2007). Gray matter loss in the ventral frontal lobe has also been found to be associated with decreased smell detection and other sensory processes (Kraus, Susmarars, Caughlin, Walker, Sweeney, & Little, 2007).

Executive Functioning Impairment



Executive functioning deficits cause significant issues for ABI survivors. Executive functions are defined as "...integrative cognitive processes that determine goal-directed and purposeful behavior and are superordinate in the orderly execution of daily life functions includ[ing]: the ability to formulate goals; to initiate behavior; to anticipate the consequences of actions; to plan and organize behavior according to the spatial, temporal, topical or logical sequences; and to monitor and adapt behavior to fit a particular task or context" (Cicerone et al., 2000, p. 1605). The pre-frontal cortex is the brain region where many executive functioning processes such as attention, concentration, problem solving, and decision making occur. Limited self-awareness found in individuals who have sustained ABI prohibits their ability to effectively problem solve and set realistic goals (Kennedy et al, 2008). Overall functioning maybe severely affected in ABI survivors, with the result that they are unable to integrate the different parts of the executive functioning system to complete even simple tasks.

Limbic System Dysfunction.

The limbic system includes the amygdala and hippocampus, which compose the limbic-cortical network that is integral in emotional regulation (Capizzano, Jorge, & Robinson, 2010). Proton MR spectroscopy (1H-MRS) studies have been used to isolate the neuronal chemicals and brain regions affected in the limbic system after injury. Studies have demonstrated that brain metabolites such as *N*-acetylaspartate (NAA), which are reduced during a trauma to the brain, cause left hippocampal dysfunction. Damage to this area of the hippocampus has been linked to psychosocial dysfunction in ABI survivors (Isoniemi et al, 2006). Deficiencies in brain metabolite were also found in a population of brain injured individuals with mood disorder and major depression (Capizzano, Jorge, & Robinson, 2010; Jorge et al, 2007). Damage to this brain region has profound effects on an individual's identity, mood, and personality.

ABI deficits effects on social cognition.

Social cognition is a broad concept that refers to an individual's ability to comprehend other person's behavior and react appropriately in social situations (Beer and Ochsner, 2006; Beer et al., 2006). Frith and Frith (2010) conceptualized that social cognition is controlled by two systems: the mentalizing system and a mirror system. The mentalizing system allows a person to comprehend another person's point of view and then use that information to understand their thoughts, feelings, and desires. The mirror system refers to an individual's capability to empathize and understand another person's emotions, thoughts, and behaviors. These two systems work together to allow individuals to synthesize information that is gathered in social encounters and participate in social exchanges.

In ABI survivors, the ability to effectively utilize these systems can be damaged. Deficits in emotional recognition and empathy pose serious problems when trying to understand social situations (Spikman, Timmerman, Milders, Veenstra, & Naalt, 2012). Damage in the orbitofrontal and ventro-medial parts of the cortex have been associated with these deficits in social cognition (Bechara et al., 2000; Naqvi et al., 2006). As indicated previously, impaired judgment, impulsivity, and lack of self-awareness make it difficult to understand what is occurring in social interactions.

Alternative theories have proposed that specialized brain regions that are damaged in ABI survivors affect their social cognition. Brain structures including the amygdala, portions of the anterior cingulate cortex, ventral striatum (caudate nucleus, putaman, nucleus accumbens), and ventromedial cortex mediate processing of emotional and socially relevant stimuli (Phillips, Drevets, Rauch, & Lane, 2003; Satpute & Lieberman, 2006). These brain regions assist individuals with detecting threats and recognition of pain in self and others. Specific damage to



the ventromedial cortex inhibits an individual's ability to respond to emotionally arousing stimuli, awareness of punishment and reward contingencies, and affects social reasoning and perception (McDonald, Saad, & James, 2011). Inability to perceive and understand environmental and social cues can limit ABI the patient's ability to effectively engage socially.

Time since injury

Research has indicated that age at the time of injury can be a mediating factor in social outcomes for ABI survivors. Children who sustain injuries early in their development have had mixed outcomes in regards to their social functioning. Typically, children with ABIs have increased difficulty with impulsivity, social problem solving issues, and other behavior problems (Tlustos et al, 2011). Additionally, children are still developmentally beginning to understand social norms and creating a support network. When a ABI occurs, this may disrupt a child's emotional and mental development, impairing their socio-emotional functioning. Children who sustain ABI may experience difficulty with emotional regulation and recognition that can impede their social development (Tlustos et al, 2011). Research with adolescents shows similar difficulties with social relationships post-injury. Adolescents can experience social isolation, diminished friendships, and decreased quality of life from social impairment (Wojslawowicz & Buskirk, 2006). Taking the perspective of others and inability to process emotions were both associated with poor psychosocial adjustment and deficits in social problem solving (Newsome et al, 2010).

Examining research with adults, similar difficulties with social cognition were found.

Adults with diminished executive functioning, decision making, and working memory had significant difficulty maintaining social relationships (Channon & Crawford, 2010). For example, participants with Acquired Brain Injury (ABI), 10 resulting from a ABI and 10 from a



cerebrovascular accident (CVA), were compared to a control group of 20 individuals on a social problem solving tasks (Channon & Crawford, 2010). Participants were given a task where they had to interpret scenarios involving either sarcastic remarks or actions on the Mentalistic Interpretation Task. The ABI group was poorer at solving problems on the Social Problem Fluency Task in comparison to the control group. Channon and Crawford (2010) found they had trouble detecting awkward aspects of social situations and poor social problem solving on the Social Problem Resolution Task. These impairments were not linked to language comprehension but were attributed to patient's decreased executive and socio-emotional functioning (Channon & Crawford, 2010). As seen with children and adolescents, difficulty with taking on another person's perspective and mentalizing tended to inhibit social functioning. Research on the effect of age at time of injury effects is still limited and requires further exploration.

The amount of time post-injury as it refers to social functioning outcomes has also received limited attention in research. Evidence regarding long term outcomes of social and emotional functioning varies among research. Longitudinal studies have found a decline in emotional and behavioral outcomes. Research completed with young adults, ages 16 to 26 years, with a recently acquired disability including ABI, SCI, and other neurological disorders 5 years post injury indicated that recovery is not consistent (Kolakowsky-Hayner et al, 2012). It is also indicated that as time elapses after injury, functional improvement is noted (Hammond, Hart, Bushnick, Corrigan, & Sasser, 2008). Brain region damage, such as decreased cortical thickness, has also been associated with social and emotional long-term outcomes (Wilde et al, 2012).

Severity of Injury

Injury severity can also mediate social functioning outcomes. Individuals who sustain mild ABI typically have fewer social adjustment issues (Hanten et al., 2008). In contrast,



researchers found that in children who sustain a moderate to severe ABI, there was increased risk of social problems specifically with social interactions and emotional regulation. Severe ABI survivors typically have focalized damage to brain areas integral in social problem solving and interpretation of social situations. However, severity of injury is also influenced by the site of injury, which lacks sufficient study (Ganesalingam et al., 2011).

Specific factors that affect social connection post injury.

Personality changes after ABI

Considering the damage that many ABI survivors sustain to their pre-frontal cortex and limbic system, patient's personalities can be affected. In individuals with severe frontal lobe damage, behavioral and mood changes such as mood lability, apathy, and social or sexual inappropriateness can be present (Mendez, Owens, Jimenez, Peppers, & Licht, 2013). These personality changes are more notable in severe ABI, in comparison to mild ABI survivors. Neuropsychological assessment and testing is integral in identifying these changes after an injury (King, 2008). Other changes that can occur include developing increased physical and verbal aggression. Behavioral outbursts that occur due to these personality changes can lead to consequences such as criminal charges and loss of significant relationships (Yeates, Gracey, & McGrath, 2010).

Psychological changes after ABI

Psychological changes that can result from a ABI can have a multitude of effects on an individual's ability to work, function in their community and family, and sustain social connections (Kennedy et al. 2008). These areas all contribute to the formation and maintenance of an individual's self-concept and their identity. In their study, Vickery, Gontovsky, and

Caroselli (2005) administered self-report measures to nineteen ABI patients in the post-acute stage of treatment that examined their self-concept, QoL, and experience of depressive symptoms. Participants were administered the Beck Depression Inventory-II and the Quality of Life Inventory, along with the Tennessee Self-Concept Scale-2 and the Head Injury Semantic Differential Scale, which are measures of self-concept. Results indicated that interpersonal variables such as self-concept and depression impact perceived QoL in brain injured survivors (Vickery, Gontovsky, & Caroselli, 2005).

A qualitative study by Nochi (1998) examined ABI patient's subjective experiences of themselves post-injury. The participants included 10 individuals (four females and six males) recruited from a ABI support group that ranged in age from 24-49 years old. The participants in the study had sustained a ABI from a motor vehicle accident or sports injury that occurred 2-12 years prior to the study. The participants were sampled theoretically, meaning that the researcher selected individuals who demonstrated some insight into the loss-of-self experience that ABI survivors experience to obtain information for theory-building. Semi-structured interviews were conducted for 45-60 minutes where participants were asked about their life before the trauma, rehabilitation experience, present concerns, and future expectations (Nochi, 1998).

Qualitative results gathered indicated that study participants expressed themes of finding it difficult to develop clear self-knowledge such as how and why they became who they are presently. Another domain of self that was lost is the recognition that where they are currently in their functioning is not the same in comparison to their past, with regard to many areas of their life. Another area that can affect ABI survivors' self-concept is the labels placed upon them by



society. Lack of understanding from society, family members, and an individual's community can impact their view of themselves and their overall QoL (Nochi, 1998).

Emotional Regulation Impairment

In conjunction with personality changes, ABI survivors can present with impaired emotional regulation. As indicated, damage to the limbic system affects ABI survivors' ability to manage and cope with fluctuations in their mood (Langlois, Rutland-Brown, & Wald, 2006). One difficulty that has been identified in the research is that there may be impairment in perception of facial emotional expression. Facial emotional perception is an individual's ability to recognize and interpret emotions on a person's face (Green, Turner, & Thompson, 2004). Damage to the posterior regions of the right hemisphere and focalized lesions on the pre-frontal cortex have been associated with decreased facial emotional recognition (Adolphs, 2002). Additionally, damage to the amygdala and basal ganglia were also implicated in deficits with emotional perception. Lacking this ability can have detrimental effects on ABI survivors' ability to build and maintain social relationships. Impulsivity and impaired self-awareness may also impede their ability to recognize emotions and social norms (Green, Turner, & Thompson, 2004). Research indicates that impaired facial emotional recognition, social judgment, and emotional regulation all influence establishment of relationships (Feinstein, 1999).

Difficulty with self-regulation is another factor that can impair emotional regulation. Impaired self-awareness and self-regulations can impair ABI survivors' ability to regulate their emotional states (Kennedy & Coehle, 2005). Manifestations of impaired self-regulation in ABI survivors can include initiation, difficulty inhibiting, over or under confidence about their abilities, and impaired self-control (Kennedy & Coehle, 2005). These deficits make it difficult



for ABI survivors to be able to accurately assess their strengths and weaknesses, which can lead to them becoming frustrated, angry, or melancholic. Tolerating these fluctuations in mood states can cause strain to patients and their families and supports.

Prevalence of psychiatric disorders

Research has shown an increased incidence of depression and anxiety disorders among ABI survivors (Jorge, Robinson, Moser, Tateno, Crespo-Facorro, & Arndt, 2004). Seel, Kreutzer, Rosenthal, Hammond, Corrigan, and Black (2003) examined a sample of outpatients 10 and 126 months post injury and found that 27% still met criteria for major depressive disorder. In a community based study with World War II veterans who sustained head injuries, Holsingger et al (2002) found a lifetime prevalence rate of depression among 18.5% in comparison to 13.4% in a comparable group who did not. Increased prevalence of depression and anxiety has been found in patients with basal ganglia lesions and ischemic deep white matter (Jorge, Robinson, Moser, Tateno, Crespo-Facorro, & Arndt, 2004). Damage to these areas, as previously discussed, is consistent with poor emotional regulation and self-awareness.

Post-traumatic stress disorder has also been found to be prevalent in this population. This has been particularly notable in mild traumatic brain injured military personnel that have been exposed to blast injuries. Research with soldiers returning from Iraq with mild ABI within 3 to 4 months of returning stateside was strongly associated with PTSD and physical health problems (Hoge, McGurk, Thomas, Cox, Engel, & Castro, 2008). Biological processes coupled with damage from the injury put individuals at increased risk for PTSD, especially after experiencing war or combat related trauma. Similar results were found among individuals who sustained a severe acquired brain injury (Bryant, Marosszeky, Crooks, & Gurka, 2000).



Studies on QoL in ABI survivors.

Status of current research.

Studies examining QoL in ABI survivors have had difficulty in isolating the factors that are positive influences. Research has generally focused on specific ABI samples such as children, adults, and females. In their study with children, Anderson et al (2012) found that severity of injury, social function, and everyday executive functioning skills were predictive of post injury status. In children, social impairment also contributed to increased behavioral difficulties (Anderson et al, 2012; Mitra, Cameron, &Butt, 2007). Early childhood development concerns can pose issues when working with children who have sustained a ABI in determining risk factors for decreased QoL. Many of the studies regarding QoL focus on functional outcomes such as coping with disability and return to employment in adults. However, having a limited focus impedes researchers treating the individual with ABIs social and psychological well-being.

A study conducted by Braden, Hawley, Newman, Morey, Gerber, and Harrison-Felix (2010) used a social skills treatment group treatment model to improve social communication skills in ABI survivors. Participants were recruited from a regional rehabilitation hospital and from other brain injury programs in the area in Colorado. Participants were obtained over a 2 year period via phone and mail from August 2006 to January 2008. The participants were recruited the 31 ABI survivors and their spouses who participated in the 13 week, 1.5 hour manualized intervention, Group Interactive Structured Treatment (GIST). GIST is a cognitive-behavioral therapy conducted in group setting that addresses the underlying cognitive, communicative, and emotional impairments that affect social competence in ABI survivors.



Results indicated that participants had statistically significant results in outcome measures that address social communication skills, life satisfaction and goal setting.

Another study by Hawley and Newman (2010) assessed the theoretical basis for GIST and clinical applications of this treatment in various rehabilitation settings. They examined the stages of GIST that are based on a holistic approach to treatment documented in the neurorehabilitation research. The domains assessed include engagement, awareness, goal setting, skill mastery, and generalization. The researchers observed the GIST intervention applied to a military personnel post-injury group. The GIST intervention was used with groups of active duty soldiers and veterans who had sustained a ABI in a study conducted in Colorado. Four treatment groups had been completed at the time of their study and another group was still in progress. Initial clinical observations indicated that participation in the GIST program improved social competence skills in active and veteran military personnel (Hawley & Newman, 2010).

Gaps in current research.

There continues to be a gap in the research examining the factors that can positively influence QoL in ABI survivors. One of the primary challenges with examining social relationships and QoL in this population is the heterogeneity of ABI. ABI survivors can have various pathophysiological processes that pose difficulty when trying to conduct treatment interventions (Madder, 2013). Additionally, published data on interventions typically does not extend beyond 6 months providing limited information about long term treatment benefits (Madder, 2013). Interventions have been targeted at improving cognitive, physical, and functional outcomes post-injury. What remains to be identified is what the central factors are that impact QoL in ABI survivors after injury. Determining the impact of social functioning



continues to remain a topic to be further explored in consideration of its link to QoL in this population.



Chapter 3: Hypotheses and Research Questions

1. Does a lower total score on the MPAI-IV predict a higher total score on the WHO-QoL-BREF?

Hypothesis: Statistical analysis will reveal that individual's total MPAI-IV score will be negatively correlated with total QoL score on the WHOQoL-BREF.

2. Does a lower score on the Participation subscale of the MPAI-IV predict a higher score on the Social Relationship's domain on the WHOQol-BREF?

Hypothesis: Statistical analysis will reveal that individual's Participation subscale score on the MPAI-IV will be negatively correlated with the Social Relationships domain on the WHOQoL-BREF.

3. Does a lower score on the Participation subscale predict a higher total score on the WHOQoL-BREF in individuals who have sustained a ABI?

Hypothesis: Statistical analysis will reveal that individual's Participation subscale of the MPAI-IV will be negatively correlated with the total score on the WHOQoL-BREF.

Social competence has been identified as a significant factor in successfully reintegrating back into the community (Struchen, Pappadis, Sander, Burrows, & Myszka, 2010). Maintaining social relationships and forming new friendships provides support to patients as they begin to address the changes in their life caused by their injury (Struchen, Pappadis, Sander, Burrows, & Myszka, 2010). Additionally, research has indicated that ABI survivors with enhanced social



relationships have fewer depressive symptoms, improved outlook on life, and improved quality of life (Hibbard et al., 2002).

In a longitudinal study, Sbordone, Litter, and Pettler-Jennings (1995) found that ABI survivors had improved cognitive, social, behavioral, vocational, and motor functioning during a time span of 2 years and an average of 10.3 years. Conversely, another long term study that examined individuals 20 years after injury indicated that 19 of these ABI survivors had minimal social contact, with only 7 patients who reported overall improved psychosocial functioning (Thomsen, 1992). Considering the conflicting results in the literature, clarification is needed on the impact of time post injury on social involvement and overall functioning.

Mental health status has been found to be strongly linked to QoL in several studies. Steadman-Pare, Colantonio, Ratcliff, Chase, and Vernich (2001) found in their study that individuals who experienced greater numbers of depressive symptoms reported significantly lower QoL ratings. In a study by Koskinen (1998), a sample of 15 severely injured patients and their caregivers 5 and 10 years post-injury were interviewed and reported various cognitive and emotional/behavioral disturbances in the patients. Additionally, Koskinen noted that neurobehavioral and emotional disturbances had the most significant effect on participant's life satisfaction and caregivers were less stressed (Koskinen, 1998). The experience of mental health symptoms could also be a variable that can affect an individual's social and family relationships.



Chapter 4: Method

Overview.

This study was a component of a larger outcomes research project being conducted by the Pennsylvania Association of Rehabilitation Facilities (PARF). PARF is an organization that seeks to monitor and improve the availability, quality, and accessibility of services to individuals with physical, emotional, mental, and social disabilities (parf.org, 2009). Currently there are seven post-acute brain injury rehabilitation facilities in the Pennsylvania and New Jersey that collect progress and patient functioning information that is placed into a database. This information is used to monitor program effectiveness, assist in treatment decisions, and offers funders a means to track the needs of program participants (Eicher, Malec, & Murphy, 2010).

Utilizing archival data from Bancroft, a comprehensive post-acute brain injury rehabilitation program located in New Jersey that is a PARF site, this study examined the relationship between components that influence social connectedness in ABI survivors, such as quality of social relationships, initiation, self-awareness, and presence of depression or anxiety and quality of life. Data from 3 of Bancroft's sites was used. The definition of social connectedness used in this study was derived from Adler's (1998) theory of social interest, which refers to an individual's attitude and relationship with society. Adler identified that social interest is a factor in developing a healthy identity and psychological well-being. Smith and Mackie (2000) indicated that *connectedness* is the driving force in pursuing social relationships. Researchers on quality of life in ABI survivors have developed a basic definition described as, "...multidimensional construct comprising physical/medical, psychological and social factors" (Berger, Leven, Pirente, Bouillon, & Neugebauer, 1999). The study sought to provide additional



support for the concept of quality of life in ABI survivors and inform treatment programs that work with this population.

Participants.

The participants for this study were selected from an archival data set of current and past participants in Bancroft's post-acute brain injury rehabilitation program in Southern New Jersey. Participants admitted to this program had sustained an acquired or acquired brain injury, either early or late in their development, and may have other co-occurring medical conditions.

Acquired brain injury is a type of acquired brain injury defined as "...an injury from a blow, jolt, or penetrating object that disrupts normal functioning of the brain" (NIH, 2012). Other types of acquired brain injury can be caused from an organic occurrence such as a stroke, tumor, or other vascular diseases (NIH, 2012). The participants ranged in age from 18 and 73 and that consisted of primarily male and Caucasian individuals. The sample used in this study is reflective of the specific population that Bancroft serves. Finally, participants were considered volunteers and a sample of convenience. The data from each participant included: time post injury, current age, age at time of injury, relationship status, individual subscale scores on both the MPAI-IV and WHOQoL-BREF, and their total scores on both measures.

Inclusion Criteria.

Participants in the archival data set included those who communicate either verbally or by an assistive device such as a Dynovox, ages 18 and older, and were primarily male and Caucasian. They currently or in the past participated in day treatment services and outpatient services in all 3 programs and have been administered both the Mayo-Portland Adaptability Inventory 4 (MPAI-4) and World Health Organization Quality of Life BREF (WHOQol-BREF).



Exclusion Criteria.

Participants who were excluded from this study were those that have not been given both of these measures and were not in archival data set.

Overview of Research Design.

The design that utilized was a cross sectional correlational design. This design is useful in identifying correlates and features of a relationship between variables (Kazdin, 2003). This design allowed the researcher to observe if there is a predictive relationship between social connectedness and QoL in ABI survivors, who currently and in the past, have participated in a long term rehabilitation program. Data collected from 2007 to 2014 was used.

Bancroft's brain injury day treatment services.

Bancroft's brain injury rehabilitation is comprised of five program sites: Flicker, Brick, Plainsboro, Cherry Hill, and Mullica Hill. Each program has an interdisciplinary team that consists of a neuropsychologist, cognitive rehabilitation, speech, occupational, and physical therapists. Each program's goal is to assist patients who have sustained brain injuries to learn ways of overcoming the effects of their injury and to maximize their functional abilities by remediating or teaching compensatory strategies for physical, cognitive, behavioral, and emotional difficulties stemming from the brain injury (Bancroft, n.d.). Bancroft also provides residential services such as group homes and apartments. In each setting, the patient is supervised, ranging from intensive, direct support to occasional checks (Brahmstadt, 2012).

Bancroft's brain injury day programs are available to individuals 5 days per week from 9 a.m. to 3 p.m. Outpatient therapy is provided depending on level of need of the patient. The



number of days per week that individuals attend is determined by funding source, level of impairment, and volunteer/vocational involvement. Individuals are provided one-to-one therapeutic services based on their level of need and impairment. Group treatment is focused on cognitive rehabilitation, emotional regulation, and adjustment to disability provided by direct support staff, cognitive rehabilitation therapists, or the neuropsychologist is (Brahmstadt, 2012).

Neuropsychologists are doctoral level psychologists who specialize in assessing brain functioning and how it affects an individual's behavior. Through individual therapy and neuropsychological assessment, neuropsychologists assess memory, attention and concentration, and executive functioning abilities such as decision making and emotional functioning.

Neuropsychologists provide recommendations for compensatory strategies that can assist patients with their deficits in these areas and provision of rehabilitation-focused psychotherapy to clients and their families (Brahmstadt, 2012).

Cognitive rehabilitation therapists have bachelor's or master's degrees, are supervised by a neuropsychologist, and are responsible for collaborating with persons served in utilizing compensatory strategies for daily activities such as budgeting, vocational assistance, and identifying community resources. Speech-language pathologists are licensed individuals with master's degrees who specialize in improving communication through the use of technology such as tablets to assist patients with verbal and nonverbal communication (Brahmstadt, 2012). They also utilize methods such as spoken or written words, gestures, and word boards. Occupational therapists are licensed master's level clinicians who assess and build functional living abilities such as daily living skills, movement of upper extremities, cognition, vision, and perception through the use of adaptive aids, therapy, and training in compensatory strategies.



Physical therapists are licensed master's level or doctoral level clinicians who treat orthopedic problems and neurologically based challenges resulting from brain injury. Physical therapists focus on therapeutic activities that address their physical deficits such as improving balance and strength, coordination, mobility, posture, and quality of movement (Brahmstadt, 2012).

Upon entry to the program, patients are generally evaluated by the interdisciplinary team to determine the services needed. Input from the team including the person served, family, and direct support staff is used in the development of an individual rehabilitation plan. The plan outlines the goals and objectives for the individual and each team member's role in order to monitor and track the patient's progress in the program. The plan is periodically reviewed based on any behavioral incidents such as aggression or elopement and any physical, cognitive, or emotional changes that may occur. Incidents are documented and tracked so alterations can be made to the individual rehabilitation plan as needed. Pending no significant changes, the individual rehabilitation plans are reviewed and modified on an annual basis during the individual rehabilitation planning meeting (Brahmstatdt, 2012).

Measures.

Mayo-Portland Adaptability Inventory-4.

The measures used in the archival data will consist of the Mayo-Portland Adaptability

Inventory 4 and the World Health Organization Quality of Life-BREF. The MPAI-4 is used as an outcome measure to monitor participant's progress in the program and is scored by the participant's treatment team by professional consensus. The measure was created by Dr. James Malec and Dr. Muriel Lezak. It was initially published in 1987 by Dr. Lezak and was named the Portland Adaptability Inventory. It was later revised using both classical test theory and Rasch

analysis and was renamed the Mayo-Portland Adaptability Inventory. The MPAI-4 is currently in its 4th revision and was designed to assist in clinical evaluation of individuals in the post-acute period after a sustaining a brain injury. It can also be beneficial in assessing outcomes in rehabilitation programs that service this population. It consists of 29 items that are rated on a 5-point Likert scale (range from 0 to 4; 0 = no or minimal problems, interferes with activities less than 5% of the time, 4 = severe problems, interferes with activities over 75% of the time. It offers six additional items (items 30 to 35) that record pre-morbid functioning and post-injury information on the individual being evaluated. The items on the MPAI-4 assess the following deficits after sustaining a brain injury: cognitive, emotional, behavioral, and social problems (Malec, 2005).

The MPAI-4 has three subscales that include: ability index, adjustment index, and participation. The inventory is composed of 35 items that address each of the subscales. The scale was designed so that professionals, people with brain injury, and their significant others can complete it (Malec, 2005). Rasch analyses of the MPAI were performed on data obtained from 386 individuals with moderate-to-severe ABI in outpatient, community-based, and residential settings. Results indicated that the MPAI-4 has satisfactory person reliability (.88) and item reliability (.99), and internal consistency was demonstrated by Cronbach's Alpha (.89) for the entire measure and each of the subscales. Factor analyses revealed that subscales were developed on a rational clinical basis and were grouped with similar items in each subscale (Malec, Kragness, Evans, Finlay, Kent & Lezak, 2003). Malec (2004) examined the internal consistency of the scale and Rasch indicators were within acceptable limits for 3-rater composite for full scale and subscale measures. Kean, Malec, Altman, and Swick (2011) reassessed the psychometric properties of the MPAI-4 and Rasch measurement revealed an interrater reliability

of .90, which was consistent with previous psychometric analysis. A copy of this measure is located in Appendix A.

World Health Organization Quality of Life-BREF.

The WHOQol-BREF was initiated as a project by the World Health Organization in 1991. Their goal was to develop a quality of life assessment that was internationally cross cultural. The assessment was designed to examine an individual's perceptions of their cultural context, value system, and personal goals. The WHOQoL-BREF is a self-report measure comprised of 26 items and assesses the following domains: physical health, psychological health, social relationships, and environment (WHO, 2013). Each scale has the following descriptors: capacity, frequency, intensity, and evaluation (Yao, Chung, Yu, and Wang, 2002). Each factor of the scale has 4 items to address these descriptors. Physical health domain addresses experience of pain, overall view of physical health, overall energy level, and need for medical treatment. The psychological health domain addresses is their life meaningful and enjoyable and their perception of themselves regarding appearance, and presence of psychiatric symptoms. The social relationships domain discussed an individual's perception of the quality, support, and intimacy in their relationships. The environmental domain references an individual's satisfaction with their living arrangements, access to transportation, and feeling safe and healthy in their environment (Yao, Chung, Yu, and Wang, 2002).

Skevington, Lofty, and O'Connell (2004) conducted a cross sectional study to examine the psychometric properties of this measure. They found that values for Cronbach's alpha were acceptable (>.70) for the entire sample and it was internally consistent. Factor analyses of the data show four factors that explained 53% of the variance in the data. Items in the measure also



demonstrated construct and discriminant validity (Skevington, Lofty, & O'Connell, 2004). Chiu, Huang, Hwang, Tsauo, Chen, Tsai, and Lin (2006) examined the validity of the WHOQoL in assessing a acquired brain injury population. They found that all domain scores had "...nearly symmetrical distributions: low percentages of ceiling and floor values (0 _ 3%), low missing rates (0 _ 0.5%) for all but one item (43.2%), and very good internal consistency (0.75 _ 0.89) and test-retest reliability (0.74 _ 0.95)" (Chiu, et al., 2006). They indicated that this measure would be appropriate to use with a ABI population (Chiu et al., 2006). A copy of this measure is provided in Appendix B.

Procedures.

The long term rehabilitation site has a current outcome measure database that contains demographic and outcomes information. Permission to use this data was obtained in writing. The primary investigator selected all participants from the archival data set that the interdisciplinary team had completed a MPAI-4 for and had completed the self-report measure WHOQol-BREF and met the study inclusion criteria. The primary investigator exported the variables and demographic information from Bancroft's outcome database into the researcher's own excel file and participants were de-identified and assigned a number, and included the following variables: time post injury, current age, age at time of injury, marital status, individual subscale scores on both the MPAI-IV and WHOQoL-BREF, and their total scores on both measures.

The original data was collected after a neuropsychologist educated program directors and managers on the measures and how to complete them. The supervisors then trained direct care staff on the measures and how to complete them. During the first 3 years of data collection, the measures were completed primarily by day and residential program managers with some input



provided by clinicians. Currently, the MPAI-IV is completed by the interdisciplinary team prior to each individual's individual rehabilitation plan (IRP) meeting and is completed every 6 months with treatment team consensus to monitor progress. The MPAI-4 manual is used as a reference to ensure that each measure is completed accurately (Brahmstadt, 2012). The WHOQoL-BREF is completed by each individual upon admission to program and is given to them yearly to monitor their perception of their QoL.

Data Analysis.

The principal investigator conducted simple regressions to determine the correlation between the total MPAI-IV score and the total WHOQoL-BREF score, the Participation scale on the MPAI-IV and the Social Relationships domain on the WHOQoL-BREF, and the Participation scale on the MPAI-IV and the total WHOQoL-BREF score. A multiple regression was also done to also compare additional variables collected including time since injury, age at time of injury, marital status, and current age and how it correlates with total QoL. Test assumptions of the regression were done to ensure assumptions were met.



Chapter 5: Results

Study demographics.

Data analysis was completed using the Statistical Package for the Social Sciences (IBM SPSS Statistics 22; SPSS Inc., 2012). Descriptive statistics were calculated for all participants within the overall sample (N = 71) and summarized the basic features of the data. The mean age of the sample was 47.91 (SD = 11.35). Means, medians, and frequencies are presented below to describe the main characteristics of the sample (Table 1).

Study Demographics						
	N	Minimum	Maximum	Mean	Std. Deviation	
Time Post Injury	71	4	40	21.68	10.322	
Current Age	71	24	73	47.91	11.349	
Age at injury	71	3	58	27.44	13.793	
Abilities	71	6	40	20.14	7.062	
Adjustment	71	4	36	20.87	7.276	
Participation	71	5	29	19.97	5.921	
MPAI-IV Total	71	27	80	54.83	13.373	
Physical Health	71	16	31	23.24	3.420	
Psychological Healt	h 71	14	30	22.07	3.490	



Social Relationships	71	3	15	10.07	3.118
Environment	71	21	40	32.17	4.864
WHOQol Total	71	51	110	86.39	11.925

^{*}Mean of current age, age at time of injury, and time since injury was measured in years. Means for the other variables included for the MPAI-V and WHOQoL subscales and total scores were the average of each reported score.

For the MPAI-IV, the participation subscale was used in examining social connectedness in the study sample. Items in this subscale include paid and unpaid employment, managing money and finances, transportation, residence, self-care, social contact, leisure and recreational activities, and initiation. Scoring ranges from a 0 indicating that there are no issues in this area, a 1 which means this area is a mild problem but does not interfere with activities and may require the use of assistive devices, a 2 means there is a mild problem and interferes with activities 5-24 % of the time, a 3 indicates that there is a moderate problem that interferes with activities 25-7 % of the time, and a 4 means that there is a severe problem in that area that interferes with activities more than 75 % of the time. The scores ranged 5 to 29 with a mean of 19.97 in this sample with the highest you can get on that subscale being 36. This reflects that participation in this sample was a barrier to functioning. Participants were mostly comprised of those residing in a residential setting and are unable to engage in work, cannot drive, and likely need support with money management and initiation. For the total MPAI-IV score, the scores ranged 27 to 80 with the mean score being 54.83. As stated based on the scoring for this measure, a higher score on the subscales and total MPAI-IV reflects poorer overall functioning.

On the WHOQol-BREF, the social relationships subscale which measures quality of social relationships was used to see if it predicts overall QoL. The social relationships subscale

examines personal relationships, social support, and sexual activity. The social relationship subscale on the WHOQoL-BREF is scored as follows: 1 is very dissatisfied, a 2 is dissatisfied, a 3 is neither satisfied nor dissatisfied, a 4 is satisfied, and a 5 is very satisfied. Scores on the social relationship subscale ranged from 3 to 15 with a mean of 10.07 with the maximum score you can report would be 12. This means individuals in this sample on average reported being satisfied with the quality of their social relationships. Both subscales of the Participate subscale of the MPAI-IV and social relationships subscale on the WHOQoL-BREF items targeted very specific attributes of social functioning, which or may not be accurately reflecting the experiences of program participants. Additionally, the WHOQoL-BREF is a self-report measure which may not be the best type of measure to use with this population considering some of the deficits in self-awareness and insight.

Hypothesis 1

Based on the existing literature, social connectedness was found to be a predictor of overall QoL in acquired brain injury survivors. Social connectedness was operationalized as the pursuit of and quality of social relationships and quality of life was a multidimensional concept related to all areas of functioning including social relationships, environment, health, and wellbeing. To examine this relationship, it was hypothesized that social connectedness measured by the total score on the MPAI-IV would be negatively correlated with the total score of the WHOQOL-BREF. To test this hypothesis, a Pearson correlation was conducted to determine the relationship between Adjustment, Abilities and Participation subscales totaled on the MPAI-IV and the Psychological Health, Physical Health, Environment, and Social Relationships subscale scores totaled on the WHOQOL-BREF. A significant correlation was not obtained indicating a lower total score on the MPAI-IV does not predict a higher total QoL score on the WHOQOL-



BREF, r(71)=.-183, p=.063. There was a non-significant correlation of between total MPAI-IV and total WHOQOL-BREF. This approached significance and the likelihood is that with more subjects it may have been significant.

Hypothesis 2

Secondly, it was hypothesized that a lower score on the Participation subscale that measures social connectedness would predict a higher score on the Social relationship's domain on the WHOQoL-BREF. The Participation subscale of the MPAI-IV specifically looks at an individual's initiation, social contact, leisure/recreational activities, self-care, residence transportation, and money management. A lower score on the Participation subscale indicates the individual is more engaged with social contacts, leisure activities, and demonstrates initiative. A higher score on the Participation subscale would indicate diminished social interactions, initiation, and functional abilities such as money management, planning, and participating in leisure/recreational activities. The Social Relationships subscale on the WHOQoL-BREF addresses similar aspects of social functioning such as satisfaction with intimate and family relationships, friendships, and intimacy in relationships. A higher score on this subscale means an individual has higher reported satisfaction in relationships as opposed to a lower score which would indicate an individual who reports decreased social engagement and satisfaction with social contacts. A Pearson correlation was obtained indicating that the Participation subscale score on the MPAI-IV was negatively correlated with the Social Relationships subscale score on the WHOQoL-BREF, r(71)=-.252, p=.018. There was a significant correlation of between Participation subscale score and the Social Relationships subscale score.



Hypothesis 3

Third, it was hypothesized that a lower score on the Participation subscale of the MPAI-IV would be associated with a higher total WHOQoL-BREF score. A lower score on the Participation subscale of the MPAI-IV corresponds with an ability to initiate and engage in social, work, and other activities. A Pearson correlation was obtained indicating a lower Participation subscale score predicted a higher total WHOQoL-BREF, r(71)=-.211, p=.038. There was a significant correlation of between Participation subscale score and total WHOQoL-BREF. This further reinforces that aspects of social connectedness contributes to improved overall life satisfaction.

Additional variables including relationship status, age, age at time of injury and time since injury were analyzed to examine their relationship to overall QoL. Table 2 below demonstrates results from each correlation:

Table 2

Correlations		

QoL Total	QoL Total	Time Post Injury	Current Age	Relationship Status	Age at injury
Pearson Correlation	1	073	263	.227	099

Sig (1-tailed)		.273	**.013	.056	.207
N	71	71	71	71	71



Time Post injury					
Pearson Correlation	073	1	.190	142	525
Sig (1-tailed)	.273		.056	.119	**.000
N	71	71	71	71	71
Current Age					
Pearson Correlation	263	.190	1	054	.548
Sig (1-tailed)	**.013	.056		.328	**.000
N	71	71	71	71	71
Relationship Status					
Pearson Correlation	.227	142	54	1	.035
Sig (1-tailed)	**.029	.119	.328		.385
N	71	71	71	71	71
Age at Injury					
Pearson Correlation	099	525	.548	.385	1
Sig (1-tailed)	.207	.000	.000	**.035	
N	71	71	71	71	71

Correlations were conducted to examine how these variables found in the research indicated in the table above correlated with QoL. As indicated in the research, relationship status, operationally defined as being in a relationship, either married or in a committed relationship,



was positively correlated with total QoL on the WHOQoL-BREF, r(71)=.227, p=.029. Current age was found to be negatively correlated with total QoL in WHOQoL-BREF, r(71)=-.263, p=.013. This demonstrated that those more advanced in age had reported poorer QoL compared to younger counterparts. Time post injury and age at time of injury were not correlated with total QoL r(71)=-.073, p=.273 and r(71)=-.099, p=.207 respectively.

The Durbin-Watson statistic, which tests for serial correlations between errors in regression models (assessing the assumption of independent errors=2.170). According to Field, using a conservative approach, a value less than 1 or greater than 3 is a cause for concern (Field, 2009). For each of the predictors, the Variance Inflation Factor (VIF), indicated that for each of the predictors VIF's were approximately 1. The Tolerance statistic (T), also a measure of collinearity, revealed collinearity was not a problem, revealing that none of the tolerance predictors were less than .1. By graphing the relationship, linear relationships were revealed. Therefore the assumptions for multiple regressions were met.

Table 3

Model Summary	,		
Model	df2	Sig. F Change	Durbin-Watson
1	65	.000	2.170



Table 4

ANOVA					
Model	Sum of Squares	df	Mean Square	F	Sig.
1					
Regression	3565.161	5	713.032	7.253	.000
Residual	6389.797	65	98.305		
Total	9954.958	70			

Table 5

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Model	Uı	nstandardize	d Coefficients	Standardized Coeffice	cients	
		В	Std. Error	Beta	t	Sig.
1	(Constant)	82.205	8.979	9.155		.000
	Current Age	201	.107	191	-1.875	.066
	Relationship State	us 5.506	2.622	.220	2.100	.040
	Participation	050	.228	025	219	.828
	Social Relationsh	ips 1.651	.400	.432	4.129	.000
	Adjustments	176	.191	107	922	.360



A linear multiple regression was conducted using the enter method. The predictor variables included adjustment, age, relationship status, social relationships, and participation; the criterion variable was QoL. As shown in Table 4, the ANOVA was significant (f(5,65)=7.253, p<.000). As summarized in Table 3, the model summary, the multiple correlation (R=.598), reflected that almost 36% of the variability in QoL was attributed to the predictor variables. However, in examining the predictability of the individual predictors, only *social relationships* and *relationship status* significantly contributed to the predictability of QoL.



Chapter 6: Discussion

Summary and Integration of Findings.

This study's goal was to augment current research in regard to the importance of social relationships for ABI survivors post injury. As indicated previously, limited research exists about the significance of social supports in ABI survivors recovering post injury (Madder, 2013). Additionally, the bulk of research available has focused on improving physical, cognitive functioning, and mental health, which have all been associated with QoL in ABI survivors (Dawodu, 2011). Investigating the benefits of ABI survivors' quality of their social relationships could help inform researchers who construct treatment protocols to improve QoL in this population. This study examined if social connectedness as measured by the MPAI-IV and WHOQoL-BREF was predictive of QoL in ABI survivors.

Since both the MPAI-IV and WHOQoL-BREF measure aspects of QoL and social connectedness, it was predicted that the total MPAI-IV score would be correlated with the total WHOQoL-BREF score. This relationship approached statistical significance; however, the study sample was not large enough to detect a possible relationship that might exist in the population. Similar issues have been noted in other research assessing outcomes in this population (Cicerone, 2004; Dawodu, 2011). It was also found that Participation subscale as measured by the MPAI-IV, was also negatively correlated with the social relationships domain on the WHOQoL-BREF. This was consistent with the literature regarding overall functioning in ABI survivors. Cicerone (2004) conducted a literature review of the limited studies available regarding participation that suggested that post acute rehabilitation treatment facilities can produce enhancement in



community integration and participation. He noted that social participation appears to be indicative of better rehabilitation outcomes however these aspects of post acute rehabilitation treatment have just begun to be addressed. Cicerone (2004) recommended that programs should examine social participation as an outcome of ABI rehabilitation to promote improved life satisfaction and overall functioning.

Finally, it was hypothesized that a lower *Participation* subscale score on the MPAI-IV would be negatively correlated with the total WHOQoL-BREF score. A statistically significant relationship was found indicating that the *Participation* subscale score was negatively correlated with WHOQoL-BREF total score. These results have been noted in several other studies in the research. Haslam, Jetten, Postmes, and Haslam (2009) completed an editorial examining how the social environment influences social identity in ABI survivors and how that contributes to their perception of their health. They proposed that incorporating an understanding of an individual's social identity should be added into health care policy making and practice. The authors looked at five central themes in the literature that included symptom appraisal and response, health-related norms and behavior, social support, coping, and clinical outcomes and their relationship to social identity (Halsam, Jetten, Postmes, & Haslam, 2009). They noted that self and identity were identified as a central theme in outcomes research with ABI patients and their recovery. Social context in rehabilitation continues to be an emerging theme that needs to be addressed in treatment (Cicerone, Jetten, Postmes, & Haslam, 2008).

Additional analysis revealed that relationship status was positively correlated with QoL.

As stated, ABI survivors with intact relationships reported better perception of their overall QoL.

Sander and Struchen (2011) explored the role of interpersonal relationships and ABI. They identified that though individuals with ABI have reported issues maintaining pre-morbid



relationships, there is evidence that having those supports produce better overall functioning outcomes. They also shared that despite this, there are very few programs targeted at helping ABI survivors address factors that impair social functioning such as impulsivity, emotional regulation, and initiation (Sander & Struchen, 2011).

It was also found that current age was indicative of a poorer overall QoL. This could be related to declining health related and unrelated to injury. From a developmental perspective, those later in life are adjusting to a change in their role as provider and employee, which could have been preceded by their injury. This change in identity and role has been linked in several studies to a decline in self-esteem and overall QoL. Erikson (1950) defines this stage as "generativity versus stagnation:"

"Generativity, then is primarily the concern in establishing and guiding the next generation ...the concept is meant to include... productivity and creativity" (Erikson, 1950, p. 267).

This stage of development in relationship to ABI could have occurred later in life for those whose injury took place in their prime working years. As described previously, difficulty or inability to work, engage in meaningful activities, and engage with others has been linked to poorer QoL in ABI survivors (Langlois et al., 2006). Both time since injury and age at time of injury were not significantly linked to QoL. These variables had a wide range within the sample used in this the present study, which could have affected their relationships to QoL. Overall, the study indicated that social connectedness does influence QoL, however, the amount and specific aspects of social functioning still need to be explored in future research.

Limitations.



Despite the importance of this research, several limitations must be addressed. The sample that was used for this study was comprised solely of patients who had sustained severe traumatic brain injuries, which limits the generalizability of the results to mild to moderate ABI survivors. Also, the original outcome database only used data collected from the MPAI-4 and WHOQoL-BREF, which may not be an accurate assessment of social connection and QoL in a ABI population. These measures were completed by staff members who observed each patient's behavior. As such, they were unable to tap the inner experience of subject's responses to their injuries and the impact on their perceived social function and quality of life.

Another thing to consider is that the measure used to measure QoL was a self-report measure. Considering the potential for affects on self-awareness, increase impulsivity, and damage to the limbic system present in ABI survivors, individuals may not be able to accurately report their experiences of their QoL. The measures used also targeted very specific aspects of social connection such as satisfaction with relationships, engagement in employment, leisure activities that may not be accurate measures of social connection in this population.

Another limitation of this study was that it was retrospective. In a similar study examining a peer mentoring community program, Hibbard et al. (2002) found that participants and their families reported increased knowledge of ABI and helped with improved coping with ABI. Despite this initial positive results, one of the limitations they noted was that the retrospective nature of the study, individual's cognitive impairments could have influenced their ability to report on the program intervention (Hibbard et al., 2002). Similarly, participants in Bancroft's programs may have had a difficult time recognizing or evaluating aspects of the program that they felt helped enhance their QoL. It was also unclear, based on the measures



used, how participants in Bancroft's programs viewed aspects of the program that target enhancing community integration and positive social support.

In recognizing the limitations of a small sample size the results found, while promising, would be beneficial to replicate this study with a large population of ABI survivors and include those with different severity of injury. Struchen and colleagues conducted a randomized control trial with a peer mentoring program that was targeted at improving social integration outcomes. The mentors in the study were screened for adequate social integration before being matched with mentees (Struchen, Pappadis, Sander, Burrows, & Myszka, 2011). Due to the small sample size, the study results did allow for researchers to ascertain differences between the treatment and control group. There were positive changes observed in the mentored person's expansion of their social network (Struchen, Pappadis, Sander, Burrows, & Myszka, 2011). Struchen and colleagues shared that the study was difficult to implement, but did demonstrate a foundation for further research into similar programs.

Future Research.

Results from this study offer a promising direction for research in rehabilitation programs with ABI survivors. A select number of programs nationally have begun to target social relationships as a treatment focus that warrants further study. In a study by Bulinski (2010), a sample of 200 married couples with an ABI spouse enrolled in the "Academy of Life" program, a long-term program designed to provide social support to ABI survivors, were evaluated to determine if they had an improved QoL. Results from the study indicated that, "The best effects were achieved in the reduction of social dysfunctions, the growth of purposeful social activity,



and improvement in the type of support received, and a reduction of selected parameters of social isolation" (Bulinski, 2010, p. 14).

Cicerone, Mott, Azulay, Sharlow-Galella, Ellmo, Paradise, and Friel (2008) conducted a randomized control study of a holistic neuropsychologic rehabilitation program. The study was a prospective randomized clinical trial in which patients were assigned to an intensive cognitive rehabilitation program (ICRP) or the standard neurorehabilitation program (SNRP). They proposed that in the ICRP group, community reintegration which assess various aspects social functioning and improved life satisfaction. The ICRP focused on strengths, as opposed to cognitive deficits, group cohesion and engagement, and taught skills such as social problem solving, goal setting, task analysis, and planning/organization (Cicerone, et al., 2008). They found that program components such as using a group model for cognitive and social communication produced a moderate clinical effect when compared to standard treatment. However, they were unable to isolate which specific components were more effective in the ICRP condition (Cicerone et al., 2008). These studies provide promise for incorporating a social component into rehabilitation programs as a strategy to improve overall functioning and life satisfaction.

Recommendations.

Based on the study results and current research, incorporating a social component into rehabilitation treatment has been shown to improve QoL in this population. Bancroft currently offers a comprehensive treatment program to its "person's served," including cognitive rehabilitation, individual psychotherapy, psychoeducation groups, residential treatment, physical and occupational therapies, as well as community outings where participants can socialize. Based



on the findings discussed here, this researcher has outlined several other recommendations to continue with the work that is being done to support this population.

Including a specific assessment of an individual's satisfaction with their social supports could beneficial to target this area of functioning since it is shown to have a powerful influence on QoL. Such measures as the Community Integration Questionnaire or the Katz Adjustment Scale could prove useful in targeting satisfaction with social relationships (Fleming, Strong, & Ashton, 1996; Willer, 1990). Identifying social support needs upon admissions can help clinician's and program managers with potential creation of social support groups, cognitive rehabilitation and psychotherapy treatment planning. Additionally, the use of self-report measures may not be the best option for this population considering the impairments that some individuals face in self-awareness and insight that may limit their ability to accurately assess their needs.

While the current study examined individuals across all programs, it would be beneficial to see how each program's participants view their social connectedness and their overall QoL. It could be valuable to see if those who live in the community versus those in the residential program compare when it comes to having social support. This would also be helpful in identifying which programs require additional support with building and maintaining a positive social network. In the current study, certain programs may have better social outcomes which could be affecting the overall generalizability of the study.

Another important aspect regarding the measures used in this study is ensuring that staff members are trained regularly on their completion to ensure high interrater reliability. It is important that measures be completed thoroughly and on the regular schedule noted by the organization so individuals' progress can be tracked accurately. Also, ensuring that these



measures are scanned into the electronic medical record system is essential to monitor progress. Being able to readily access these measures will allow all employees to be aware of each individual's strengths and needs, so treatment can continue to be tailored to them. Additionally, the use of self-report measures may not be the best choice for this population with the deficits that can be present in self-awareness, executive functioning, and functional impairments secondary to injury.

Bancroft continues to maintain a standard of connecting with individuals within their program's families to provide support and to certify that each individual served and their family's needs are being met at the highest quality possible. Including family members in assessing each individual's social functioning and QoL is also important for continuity of care. ABI survivors may have a difficult time due to lack of insight, initiation, and other deficits in recognizing areas they could benefit from support in. Also, family members and other supports can provide valuable information regarding pre-morbid social functioning and QoL that can help with programming for each individual.

As reflected in Bancroft's population, they have a large cohort of individuals who are in middle to older adult range with mean age of 47.91. As indicated previously, individuals in this age group may have different needs regarding self-concept, identity, and social connection. It may be beneficial to explore adding a social component for this population that targets meaning making at this stage in life and incorporates positive social interaction through groups and community activities.

In the current study, we observed the impact of very specific aspects of social connection that may not be accurately reflecting this population's experiences in social relationships with family,



friends, or members in the community. Further research with Bancroft's population could help with identifying what are the variables that promote increased connection among participants and help identify what factors contribute to their perception of the quality of their social relationships.



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Name:

Appendix A

Mayo-Portland Adaptability Inventory-4 Muriel D. Lezak, PhD, ABPP & James F. Malec, PhD, ABPP

Clinic #	Date	

Person reporting (circle one):	Single Professional	Professional Consensus	Person with brain injury	Significant other:

Below each item, circle the number that best describes the level at which the person being evaluated experiences problems. Mark the greatest level of problem that is appropriate. Problems that interfere rarely with daily or valued activities, that is, less than 5% of the time, should be considered not to interfere. Write comments about specific items at the end of the rating scale.

For Items 1-20, please use the rating scale below

	For Hems 1-20, please use the rating scale below.									
Г	0	None	1	Mild problem but does	2	Mild problem; interferes	3	Moderate problem;	4	Severe problem;
				not interfere with		with activities 5-24% of		interferes with activities		interferes with activities
				activities; may use		the time		25-75% of the time		more than 75% of the
				assistive device or						time
				medication						

medication								
Part A. Abilities								
Mobility: Problems walking or moving; balance problems that interfere with moving about	ıt							
0 1 2 3 4								
 Use of hands: Impaired strength or coordination in one or both hands 								
0 1 2 3 4								
3. Vision: Problems seeing; double vision; eye, brain, or nerve injuries that interfere with seeing								
0 1 2 3 4								
4. *Audition: Problems hearing; ringing in the ears								
0 1 2 3 4								
Dizziness: Feeling unsteady, dizzy, light-headed								
0 1 2 3 4								
6. Motor speech: Abnormal clearness or rate of speech; stuttering								
0 1 2 3 4								
7A. Verbal communication: Problems expressing or understanding language								
0 1 2 3 4								
7B. Nonverbal communication: Restricted or unusual gestures or facial expressions; talking too much or not enough; missing nonverbal cues from others								
0 1 2 3 4								
 Attention/Concentration: Problems ignoring distractions, shifting attention, keeping more than one thing in mind at a time 	g							
0 1 2 3 4								
9. Memory: Problems learning and recalling new information								
0 1 2 3 4								
 Fund of Information: Problems remembering information learner in school or on the job; difficulty remembering information about self and family from years ago 	d							
0 1 2 3 4								
11. Novel problem-solving: Problems thinking up solutions or picking	3							
the best solution to new problems								
the best solution to new problems 0 1 2 3 4								
0 1 2 3 4 12. Visuospatial abilities: Problems drawing, assembling things,								
0 1 2 3 4								

Pai	t B. Adius	tment				
13.	Anxiety:	Tense, ner	vous, fearf	ul, phobia	s, nightma	res,
	flashbacks	s of stressfu	l events			
	0	1	2	3	4	
14.		on: Sad, bli	ne, hopeles	s, poor app	etite, poor	sleep,
	worry, sel	f-criticism				
	0	1	2	3	4	
15.		ty, anger, a	ggression:	Verbal or	physical	
	expression	ns of anger				
	0	1	2	3	4	
16.		d headache		nd nonverl	oal express	ions of
	pain; activ	vities limite	d by pain			
	0	1	2	3	4	
17.	Fatigue:	Feeling tire	d; lack of e	energy; tiri	ng easily	
	0	1	2	3	4	
18.		y to mild s				
		or emotional				
		how concer				
		rrent function		and above	the effects	of the
	symptoms	s themselve	S			
	0	1	2	3	4	
19.		riate social				illy,
	rude, beha	avior not fit	ting for tim	e and plac	e	
	0	1	2	3	4	
20.		self-aware				
		s and disabi			iterfere wit	h
	everyday	activities ar	id work or	school		

Use scale at the bottom of the page to rate item #21

21. Family/significant relationships: Interactions with close others; describe stress within the family or those closest to the person with brain injury; "family functioning" means cooperating to accomplish those tasks that need to be done to keep the household running

family or other close interfere with family with family functioning inter-	derate stress that referes with family tioning 25-75% of time 4 Severe stress that interferes with family functioning more than 75% of the time

MPAI-4 3/31/03



Par	rt C. Participation								
22.	Initiation: Problems	gett	ing started on activities	with	out prompting				
0 N	ione	1	Mild problem but does <u>not</u> interfere with activities; may use assistive device or medication	2	Mild problem; interferes with activities 5-24% of the time	3	Moderate problem; interferes with activities 25-75% of the time	4	Severe problem; interferes with activities more than 75% of the time
23.	Social contact with f	rien	ds, work associates, an	d otl	ier people who are not	fan	nily, significant others,	or p	rofessionals
0	Normal involvement with others	1	Mild difficulty in social situations but maintains normal involvement with others	2	Mildly limited involvement with others (75-95% of normal interaction for age)	3	Moderately limited involvement with others (25-74% of normal interaction for age)	4	No or rare involvement with others (less than 25% of normal interaction for age)
24.	Leisure and recreati	onal	activities						
0	Normal participation in leisure activities for age	1	Mild difficulty in these activities but maintains normal participation	2	Mildly limited participation (75-95% of normal participation for age)	3	Moderately limited participation (25-74% of normal participation for age)	4	No or rare participation (less than 25% of normal participation for age)
25.	Self-care: Eating, dr	essin	g, bathing, hygiene				0,		
0	Independent completion of self-care activities	1	Mild difficulty, occasional omissions or mildly slowed completion of self-care; may use assistive device or require occasional prompting	2	Requires a little assistance or supervision from others (5-24% of the time) including frequent prompting	3	Requires moderate assistance or supervision from others (25-75% of the time)	4	Requires extensive assistance or supervision from others (more than 75% of the time)
26.			ies of independent living ce beyond basic hygiene						
0	Independent; living without supervision or concern from others	1	Living without supervision by others have concerns about safety or managing responsibilities	ut	2 Requires a little assistance or supervision from others (5-24% of the time)	3	Requires moderate assistance or supervision from others (25-75% of the time)	4	Requires extensive assistance or supervision from others (more than 75% of the time)
27.	*Transportation								
0	Independent in all modes of transportation including independent ability to operate a personal motor vehicle	1	Independent in all modes of transportation, but others hav concerns about safety	- 1	2 Requires a little assistance or supervision from others (5-24% of the time); cannot drive	3	Requires moderate assistance or supervision from others (25-75% of the time); cannot drive	4	Requires extensive assistance or supervision from others (more than 75% of the time); cannot drive
prii helj	nary social role is paid p from another person	emp with	te either item 28A or 28I ployment. If another soc responsibilities (such as at facilitate employment Part-time (3 to 30 hrs/ wk) without support	ial ro , a jo	ole is primary, rate only ob coach or shadow, tuto	28B or, he	 For both 28A and 281 	B, "sī	upport" means specia
Che S	eck only one to indicate	<u>pri</u> Reti	avolved in constructive, mary desired social role: red (Check retired only i	(Childrearing/care-giving	; F	Homemaker, no childrea		
)	Full-time (more than 30 hrs/wk) without support; full-time course load for students	1	Part-time (3 to 30 hrs/ wk) without support	2	Full-time or part-time with support	3	Activities in a supervised environment other than a sheltered workshop	4	Inactive; involved in role appropriate activities less than 3 hours per week
29.			nances: Shopping, keep nt with small purchases t						
0	Independent, manages small purchases and personal finances without supervision or concern from others	1	Manages money independently but others have concerns about larger financial decisions	2	Requires a little help or supervision (5-24% of the time) with large finances; independent with small purchases	3	Requires moderate help or supervision (25-75% of the time) with large finances; some help with small purchases	4	Requires extensive help or supervision (more than 75% of the time) with large finances; frequent help with small purchase

MPAI-4 3/31/03



	Part D: Pre-existing and associated conditions. The items below do not contribute to the total score but are used to identify special needs and circumstances. For each rate, pre-injury and post-injury status.								
		each rate, pre-injury and pos	st-mjury status.						
30. Alcohol use: Use of	alcoholic beverages.								
Pre-injury Post-in No or socially acceptable use	njury	2 Frequent excessive use that occasionally	3 Use or dependence interferes with everyday	4 Inpatient or residential treatment required					
	but does not interfere with everyday functioning; current problem under treatment or in remission	interferes with everyday functioning; possible dependence	functioning; additional treatment recommended	·					
31. Drug use: Use of ille	egal drugs or abuse of prescri	iption drugs.							
Pre-injury Post-in	ninev								
0 No or occasional use	1 Occasional use does not interfere with everyday	2 Frequent use that occasionally interferes	3 Use or dependence interferes with everyday	4 Inpatient or residential treatment required					
	functioning; current problem under treatment or in remission	with everyday functioning; possible dependence	functioning; additional treatment recommended						
32. Psychotic Symptoms			storted perceptions of reality.						
Pre-injury Post-in	njurv								
0 None	Current problem under treatment or in remission;	2 Symptoms occasionally interfere with everyday	3 Symptoms interfere with everyday functioning;	4 Inpatient or residential treatment required					
	symptoms do not interfere with everyday functioning	functioning but no additional evaluation or treatment recommended	additional treatment recommended						
33 I aw violations: Hist	fory before and after injury.								
33. Law violations. That	ory before and after injury.								
Pre-injury Post-in None or minor traffic	njury 1 Conviction on one or	2 History of more than two	3 Single felony conviction	4 Repeat felony convictions					
violations only	two misdemeanors other than minor traffic violations	misdeameanors other than minor traffic violations							
34. Other condition caus			edical conditions other than b	orain injury, such as,					
	putation. Use scale below#								
Pre-injury Post-in	· ·								
	sing cognitive impairment: ntia, stroke, developmental d		nonpsychiatric medical cond	litions other than brain					
Pre-injury Post-in	njury								
0 None	1 Mild problem but does not interfere with	2 Mild problem; interferes with activities 5-24% of	Moderate problem; interferes with activities	4 Severe problem; interferes with activities					
	activities; may use assistive device or	the time	25-75% of the time	more than 75% of the time					
	medication								
Comments:									
Item#									



_					
Sco	ring	· M	/nr	ZC	166

Items with an asterisk (4, 16, 27, 28/28A) require rescoring as specified below before Raw Scores are summed and referred to Reference Tables to obtain Standard Scores. Because items 22-24 contribute to both the Adjustment Subscale and the Participation Subscale, the Total Score will be less than the sum of the three subscales.

Abilities Subscale	
Rescore item 4. Original score = If original score = 0, new score = 0 If original score = 1, 2, or 3, new score = 1 If original score = 4, new score = 3 A. New score for item 4 = B. Sum of scores for items 1-3 and 5-12 = (use highest score for 7A or 7B)	
Sum of A and B = Raw Score for Abilities subscale =	(place in Table below)
Adjustment Subscale	
Rescore item 16. Original score = If original score = 0, new score = 0 If original score = 1 or 2, new score = 1. If original score = 3 or 4, new score = 2 C. New score for item 16 = D. Sum of scores for items 13-15 and 17-24 Sum of C and D = Raw Score for Adjustment Subscale	(place in Table below)
Participation Subscale	
Rescore item 27. Original score = If original score = 0 or 1, new score = 0 If original score = 2 or 3, new score = 1 If original score = 4, new score = 3	
Rescore item 28A or 28B. Original score = If original score = 0, new score = 0 If original score = 1 or 2, new score = 1 If original score = 3 or 4, new score = 3 E. New score for item 27 = F. New score for item 28Aor 28B = G. Sum of scores for items 22-24 = H. Sum of scores for items 25, 26, 29 = Sum of E through H = Raw Score for Participation Subscale =	(place in Table below) (place in Table below)
Use Reference Tables to Convert Raw Scores to Standard Scores Raw Scores	Standard
I. Ability Subscale (Items 1-12) II. Adjustment Subscale (Items 13-24) III. Participation Subscale (Items 22-29) IV. Subtotal of Subscale Raw Scores (I-III) V. Sum of scores for items 22-24 VI. Subtract from V. from IV = Total Score	



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Appendix B

WHOQOL-BREF

The following questions ask how you feel about your quality of life, health, or other areas of your life. I will read out each question to you, along with the response options. **Please choose the answer that appears most appropriate.** If you are unsure about which response to give to a question, the first response you think of is often the best one.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last four weeks.

		Very poor	Poor	Neither poor nor good	Good	Very good
1.	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2.	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last four weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3.	To what extent do you feel that physical pain prevents you from doing what you need to do?	5	4	3	2	1
4.	How much do you need any medical treatment to function in your daily life?	5	4	3	2	1
5.	How much do you enjoy life?	1	2	3	4	5
6.	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7.	How well are you able to concentrate?	1	2	3	4	5
8.	How safe do you feel in your daily life?	1	2	3	4	5
9.	How healthy is your physical environment?	1	2	3	4	5



The following questions ask about how completely you experience or were able to do certain things in the last four weeks.

		Not at all	A little	Moderately	Mostly	Completely
10.	Do you have enough energy for everyday life?	1	2	3	4	5
11.	Are you able to accept your bodily appearance?	1	2	3	4	5
12.	Have you enough money to meet your needs?	1	2	3	4	5
13.	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14.	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
15.	How well are you able to get around?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16.	How satisfied are you with your sleep?	1	2	3	4	5
17.	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18.	How satisfied are you with your capacity for work?	1	2	3	4	5
19.	How satisfied are you with yourself?	1	2	3	4	5

20.	How satisfied are you with your personal relationships?	1	2	3	4	5
21.	How satisfied are you with your sex life?	1	2	3	4	5
22.	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23.	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24.	How satisfied are you with your access to health services?		2	3	4	5
25.	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to how often you have felt or experienced certain things in the last four weeks.

		Never	Seldom	Quite often	Very often	Always
26.	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	5	4	3	2	1

Do you have any comments about the assessment?					

[The following table should be completed after the interview is finished]

		Equations for computing domain scores	Raw score	Transformed scores*	
		Equations for computing domain scores	Raw score	4-20	0-100
27.	Domain 1	(6-Q3) + (6-Q4) + Q10 + Q15 + Q16 + Q17 + Q18		1.	
			a. =	b:	c:
28.	Domain 2	Q5 + Q6 + Q7 + Q11 + Q19 + (6-Q26)		h.	
		O+O+O+ O + O + O	a. =	b:	c:
29.	Domain 3	Q20 + Q21 + Q22		1	
		O + O + O	a. =	b:	c:
30.	Domain 4	Q8 + Q9 + Q12 + Q13 + Q14 + Q23 + Q24 + Q25		1.	
			a. =	b:	c:

^{*} See Procedures Manual, pages 13-15

